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FAMILY-CENTERED CARE IN AN ACADEMIC HOSPITAL IN GAUTENG: PERCEPTIONS AND PRACTICES OF NURSES WORKING IN THE PAEDIATRIC WARDS

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

Master of Science in Nursing.

Johannesburg, 2019

DECLARATION

I, Tshireletso Pascaline Mosito, declare that this report is my own work. It is being submitted for the degree of Master of Science (Nursing) in at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree at any other university.

Signature: _____

_____ day of _____

Protocol Number: M170459

DEDICATION

"When the time is right, I, the Lord will make it happen." *Isaiah 60:22*

I dedicate this work to my mom and dad; I hope it makes you proud. Above all I dedicate it to my Lord who made it all possible.

ACKNOWLEDGEMENTS

I would like to acknowledge and give heartfelt thanks to the following people who have helped me through this journey:

- My supervisor, Sizakele Khoza, for your on-going support, advice and guidance.
- My family and friends, for all the prayers and for always believing in me. I could not have done this without your support.
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- All the biomedical statisticians from the University of the Witwatersrand Research Office, for the statistical support and guidance they provided.

ABSTRACT

Changes in health care to take account of human rights, especially the rights of children, have occurred because of recognition that family is important in the care of sick and hospitalised child patients. As a result, family-centered care (FCC) is considered the acceptable standard of nursing care to support and facilitate the psychosocial care of the child–parent dyad in paediatric care. However, in South Africa, although advances have been made with regards to the management of childhood conditions, evidence suggests that the emotional and psychological well-being of the child and family are not always considered while in care. The inconsistencies observed in FCC-related care practices can be partially attributed to the various definitions, and therefore differing interpretations and perceptions of FCC by nurses. Hence, the purpose of this study was to describe the perceptions and practices of professional nurses concerning FCC in paediatric care at a tertiary academic hospital in Gauteng.

A quantitative descriptive survey and cross-sectional design was used. Data was collected by means of self-administered questionnaires, the amended FCCQ-R, from the targeted population of 92 (N = 92) professional nurses working in the paediatric wards. Seventy-two (n = 72) questionnaires were distributed to the convenient sample over a three (3) month period. The overall response rate was 51.1% with forty-seven (n = 47) questionnaires adequate for data analysis. Data was captured on Microsoft Excel and entered in the STATA 14 software for descriptive and comparative statistical tests.

The findings revealed that nurses perceived the following elements: *recognising family individuality, emotional and financial support for families* and *emotional support for staff* as necessary to practise FCC. Whereas they reported being able to *recognise family individuality* and provide *emotional and financial support to the families* as elements they practised daily. No association was found between the nurse's perceptions and current practices evidenced by no statistical significance (p-value > 0.05). Meaning, their perceptions did not have an influence on their practice.

Recommendations from the study are that there should be ongoing in-service training provided for nurses on how FCC should be implemented. In addition, nurse educators should be knowledgeable of current policies regarding child health in the work pace to be able to better equip students on how they can put their theoretical knowledge of FCC into practice.

In conclusion the cohort of nurses were found to have a good understanding and knowledge of FCC evidenced by their perceptions but practised FCC inconsistently when rendering care daily.

Key words: family-centered care, paediatrics, nurses

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LIST OF ABBREVIATIONS

FCC	Family Centered Care
FCCQ-R	Family Centred Care Questionnaire – Revised

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

This chapter serves as an overview of the study. It provides the reader with an introduction to the background, problem statement, the purpose, and objectives. A discussion of the significance of the study and conceptual definitions are presented. Finally, a brief description of the methodology is outlined.

1.1 BACKGROUND

The admission of a child to hospital can be detrimental to his or her physical, emotional and psychological well-being (M. Foster, Whitehead, & Maybee, 2010). In most industrialised countries, admitting a child to hospital means separating the child from the family (Irlam & Bruce, 2002). Furthermore, the family's role of caring for the child is transferred to health care professionals, who thus assume the parental role. Unfortunately, in most cases, this means exclusive care, and limits the family's access to the child during the hospital stay (Harrison, 2010). As a result, the child is effectively cut off from their family, the social institution proven to have one of the greatest influences on a person's health. The family unit is important to children because they depend on it to provide for their needs and protect them, particularly during times of distress, such as admission to hospital. (Foster, Young, Mitchell, Van and Curtis,*et al.*, 2017).

A global focus on human rights, especially the rights of children, led to the realisation that family is important in the care of sick and hospitalised patients. Thus family-centred care

(FCC) emerged over 40 years ago, as an approach that enables health care professionals to give optimal physical, emotional, and psychological care to a child. Though FCC has been adopted as a way of caring for children and their families, there remains to be no clear definition thereof. Shelton, Jeppson and Johnson (1987: p2) defined FCC as "a pivotal role of the family in the lives of children with special health needs. It is a philosophy that strives to support families in their natural caregiver's roles by building upon their unique strengths as individuals and as families. It is a philosophy that views parents and professionals as equals in a partnership committed to excellence at all levels of health care." Therefore, to encompass the family, healthcare professionals must intentionally form parent-professional relationships (Harrison, 2010).

Implementing FCC has been to found to strengthen the family unit during hospitalisation, by keeping it intact; while empowering parents in respecting the role and function, they play in the child's life (Mikkelsen and Frederiksen, 2011). Concerning nurses, it is said that they experience increased work satisfaction as they are less stressed when family and children are less anxious thus in turn positively affecting their ability to provide treatment (Mikkelsen and Frederiksen, 2011; Saleeba, 2008).

In hospital settings, nurses are recognised as the frontline of health care delivery (James, 2016). As nurses are the collaborators of the health care professional team, much research has been conducted on FCC in nursing. In their seminal work on FCC, Bruce and Ritchie (1997) developed a questionnaire: The Family-Centred Care Questionnaire (FCCQ). The questionnaire was conceptually based on the eight (8) elements of FCC based on the concepts of the Association for the Care of Children's Health (ACCH) (Shelton, Jeppson and Johnson for the Association for the Care of Children's Health, 1987). It was then modified by committee for family centred care at the Izaak Walton Killam Hospital for

Children which added a ninth element 'Implementing appropriate policies and programs that are comprehensive and provide emotional support to meet the needs of staff" (Bruce and Ritchie, 1997). The elements are: 1) recognising that the family is the constant in the child's life; 2) facilitation of collaboration between parents and professionals across all levels of health care; 3) recognising family strengths and individuality; 4) sharing unbiased and complete information with parents concerning their child's care on an ongoing basis; 5) encouraging parent-to-parent support; 6) incorporating the developmental needs of infants, children, adolescents and their families into health care systems; 7) implementing appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families; and 8) assuring that there is flexibility, accessibility and responsiveness in the design of the health care delivery system to family needs (Shelton, Jeppson and Johnson for the Association for the Care of Children's Health, 1987). These elements are discussed in detail in Chapter Two. The questionnaire was used to measure the nurses' perceptions of activities they found necessary to implement FCC, under the necessary scale, and their practice of activities reflective of FCC, under the current scale. The findings from the Bruce and Ritchie (1997) study showed that nurses demonstrated a general knowledge and understanding of the FCC elements, but applied the elements inconsistently in practice. Four years later Caty, Larocque, and Koven (2001) confirmed these findings amongst Canadian nurses using a revised version of the Family-Centred Care Questionnaire (FCCQ-R). Thus the findings suggested that there exist varied perceptions and practices amongst nurses about implementing FCC (Caty, Larocque, & Koren, 2001; I. Coyne, Murphy, Costello, O'Neill, & Donnellan, 2013; Peterson, Cohen, & Parsons, 2004).

Other studies focused on nurse factors that may influence the application of FCC in practice. In the United States of America, Peterson, Cohen, and Parsons (2004) found that nurses' years of working experience and the clinical setting influenced their perceptions regarding FCC. Newly qualified nurses working in paediatric wards and paediatric intensive care, knew more about practices reflective of FCC elements when compared to nurses with more years of work experience in the neonatal intensive care. The researchers attributed this to the increasing inclusion of FCC in paediatric nursing curricula. In 2013, Coyne, Murphy, Costello, O'Neill, and Donnellan proved this to be true of nurses in Ireland. Irish nurses were found to have a good perception of the elements of FCC, and their practices reflected active support of FCC.

In South Africa, paediatric nursing occurs at primary, secondary and tertiary levels of care and children are cared for by all categories of nursing staff. The basic nursing education (first – fourth year) includes some aspects of child nursing the curriculum under midwifery, care of the newborn, Integrated Management of Childhood Illnesses (IMCI) and Expanded Program of Immunisation (EPI) and care of the hospitalised child which would include FCC. Although the content of the curriculum may vary across the different Nursed Education Institutions (NEIs), the specific principles of and approaches to child health are taught - most importantly the fact that nursing care of a child patient encompasses the family or caregivers. Further, the FCC approach to care is endorsed as the standard of practice in paediatric nursing, (South African Nursing Council, 2005), therefore is expected to be evident in most paediatric care settings.

From the above, it is evident that the health care context, geographical location, and economic status, as well as nurse training and experience, are variables that inform the

expression and definition of FCC. Most of the research underpinning the definition and practice of FCC in nursing offered in literature comes from the developed western countries, as there are few studies in developing countries. A preliminary review of the literature on the implementation of FCC in South Africa revealed a paucity of evidence. An historical study by Bruce and Irlam (2002) found five sources of evidence on FCC in neonatal and paediatric care in South Africa. The sources of evidence came from hospital policy and prescribed visiting times and rooming facilities for mothers of children during long-term hospitalisation. An exception was made for the siblings when the hospitalised child was terminally ill.

Almost 20 years later, with a significant increase in paediatric admissions and despite changes in the legal framework such as the Bana Principles, Chapter 2 of the Children's Act 38 of 2005 and Section 28 of the Bill of Rights that support and protect hospitalised children hospital policy reviewed show a limited application of the eight elements of FCC (Children's Act 38 of 2005, 2005 and Constitution of the Republic of South Africa Second Amendment Act, No. 3 of 2003, 2003). As a result, ongoing research and monitoring of Child Health services conducted by the Child Practice Development Unit in Cape Town continuously find that the emotional and psychological well-being of the child and family are not always considered in care (Coetzee, 2010). It is evident that the endorsement and incorporation of FCC in various legislative frameworks and in the child nursing curriculum may not guarantee implementation in practice. Based on the above, it was important for the researcher to investigate FCC as practiced by nurses in paediatric wards.

1.2 PROBLEM STATEMENT

The model of FCC expects nurses to treat patients in a holistic manner working in collaboration with families to humanise hospital stay for both the child and the families (Harrison, 2010). To better understand how nurses perceive and practice this model, studies have been conducted overseas suggesting that varied perceptions and practices occur amongst nurses when implementing FCC (Caty et al., 2001; I. Coyne et al., 2013; Peterson et al., 2004). In addition, literature offers various definitions of FCC which may contribute to inconsistencies when implementing FCC in practice (Coyne, Murphy, Costello, O'Neil and O'Shea, 2011). There have been extensive studies done on nurses' perceptions and practices of FCC, however, to date few studies have been done in South Africa in the paediatric setting. South Africa has diverse cultural, ethnic, and social differences thus rendering studies from developed countries as inappropriate to provide the essential information for the adequate implementation of FCC into practice. In practise it was noted by the researcher the lack of implementation of the 4 pillars of family centred care namely being; dignity and respect, collaboration, information sharing and participation. Though it was said that in the paediatric block of said institution care was provided for in a family centred approach, there seemed to be a disconnect between what was known and expected to be practised and what was the practised. Therefore, the researcher sought to investigate the perceptions and practices with regards to the FCC of professional nurses working in South African paediatric wards.

1.3 RESEARCH QUESTION

What are the perceptions and practices of professional nurses working in paediatric wards with regards to FCC?

1.4 PURPOSE OF THE STUDY

The purpose of this study was to describe FCC in the South African context by describing the perceptions and practices held by the professional nurses working in the paediatric wards at a tertiary academic hospital in Gauteng.

1.5 OBJECTIVES

The objectives of this study were:

- To describe the perceptions of professional nurses working in paediatric wards concerning elements of FCC
- To identify the practices as reported by the professional nurses working in paediatric wards that reflect the eight elements of FCC
- To compare the perceptions and practices of FCC of the professional nurses working in paediatric wards.

1.6 SIGNIFICANCE OF THE STUDY

The researcher anticipates that the data collected from the study may provide policy-makers and educators with insight into the gap between the theory and practice of FCC in

hospital policy. In reflecting upon perceptions of practices of FCC it is hoped that nurses will become aware of their knowledge and practice needs in implementing FCC such that they will also be actively involved in developing strategies to strengthen FCC in paediatric care. The successful implementation of FCC may have the overall result of improving the quality of care delivered to hospitalised children and enhance family satisfaction.

1.7 DEFINITIONS OF STUDY TERMINOLOGY

1.7.1 Family Centred Care

FCC in this study is defined as a model of care in which the family are essential in their children's lives whilst hospitalised that tries to upkeep their role as caregivers based on their individual and family strengths as well as viewing them as equals in partnership with health care professionals (Shelton, James and Jeppson, 1987).

1.7.2 Professional nurse

In the study, 'professional nurse' refers to a person who is qualified and found competent to be able to carry out the comprehensive nursing care prescribed as well as proficient enough to assume the responsibility and accountability that comes with it (Nursing Act No. 33 of 2005, 2005).

1.7.3 Perceptions

'Perception' is defined as "the nurse's interpretation of any given aspect of family-centred care, as described by that nurse" (Follett, 2006). In this study, perceptions refer to aspects of care that nurses believe to be necessary in the practice of FCC (Bruce and Ritchie, 1997). Perceptions were measured using the Necessary scale.

1.7.4 Practices

For this study, 'practices' refer to aspects of care or interventions that the nurse currently implements in their daily interactions with the child and family (Bruce and Ritchie, 1997). Practices were measured using the Current scale.

1.7.5 Paediatric ward

Hospital ward that specialises in the care of child patients aged 0 to 18 years.

1.7.6 Family

For this study, 'family' refers not only to one's biological family but also every person that is part of the patient's social support system (Tsaloukidis, 2010).

1.8 OVERVIEW OF RESEARCH METHODOLOGY

A quantitative, descriptive design using survey methods was used. Data collection was through a self-administered questionnaire, the amended FCCQ-R (Bruce and Ritchie,

1997), from a total sample of 92 professional nurses working in the paediatric wards at a tertiary academic hospital.

1.9 ETHICAL CONSIDERATIONS

Permission to conduct the study was sought and granted from the relevant ethical organisations; in particular the University of the Witwatersrand's School of Therapeutic Sciences postgraduate committee (**Appendix B)**, the University of the Witwatersrand Committee for Research on Human Subjects (Medical) (**Appendix C)**, the CEO and Nursing Director of the study site (**Appendix D)**, the Gauteng Department of Health National Health Research Database (GDOH NHRD) (**Appendix D)** as well as the authors of the FCCQ-R (**Appendix E and F**). Respondents were approached by the researcher and invited to participate in the study and were given an information sheet (**Appendix G**). Written consent (**Appendix H**) was obtained from each one. Confidentiality was assured by the researcher as collected questionnaires were kept in a secure place. Respondents were asked to avoid writing any names or other identifying information on their questionnaires to ensure that their anonymity was upheld. They were also reassured by the researcher that their participation was completely voluntary, and they could withdraw anytime without any penalty.

1.10 SUMMARY

This chapter introduced the background of the study and described the problem statement, research question, purpose, and objectives of the study. It presented brief outlines of the

significance of the study, relevant study definitions, an overview of the research methodology and some ethical considerations.

The next chapter presents the literature review.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Family-centred care is an approach to nursing practised in paediatric wards. This chapter will provide an overview of existing literature that has explored concepts applicable to this research study. The review of the literature has been divided into distinct areas, namely family-centred care, paediatric hospitalisation and well as family-centred care in the South African context.

2.2 FAMILY-CENTRED CARE

Family-centred care (FCC) is a model of care used to describe optimal health care given to children within which their families are seen as the experts and driving force in care (Kuo et al., 2012; Pettoello-Mantovani, Campanozzi, Maiuri, and Giardino, 2009). There is no consensus on the definition of FCC. However the following general principles have been found to be prevalent in previous studies: (a) information sharing, (b) respect and honouring differences, (c) partnership and collaboration, (d) negotiation, and (e) care in the context of the family as well as the community (Kuo et al., 2012). In order for these principles to be implemented, it is of utmost importance to ensure that the care provided honours individual family strengths, cultures, traditions and expertise (Arango, 2011).

2.2.1 Evolution of FCC

During the mid-20th century, the parents of hospitalised children had minimal to no access

to visiting them during this period which in turn was reported to have caused the children major psychological trauma and in turn lengthened their hospital stay (Jolley and Shields, 2009). With the separation of families more especially children during World War II, it brought about an interest to investigate the psychological effects this had on both adults and children (Jolley and Shields, 2009). This was the facilitating factor that would later lead to the implementation of FCC. Though psychologists such as Bowlby, Hurlingham, Freud and Illingworth directed their attention to FCC, there remained ~~to be~~ a slow acceptance and change from the medical and nursing fraternity during the 1920-1970's era (Jolley and Shields, 2009). At the outset, nurses were divided with their outlook on the model with some in support of it and some preferring to do things the "known way" (Jolley and Shields, 2009).

Despite the slow responsiveness from nursing and medicine many parent-led organisations were formed which influenced the care of hospitalised children, which resulted in the realisation of one of the precursors of FCC, care-by-parent units (Jolley and Shields, 2009). These units were first introduced in the United States of America during the 1960's and later in Britain during the 1980's (Jolley and shields, 2009). This type of care comprised of the parents living in with their hospitalised child as compared to partnership in care, which developed later during the 1990's, where it was the parents and nurses working together for the benefit of the child's health (Jolley and shields, 2009). In the same period, there was the development of parent participation which allowed parents to be involved in the care of their hospitalised child (Jolley and Shields, 2009). All three of these forms of care have been noted as the foundations of FCC as we know it today.

Although FCC has been accepted as a basis of how care should be provided for the

hospitalised child and their family, there are other common models used in providing healthcare to children. Namely being the Standard model and Professionally-centred model of care (Jolley and Shields, 2009; Shields et al., 2006). The Standard model of care is care the healthcare practitioner would plan around the child with the parents only being expected to abide by the treatment recommendations (Shields et al., 2006). In the professionally-centred model, it includes both the child-focused and family-focused models, in which the health care practitioner plans care of the child based on their views of what the child/family needs are (Shields et al., 2006). This then highlighting the importance of adopting FCC model for the provision of health care to children, as it does not consider the child alone, but it allows for parents to receive support as well of which the other models did not.

2.2.2 Elements of FCC

In 1987, Shelton, Jeppson and Johnson developed the elements that inform FCC practice, which will be discussed in further detail below (Shelton, Jeppson, and Johnson, 1987).

2.2.2.1 Family as the constant

Over the years there have been drastic advances made with regards to models of service delivery in the paediatric setting. This began with Professionally-Centred Care where the health professional was at the centre of everything: planning, intervening and evaluating, with the family side-lined and seen as unable to function without the professional (Shelton & Smith Stepanek, 1994). This was followed by a move towards the family being considered as an essential role-player in partnership with the professional, bringing about

the development of the Family-Allied model of service delivery (Shelton & Smith Stepanek, 1994). In the Family-Focused model, the family is seen as consumers who need guidance and advice from professionals (Shelton & Smith Stepanek, 1994). This model improved collaboration between the family and the professionals, which helped lead to the development of FCC. Family-centred care is not about giving the family whatever they want whenever they want it; rather, it has been described as seeing the family as the sun with healthcare services as planets revolving around it (Shelton & Smith Stepanek, 1994). In this relationship, the key decision-makers are the family, with the professionals acting as advisors and guides regarding which options and choices are available to them (Shelton & Smith Stepanek, 1994). In keeping the family as a constant in the child's life, it will provide not only the child but the family as well as comfort, especially during procedures (Saleeba, 2008).

2.2.2.2 Parent–professional collaboration

In parent-professional collaboration the professionals are often viewed according to the "Professionally-Centred Care" model of service delivery. They are considered the experts, which in turn acts as a barrier to the formation of a collaboration between the parent and the professional (Shelton & Smith Stepanek, 1994). The parent thus develops a dependence on the professional, resulting in them having feelings of guilt and diminished self-esteem (Shelton & Smith Stepanek, 1994). For effective collaboration between the two parties, the model used to understand the relationship needs to regard both parties as an independent. The Enablement model described by Dunst and colleagues in 1988 is one in which the professional creates opportunities for the parents to acquire new skills and the parent assumes the role of the help-seeker (Shelton & Smith Stepanek, 1994). The help-seeker is

seen as an individual responsible for seeking and obtaining the skills and using them accordingly to implement solutions (Shelton & Smith Stepanek, 1994). Failure to develop a meaningful parent-professional relationship will thus act as a barrier to the adequate implementation of FCC.

2.2.2.3 Recognising family diversity

In having the family define themselves and who forms part of it, is an important aspect that facilitates recognition of the uniqueness of each member. Their cultural background most often guides the family as a unit. Since there is vast diversity in South Africa, it is essential to understand the role it plays in the family. Culture, as defined by Jones (1985, in Shelton & Smith Stepanek, 1994), is a group that has particular values, beliefs and behaviours that enable it to be sustainable and successful. It is one of the factors that help define the structure and functioning of families as well as determine the role that the family plays in the community (Shelton & Smith Stepanek, 1994). When dealing with a sick child and their family, it is crucial to be familiar with their views of what they define illness to be and whom they regard to be the key decision-makers with regards to the care of the child (Shelton & Smith Stepanek, 1994). In recognising the diversity of the individual families, the healthcare professional needs to respect the differences and be able to work with the cultural variations without imposing their own beliefs and values onto the family.

2.2.2.4 Information sharing

When a child is sick, it is crucial for the healthcare team to be able to have open and honest communication with the family and to communicate in a supportive manner (Shelton &

Smith Stepanek, 1994). In doing so, the team will help reduce the anxiety, stress and upset levels of the family along with the child, and furthermore increase their satisfaction with the care being given as they are kept up to date with the care of the child (Shelton & Smith Stepanek, 1994). It also helps improve the family's overall emotional state and the healthcare team's capability to better treat the child (Saleeba, 2008). With the cross-cultural diversity found in South Africa (along with having 11 official languages), linguistic competence is a pre-requisite for the delivery of accurate, unbiased, and honest information with families. However, that is often not the case and becomes a barrier to sharing information. In addition to linguistic competence, inaccurate depiction of the child's condition to the family by the health care team along with under-sharing or over-sharing of information impedes effective communication between the two parties (Shelton & Smith Stepanek, 1994). Ascertaining what information is important to the family is vital.

2.2.2.5 Coping and support

Once family diversity has been recognised, the individual needs of the members need to be determined in order to provide them with adequate support based on previous coping mechanisms (Shelton & Smith Stepanek, 1994). Every so often, families may have high levels of stress due to the lack of support systems available to them. Increasing access to a wide range of available support services is necessary to meet their basic needs (Shelton & Smith Stepanek, 1994). Support services should include educational, financial, environmental, and material as well as emotional support. Besides providing the families with support services, other key factors of support that need to be taken into consideration are enabling and empowerment. By enabling the families, it affords the family to show the healthcare team their skills while at the same time learning and gaining new ones (Saleeba,

2008). Through empowering the families, it provides them with the ability to gain a sense of control over their lives and thus stabilise their relationship with the child and help them provide improved care to them (Saleeba, 2006).

2.2.2.6 Parent-to-parent support

The encouragement of parent-to-parent support has been reported to be one of the most effective ways to provide comprehensive support to families as it is seen as an aid to help family's better cope (Shelton & Smith Stepanek, 1994). Families offer empathy to other families going through similar experiences. This, in turn, enables the sharing of relevant information, including ways to solve problems that arise, and the opportunity to build friendships (Shelton & Smith Stepanek, 1994). Parent-to-parent support can also be referred to as family-to-family support, as peer support is not only provided for parents but mothers/fathers, siblings, professionals caring for the child and the child themselves.

2.2.2.7 Healthcare design

In order to respond to the identified needs of the family adequately and appropriately, the healthcare facility needs to be flexible and accessible (Shelton & Smith Stepanek, 1994). Due to the traditional rigid rules and regulations found in health care settings, parents may feel overwhelmed by the environment (Shelton & Smith Stepanek, 1994). To succeed in making health care facilities flexible and accessible, there needs to be a move away from the service-based approach to care, and gravitation towards the resource-based approach. The service-based approach is merely centred on the professional with strict eligibility requirements resulting in limited accessibility to facilities. Access is given to those in the

most need as determined by the professional (Shelton & Smith Stepanek, 1994). On the other hand, the resource-based approach is based on the "synergistic paradigm", which regards community resources as expandable, flexible and renewable (Shelton & Smith Stepanek, 1994). A resource-based approach increases the flexibility and accessibility of facilities and establishes more permanent support as community-based systems are formed (Shelton & Smith Stepanek, 1994).

Providing care that is culturally competent, and that also encompasses the family, in turn, helps to enhance the parent's confidence in their roles in a situation where they would typically feel helpless and uncertain of what role they are expected to, and can play, whilst their child is hospitalised (Pettoello-Mantovani *et al.*, 2009). Overall, when FCC is implemented fittingly, it strengthens the family unit by keeping it intact, along with empowering parents in their roles and functions they play in their child's life while hospitalised (Mikkelsen and Frederiksen, 2011). Also, FCC improves the interaction that parents and the child have with the healthcare team, resulting in the parents being satisfied with the healthcare organisation and overall care provided to the child (Rostami, Hassan, Yaghmai, Ismaeli and Suandi, 2015).

2.2.2.8 Benefits of implementing FCC

There are several benefits associated with the practice of FCC, ranging from psychological, physical as well as developmental. Psychologically, FCC has been found to help reduce the stress and anxiety levels of both the child and their family along with providing the family with a sense of control and allowing for better adjustment for the child in the new environment (Shields and Zhou, 2012). Regarding behaviour, it has been reported that

there is improved co-operation and compliance with care from the child and the family respectively (Shields and Zhou, 2012). Thus, in turn resulting in fewer hospitalisations and use of the emergency department as the families will be ensuring that the child is given their treatment accordingly as well as keeping to the follow-up appointments made (Shields et al., 2006).

Family centred care has been found to enhance the satisfaction with care that the child and their family have, along with the healthcare staff (Saleeba, 2006). With the fewer hospitalisations, a decrease in hospital stay and improved staff satisfaction, which would result in reduced staff turnover, FCC is associated with a decrease in health care costs, not only for the family but the government as well (Saleeba 2008).

2.2.2.8 Barriers to implementing FCC

Several barriers and constraints have previously been identified that prevent nurses from effectively implementing FCC. In previous research, the constraint most often described involved the health care systems in place. This encompassed staff shortages, workloads, financial difficulties and time constraints, which became barriers to practising FCC (Coyne et al., 2013; Paliadelis and Cruickshank, 2005). Literature also indicated that a lack of guidelines or policies regarding parental roles for the hospitalised child, lack of guidance on the implementation of FCC, nurses' lack of confidence in their knowledge and skills and their unwillingness to share their knowledge as other constraints to implementing FCC effectively (Paliadelis and Cruickshank, 2005). Nurses are faced with expanded roles today, and it is time-consuming for them to provide parents with adequate skills and training for the provision of safe nursing care (Coyne, 2015).

Furthermore, Bamm and Rosenbaum (2008) found that another major constraint is the healthcare provider's lack of self-confidence inadequately dealing with psychological issues that the patient and the family may have (Bamm & Rosenbaum, 2008). In addition, poor communication, which may be a result of language, racial or ethnic differences, may affect the willingness of families and health care providers to negotiate the roles that they play in the child's care, and exacerbate the role ambiguity of both parties (Coyne et al., 2013; Kuo et al., 2012). Besides the barriers mentioned above, another factor to bear in mind with regards to implementing FCC is the perceptions and practices nurses have of the model itself.

2.2.2.9 Perceptions and practices of the FCC model

Perception is defined as "the nurse's interpretation of any given aspect of family-centred care, as described by that nurse" (Follett, 2006), which could account for the varied definitions of FCC. A significant and growing body of evidence has come from investigating the perceptions that nurses hold about FCC. Many nurses support the FCC model, viewing it as an essential element that is important for the child in order to maintain the stability that the family provides for them (Coyne et al., 2013; da Silva Barreto, Oliveira de Arruda, Garcia-Vivar, Silva Marcon, and Anna, 2017). Although there is support for and consensual views of FCC, practices thereof still vary. In a study by Boztepe and Yildiz (2017), participants expressed that they valued parents' participation in their child's care. However, they also stated that if parents knew everything that happened with regards to their child it could potentially increase their anxiety, and therefore they felt it important to share only essential information with them.

Bruce and Ritchie (1992), Peterson (2004) and Coyne et al. (2013) found that nurses were in support of FCC and found the elements to be important. However, they did not consistently implement them in their actual practice. This could be explained by the fact that many nurses have traditionally been taught according to the medical model of care, where the health care professional is seen as the controller of treatment and as the individual whom the child and parent depend on (Letourneau and Elliott, 1996). The emergence of FCC over the past decades has caused conflict where parents are more actively involved in their child's care, as health care professionals are not willing to relinquish their control (Letourneau and Elliott, 1996). Another factor that could be credited for the inconsistent implementation of FCC is the difference in nursing education levels (i.e. university versus college level). The content taught has proved insufficient and has made the development of standards guiding FCC practice difficult (Boztepe and Kerimoğlu Yıldız, 2017). As a result, the implementation of FCC has limited and restricted parents to "participation in care activities", as opposed to being actively involved in care. This could be attributed to the skill level the nurses perceive parents to have.

Furthermore, nurses' felt that working in collaboration with families posed a threat to their professional identity (Boztepe and Kerimoğlu Yıldız, 2017; Paliadelis and Cruickshank, 2005). Parents' education levels may act as a constraint in the level of participation they have in their child's care. Most parents depend on nurses to act as mediators or translators between them and other members of the multi-disciplinary team (MDT) (Boztepe and Kerimoğlu Yıldız, 2017; Paliadelis and Cruickshank, 2005). Historically, nurses are seen as the "knowledge experts" and often act as gatekeepers to the access parents have when their child is admitted (Paliadelis and Cruickshank, 2005). This, in turn, has had an impact on the empowerment of parents in caring for their children when nurses exercise

"benevolent paternalism," and has restricted patients' and families' autonomy (Paliadelis and Cruickshank, 2005).

2.3 PAEDIATRIC HOSPITALISATION

When a child is hospitalised, not only does it provoke anxiety but it also disrupts the life of the child and their parents/family member acting as a caregiver (Rokach, 2016). The family experiences a situational crisis. 'Crisis' is defined as a temporary state of upset where the individual is unable to cope with a particular state using their usual problem-solving methods (Slaiku, 1990 in Hendricks-Ferguson, 2000). Common conditions found to result in the admission of children to hospital in Brazil were pneumonia, asthma, diarrhoea, gastroenteritis, acute bronchitis and mood disorders (Ferrer, Sucupira and Grisi, 2010). Isaacs-Long, Myer, and Zar (2017) found the same of paediatric hospital admissions in South Africa, with the exception of mood disorders. In addition, in the South African setting, convulsions, meningitis, septicaemia, chronic obstructive pulmonary disease (COPD) and bronchiectasis contributed to emergency admission. The hospital, as seen by children, is a foreign environment that they must accustom themselves to (Rokach, 2016). Hence they need to have family present to provide them with a safe, stable environment, enabling the child to cope with their new environment (Rokach, 2016). During a child's hospitalisation, the family experience loss of control and confusion due to having to place their faith in the health care professional's hands, which may manifest as physical disturbances (Commodari, 2010).

The family presence and participation is vital not only for the child during their stay but also for the parents/family member acting as the child's caregiver. Parents/family member

acting as the child's caregiver stress has implications on the child's health and behaviour (Commodari, 2010). When parents are actively involved and allowed to participate in their child's care, it helps them to alleviate their anxiety and stress, prompting them to want to learn more about the child's condition, thus enabling them to acquire functional skills to care for the child better after discharge, and to increase their satisfaction with the care received (Letourneau and Elliott, 1996). Thus, it is of utmost importance to allow the family to be present and included in the child's care to alleviate any anxiety experienced by them. Decreasing caregiver stress and promoting their emotional response is said to increase the adherence to the child's care and aid in providing them with milder perceptions of the child's illness (Commodari, 2010).

2. 4 FAMILY-CENTRED CARE IN SOUTH AFRICA

Within the tertiary academic hospitals, a multidisciplinary (MDT) approach has been adopted to provide care, which involves doctors, physiotherapists, occupational therapists, dieticians, and ~~most importantly~~ the nurses who are usually the first contact for the child and their family and who are consistently present by their bedside (Coats, Bourget and Doorenbos, 2018). When a child is admitted into the hospital, they spend most of their time in the care of the paediatric nurse. Paediatric nurses are specialist nurses with a postgraduate qualification in Child Nursing Science. In South Africa, only 4 universities are accredited to offer the paediatric nursing course, all of which have different curricula (Coetzee, 2010). Though curricula may differ, at the end of the training a paediatric nurse is expected to register with the South African Nursing Council (SANC) and fulfil all the competencies of being a paediatric nurse specialist, which includes providing family-centred care (South African Nursing Council, 2005). Over the years there has been a

decline in the number of paediatric nurses being trained, with less than 5% making up the nursing fraternity in South Africa as of 2017 ("Registrations and Listed Qualifications," 2017). Paediatric nursing in South Africa occurs across all levels of care, being primary, secondary, and tertiary levels. So, of the less than 5% of paediatric nurses in South Africa, they are dispersed throughout both private and government institutions across all nine provinces, further highlighting the scarcity of the speciality.

As far as has been established, there is ~~insufficient literature~~ paucity on FCC in paediatrics in the South African setting. De Beer and Brysiewicz (2017) conducted a study in which they conceptualised family-centred care in the adult ICU. Their study participants redefined the term of family-centred care as family care described by two common values in South African communities, being *ubuntu* and *ukuhlonipha*, which mean respect and dignity respectively (de Beer and Brysiewicz, 2017). In the paediatric setting at the study site, although various protocols such as the Kangaroo Mother Care and conditional Lodging Policy exist in hopes of guiding the implementation of FCC, inconsistent implementation of these occurs. Visiting policies are rigid and restrictive as to who may and may not see the child, as well as the times during which parents have access to their children. The researcher found that much of the time, parents are told of the medical and nursing management for the child and expected to conform, without being given a choice to participate actively. Although advances have been made with regards to the management of childhood conditions, the emotional and psychological well-being of the child and family are not always considered during care (Roets, Rowe-Rowe, and Nel, 2012).

2.5 SUMMARY

The literature reviewed shows that admission of a child to hospital puts the family in crisis, leaving them feeling anxious and helpless. Keeping the family as the child's constant along with offering the family the support it needs to cope with the admission adequately is vital in the provision of FCC. In the provision of such care, the nurse plays a critical role and incorporates all members of the MDT. In South Africa, despite the advancements in managing the various conditions of children admitted to the hospital, a gap remains in providing emotional support to their families. Despite the immense amount of research published on FCC in developed countries, there remains a paucity of similar studies in South Africa. Such studies would help to bridge the gap where theory meets practice and aid in the development of strategies to adequately implement FCC in paediatric wards.

The next chapter provides a detailed discussion of the research methods used to meet the study objectives.

CHAPTER THREE

RESEARCH METHODS

3.1 INTRODUCTION

The study was conducted in two phases. Phase one comprised of the validation and contextualisation of the data collection instrument used, and Phase Two comprised the collection of the data. Chapter Three presents the research methodology, which includes the paradigm, research design, methods, setting, population, sample and the instrument used for data collection. The process of data collection and analysis are discussed. The chapter concludes with an overview of the measures used to protect the rights of the respondents.

3.2 RESEARCH METHODOLOGY

This study adopted a quantitative descriptive approach to describe FCC and investigate the gap between the theory and practice of FCC implementation by nurses working in paediatric wards.A survey method was used in order to "gather a broad spectrum of information" from nurses with the purpose of describing FCC in paediatric wards (Burns and Grove, 2007; Nieswiadomy, 2008).

3.2.1 Research Setting

The research setting was the paediatric section at a public tertiary academic hospital in Johannesburg, Gauteng. The hospital offers specialist and sub-specialist services on a

referral basis from primary health care centres, and district and regional hospitals (Department of Health, 2012). It is affiliated with the University of the Witwatersrand, which educates and trains healthcare professionals. The paediatric section consists of 11 wards, 5 of which are outpatient departments. The range of specialist wards includes wards for orthopaedic, plastic surgery, oncology, surgical high care, renal, pulmonology and neuro-developmental care. A multi-disciplinary team approach is used to manage patients and families from diverse cross-cultural backgrounds.

3.2.2 Population and Sample

Population refers to the entire group of persons that the researcher has an interest in studying who meet the criteria set by the researcher (Brink et al., 2016). The total population of this study consisted of ninety-two (N = 92) currently practicing professional nurses in the paediatric wards. Due to the small population, a census sample consisting of the entire population was recruited for the study. The sample would have allowed for an accurate representation of the respondents and decreased bias in the results ("Statistical Language - Census and Sample Research," 2003). Non-probability convenience sampling was used as the sample was conveniently available and accessible to the researcher (Burns and Grove, 2007).

In order to participate in the study, the respondents were required to be professional nurses registered with the South African Nursing Council, permanently employed, have at least three months of working experience in the paediatric ward, and be willing to participate. Three months of work experience was selected as the researcher saw it as enough time for

the professional nurse to have accustomed themselves to the way nursing care is delivered in the paediatric ward.

The researcher was only able to reach 72 out of the 92 population members for the study, many of the nurses were on annual leave, while some had resigned, and others had been granted study leave for the year, and as a result were not available to participate in the study. Under-sampling of the respondents has been noted as one of the limitations of the study in Chapter five.

3.3 DATA COLLECTION

3.3.1 The Instrument

The data collection instrument was the "Family-Centred Care Revised Questionnaire" (FCCQ-R) developed by Bruce and Ritchie (1997) and initially used in a study by Coyne et al. (2013) (**Appendix A**).

The questionnaire was made up of two scales, current practice and necessary practice, which consisted of 45 closed-ended questions as applied to both the scales. The questions were organised into 9 subscales which are based on the elements of FCC namely;

a) Family is the constant items 1,2,3
b) Parent/professional collaboration items 4,5,6,7,8,9
c) Recognition of family individuality items 10,11,12,13,14
d) Sharing information items 15,16,17,18,19
e) Developmental needs items 20,21,22,23

f) Parent-to-parent support items 24,25,26,27,28

g) Emotional/financial support items 29,30,31,32

h) Design of health care system items 33,34,35,36,37,38,39

i) Emotional support for staff items 40,41,42,43,44,45

Respondents were asked to rate items on a 5-point Likert scale (5 = strongly agree, 4 = agree, 3 = neutral, 2 = disagree, 1 = strongly disagree) the extent to which they represent the current and necessary practices of FCC. Total scores for each scale ranged from 45 to 225 points. The higher the total score indicated that there was a higher level of agreement with the items whereas a low-level score indicated a low level of agreement. A demographic section was included in the study to capture the characteristics of the respondents.

Also, the following open-ended questions were added at the end of the questionnaire:

- How would you define Family-Centered Care? - Question 1 on page 92 - 93.
- Briefly list activities (not on the questionnaire) which represent Family-Centered Care practised in your ward – Question 2 on page 93.

3.3.2 Validity and reliability of the FCCQ-R

According to Burns and Grove (2007), validity refers to the determination of how well the instrument reflects the concepts under examination. The original instrument was used in a study by Bruce and Ritchie (1997) in Nova Scotia (Canada), where a panel of FCC concept experts were used to establish the instrument's validity.

To establish the questionnaire's face and content validity in the South African context, a panel consisting of five (5) paediatric nurse experts were asked to review the questionnaire. In this study, a nurse expert was defined as a professional nurse who held a post-basic qualification in Child Health nursing with 7 or more years' clinical/educational/ managerial experience. The panel was asked to rate the questions on the questionnaire on a scale of 1-4 for clarity, readability and relevance to the South African setting. This was done to establish the suitability of the questionnaire for the study. Items which received an average score of 3 (≥75%) or more as rated by the reviewers were included in the final questionnaire used for the data collection. A score of 3 or more was used as the cut off score as it showed a higher proportion of agreement about relevance between the experts (Polit, Beck and Owen, 2007). The following adaptations were made to the questionnaire with the permission of the authors (**Appendix F**):

- Question 32: "French/English" was changed to the languages commonly spoken in the area, i.e. "English/Zulu/Africa/Sotho/French."
- The questions removed from the original 45 items as their average scores were lower than 3 are:

  – Question 11: "Explanations are presented to the family, using a variety of techniques depending on the individual needs and learning styles of the family."

  – Question 16: "After an emergency admission or unscheduled admission, there is an organised system for helping children and families understand and adjust to the health care experience."

Overall 43 out of the 45 questions on the original questionnaire were included in the questionnaire used to gather data from this South African study.

An overview of the local domain expert nurses review of the FCCQ-R for content and face validation is presented in **table 3.1.**

Table 3.1 Expert nurses review of the FCCQ-R for content and face validation

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Experts in Agreement	Item CVI
Directions	-	✓		✓	✓	3	.60
1		✓	✓	✓	✓	4	.80
2	✓	✓	✓	✓	✓	5	1.00
3	✓	✓	✓	✓	✓	5	1.00
4	✓	✓	✓	✓	✓	5	1.00
5	✓	-	✓	✓	-	3	.60
6	✓	✓	-	✓	-	3	.60
7	-	✓	✓	✓	✓	4	.80
8	✓	✓	✓	✓	✓	5	1.00
9	✓	✓	✓	✓	✓	5	1.00
10	✓	✓	✓	✓	✓	5	1.00
11	✓	✓	-	✓	✓	4	.80
12	✓	✓	✓	✓	-	4	.80
13	-	✓	✓	✓	-	3	.60
14	-	✓	✓	✓	✓	4	.80
15	-	✓	✓	✓	-	3	.60
16	✓	✓	✓	-	-	3	.60
17	✓	✓	✓	✓	✓	5	1.00
18	✓	✓	✓	✓	-	4	.80
19	✓	✓	✓	✓	✓	5	1.00
20	✓	✓	✓	✓	-	4	.80
21	✓	✓	✓	✓	✓	5	1.00
22	✓	✓	✓	✓	-	4	.80
23	-	✓	✓	✓	✓	4	.80
24	✓	✓	✓	✓	✓	5	1.00
25	✓	✓	✓	✓	-	4	.80

Table 3.1 continued

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Experts in Agreement	Item CVI
26	✓	✓	✓	✓	✓	4	.80
27	✓	✓	✓	✓	✓	4	.80
28	✓	✓	✓	✓	✓	4	.80
29	✓	✓	✓	✓	-	4	.80
30	✓	✓	✓	✓	✓	5	1.00
31	✓	✓	✓	✓	-	4	.80
32	✓	✓	✓	✓	✓	4	.80
33	✓	✓	-	✓	✓	4	.80
34	-	✓	-	✓	-	2	.40
35	✓	✓	✓	✓	-	4	.80
36	✓	✓	✓	✓	-	4	.80
37	✓	✓	✓	✓	✓	5	1.00
38	✓	✓	✓	✓	-	4	.80
39	✓	✓	✓	✓	-	4	.80
40	✓	✓	✓	✓	-	4	.80
41	✓	✓	-	✓	-	3	.60
42	✓	✓	✓	✓	✓	4	.80
43	✓	✓	✓	✓	-	4	.80
44	✓	✓	✓	✓	-	4	.80
45	-	✓	✓	✓	✓	4	.80
Open-Ended Question 1		✓	✓	✓	✓	4	.80
Open-Ended Question 2		✓	✓	✓	✓	4	.80
						Average I-CVI = 0.81	

Table 3.1 presented a summary of the item-CVI (I-CVI) and average I-CVI (scale-CVI/S-CVI). It was concluded that the questionnaire was found to have a good content validity as the scale-CVI (S-CVI) was calculated to being 0.81 with more than 83% of the items on the questionnaire having an I-CVI of >0.78 (Polit, Beck, & Owen, 2007).

Reliability is related to the questionnaire's consistency, i.e. its ability to yield stable results if used repeatedly on the same persons (Brink et al., 2016). Bruce and Ritchie (1997) tested the questionnaire's internal consistency using the Cronbach's alpha and found it to range from 0.5 to 0.8 for subscales and 0.5 to 0.9 for both total scales (i.e. the Current and Necessary scales). Tavakol and Dennick (2011) describe internal consistency as "the extent to which all items in a test measure the same concept or construct" with the acceptable value ranging from 0.70 to 0.95; thus, the values for the original questionnaire indicate acceptable reliability as they are above 0.70 (Tavakol & Dennick, 2011).

On completion of data collection, the Cronbach's alpha in this South African study was computed as 0.85 for both scales (current practice and necessary practice) using the STATA version 14 statistical software, indicating that the instrument-maintained reliability in this South African study.

3.3.3 Pre-testing Procedure

A small pre-testing procedure was conducted to measure the level of understanding of the wording and language used for the South African context as English is not the first language for most people in South Africa. The adapted FCCQ-R was administered to eight (8) nurses working in the Neonatal/Paediatric Intensive Care Units of the hospital, who were not included in the main study. The feedback from the nurses was that the completion of the questionnaire took 10–15 minutes, that it was easy to read, and that they could understand the instructions.

Following consultation with the statistician after the pre-testing procedure, some changes were made to the demographic section of the questionnaire:

- Participants were asked to give their age numerically in years and numerically state how many years they have been working in the wards.

3.3.4 Data collection procedure

The initial data collection period ran over a two-month period from 30 October till 29 December 2017 after permission from the relevant ethical, academic, and professional organisations was obtained.

The researcher went into the different wards and introduced herself to the operational managers from whom permission was sought and obtained. The researcher then approached the registered nurses, presented the study briefly and invited them to participate in the study, handing out information letters along with consent forms and questionnaires. Respondents were given verbal instructions on how to complete the questionnaire and were asked to place the completed questionnaires in the sealed demarcated box left at the nursing station. Signed written consent forms were collected from the respondents at the time of questionnaire distribution. The collection boxes were emptied every 24 hours and kept under lock and key.

Forty-eight (48) questionnaires were collected at the end of the initial data collection period. Following consultation with the statistician and supervisor a decision was made to extend data collection by a month (January 2018) and a further 10 questionnaires were

distributed. Only two (2) completed questionnaires were returned after which data collection was closed, resulting in a total of fifty returned questionnaires.

3.4 DATA ANALYSIS

Data from the collected questionnaires was organised, numbered and captured in a Microsoft Excel spreadsheet. In preparation for data analysis, two (2) returned questionnaire were dropped from the study because respondents had not completed the full questionnaire (more than 80% had been omitted). Thus, leaving a sample of 47 (n = 47) completed questionnaires for data analysis.

The statistical tests used in this study were as follows:

- Percentages, means, and the standard deviation was used to describe the respondent's demographic data.
- Means (or medians) and standard deviation were used to summarise the respondent's survey data.
- Paired t-tests were used to compare the group mean scores on nurse responses in the nine subscales to determine whether the differences were statistically significant or not (LoBiondo-Wood & Haber, 2010).
- Wilcoxon Signed Rank test was used to determine the degree of congruency between nurse responses in the nine subscales of paired observations (LoBiondo-Wood & Haber, 2010).
- Kruskal Wallis test was used to compare the differences in mean scores and to determine whether this difference was statistically significant or not (LoBiondo-Wood & Haber, 2010).

The responses from the open-ended questions were captured in a Microsoft Word document and analysed using a summative content analysis (Hsieh & Shannon, 2005). In this approach, descriptive words were identified, numbered and grouped under the different themes. The following themes were identified for the first open-ended question: family involvement, partnership with the family, family importance, care focused on patient and family, culture/language sensitivity, decision making, family inclusion, beneficial health care approach, family education, gauging parental/family knowledge on child's condition and promotion of health services. Counselling support, keeping the family constant, sibling involvement and support, discharge management and family involvement were the identified themes for the second open-ended question. The themes were allocated frequencies and percentages accordingly.

3.5 ETHICAL CONSIDERATIONS

The relevance of the study was affirmed by peers in the Department of Nursing Education. The protocol was submitted to the University of the Witwatersrand's School of Therapeutic Sciences Postgraduate Research Committee and permission was granted (**Appendix B**). The proposal was submitted to the University of the Witwatersrand Committee for Research on Human Subjects (Medical) for ethical clearance to conduct the study, which was granted (**Appendix C**). Permission was obtained from the Chief Executive Officer and the Director of Nursing to access the study sites with directive from the Gauteng Department of Health NHRD (**Appendix D**). The authors of the FCCQ-R granted permission for the use as well as amendment of the instrument (**Appendix E and F**).

All the registered nurses who met the inclusion criteria were approached by the researcher and invited to participate. Information letters (**Appendix G**) were handed out prior to the collection of the questionnaires to obtain written informed consent (**Appendix H**) from each of the nurses. The researcher assured the respondents that the information collected would be kept in the strictest confidence. They were informed that their questionnaires would be kept in a secure place with only the researcher, the supervisor as well as the biomedical statistician having access to them. To ensure anonymity, respondents were requested to abstain from writing their names or any identifiable information on their questionnaires. They were assured that their participation was entirely voluntary and that withdrawal from the study was allowed at any time without any penalty.

As a student of this university, the researcher is expected to uphold the principles of the Declaration of Helsinki for protection of human subjects (World Medical Association, 2013), as well as the Singapore declaration of research integrity (Resnik and Shamoo, 2011).

3.6 VALIDITY AND RELIABILITY OF THE STUDY

To ensure that validity and reliability was upheld throughout the study the following was done:

- The research process was followed as described in the study proposal.
- A panel of nurse experts were consulted to establish the instrument's content validity and contextualise it for the South African setting.
- A small pre-testing procedure of the instrument was performed to ensure the feasibility of the data collection process

- The researcher conducted the data collection herself, and therefore there was no inter-rater reliability breech
- A statistician was consulted throughout the study to ensure scientific integrity

3.7 SUMMARY

In this chapter, the research methodology, target population and sampling, as well as the data collection process and analysis was described. Measures to ensure validity and reliability have also been discussed. Ethical considerations were addressed.

In the next chapter, data analysis and the findings of the study are presented.

CHAPTER FOUR

RESULTS AND FINDINGS OF THE STUDY

4.1 INTRODUCTION

This chapter describes the nurse's perceptions and practices of FCC. This was achieved within a descriptive, quantitative survey. The total population (N = 92) included nurses practicing in paediatric wards at one academic hospital in Gauteng. A sample size of 47 (n = 47) respondents was obtained by means of convenience sampling. This is a response rate of 51.1% for the study. Data was collected by means of a data collection tool (**Appendix A**). Data were analysed by means of descriptive and comparative tests. The descriptive tests (frequency, mean and standard deviations) were used to synthesise nurse respondents' demographic data and questionnaire schedule. Whereas comparative statistics were used to describe and synthesise total questionnaire scores to compare the socio-demographic data with obtained levels of measurements to test for statistical significance. Statistical tests included Cronbach's reliability alpha, Wilcoxon signed rank test and Kruskal-Wallis equality of populations rank test. Testing was done on the 0.05 ($p<0.05$) level of significance.

4.2 APPROACH TO DATA ANALYSIS

Descriptive statistics were used to present the interpretation of demographic data of nurses: age, years of experience, education level and clinical setting. Frequency distributions and cross tables were used to provide an overall coherent presentation and description of the

data. Since percentages in these findings were rounded off to one decimal place, the cumulative percentages may not add up to 100% in all cases.

Descriptive statistics were then employed to describe and synthesise the distribution of the nurse responses that are inclusive of nine subscales and total questionnaire scores for the 1) Current practice and 2) Necessary practice scales. The level of agreement for each scale was added to give a total score for each of the nine subscales, and all items were added together to give a total score for current and necessary practices subscales. Mean scores were calculated by following the analytical method as advocated by Bruce and Ritchie (1997).

The Cronbach's reliability coefficient, which was reported on in Chapter 3, was then applied to assess the reliability of the summative (Likert scale) rating scale composed of all subscales of the 1) Current practice and 2) Necessary practice scales of the FCCQ-R. Furthermore, the data was assessed for normal distribution using the Shapiro Wilk statistic. The test statistic provided small w values in all the 1) Current practice and 2) Necessary practice subscales of the FCCQ-R, which demonstrated the sample was found *not to be normally distributed*. Thus, non-parametric statistical tests were then applied in this study.

The process of data analysis was achieved by using two levels of measurement in this study. Descriptive statistics was used to describe, display or summarise data in a meaningful manner, whereas comparative (inferential) statistics were used to draw conclusions and make generalisations about the larger population.

When comparing the degree of congruency between nurses' responses in the nine subscales of the 1) Current practice and 2) Necessary practice scales of the FCCQ-R, the Wilcoxen Signed Rank test was employed to provide this statistic. According to Glantz (2012), the Wilcoxen Signed Rank test is a non-parametric equivalent of the paired t-test and used to test for a difference in the mean (or median) of paired observations. Testing was done on the subscale level to further explore the data. In addition, when comparing the relationships and differences between the demographic variables (age, years of experience, education level and clinical setting) of nurses' responses in the 1) Current practice and 2) Necessary practice scales of the FCCQ-R, the Kruskal Wallis one-way analysis of variance was used to provide this statistic (Glantz, 2012). In the STATA statistical software application, the Kruskal Wallis test is used to compute the H-test which is then chi-squared ($\chi 2$) to determine the p-value. The application of the Kruskal-Wallis test to the study was used to compare ***median*** ranked differences between nurses' responses on subscale levels of the FCCQ-R. Frequency distributions and cross tables were used to provide an overall summary of the data.

Collapsing of the categories on the Likert scale was done to facilitate the presentation of the data. However, it was noted that a larger percentage of respondents answered "*agree*" or "*disagree*" in the itemised analysis. Measurement of central tendency and variation (mean and standard deviation) were used to summarise the data. The level of statistical significance was set at the level of $p<0.05$. A statistician from the University Faculty of Health Sciences Research Office assisted with analysis of the data using the statistical package STATA version 14.

4.3 RESULTS AND FINDINGS

4.3.1 Section One: Characteristics of Nurse Respondents

Results of this process are summarised in **table 4.1** for the total sample.

Table 4.1 Demographic data for nurse respondents for the total sample (n = 47)

Demographic variables	Frequency	Percentage
Age (n = 45)		
< 30 years	4	8.9%
31 to 40 years	9	20.0%
41 to 50 years	15	**33.3%**
>50 years	17	**37.8%**
Years of Experience (n = 46)		
< 5 years	12	**26.1%**
6 to 10 years	7	15.2%
11 to 15 years	11	23.9%
16 to 20 years	7	15.2%
>21 years	9	19.6%
Education level (n = 43)		
Undergraduate	14	32.6%
Postgraduate	29	**67.4%**
Clinical setting (n = 41)		
Emergency care	2	4.9%
Medical care	11	26.8%
Surgical care	8	19.5%
Out-patient department	20	**48.8%**

4.3.1.1 Age

In this study, it was noted that two respondents did not respond to this item. Of the remaining sample (n = 45) the largest (37.8%; n = 17) group of nurse respondents were older than 50 years, followed by 33.3% (n = 15) and 20.0% (n = 9) in the 41 to 50 and 31 to 40 age categories, respectively. The smallest (8.9%; n = 4) group of respondents were younger than 30 years of age. This finding is in line with the age distribution of the professionals at the South African Nursing Council (SANC) as of 2017/12/31, with most professionals being older than fifty whereas only 13% were younger than thirty (South African Nursing Council, 2018).

4.3.1.2 Years of experience

In this study, it was noted that one respondent did not respond to this item. Of the remaining sample (n = 46) the largest (26.1%; n = 12) group of nurse respondents had less than five years of experience, followed by 23.9% (n = 11) and 19.6% (n = 9) in the 11 to 15 and more than 21 years categories, respectively. Only 15.2% (n = 7) of the respondents had between 6 to 10 and 16 to 20 years of experience, respectively.

4.3.1.3 Education level

In this study, it was noted that four respondents did not respond to this item. Of the remaining sample (n = 43), the majority (67.4%; n = 29) of the respondents were educated at a postgraduate level, while 32.6% (n = 14) had an undergraduate education level. In the South African context, the respondents could have a diploma or degree in nursing as a qualification, whereas the majority (67.4%; n = 29) had an additional postgraduate

qualification. The additional nursing qualification covered a range of clinical and non-clinical specialities, including paediatric nursing. According to Duma et al. (2012), postgraduate nurses are autonomous practitioners, able to practice independently (Duma, Dippenaar, Bhengu, Oosthuizen, Middleton, Phillips, Naude and Uys, 2012).

4.3.1.4 Clinical setting

In this study, it was noted that six respondents did not respond to this item. Of the remaining sample (n = 41) the largest (48.8%; n = 20) group of the respondents worked in the out-patient departments, meaning short and intermittent engagement with patient and family. This was followed by 26.8% (n = 11) and 19.5% (n = 8) in medical and surgical care, respectively. Potentially, these professional nurses had a longer period of engaging with the patients and their family. The patients in these wards would be admitted for short-term (2 to 5 days) and longer term (2 weeks to 3 months) hospital stays. Only 4.9% (n = 2) of the respondents worked in emergency care, which means they would have engaged the family for a short period in the emergency department.

4.3.2 Section Two: Nurses' perceptions on the Necessary Scale of the FCCQ-R

The total sample comprised of 47 (n = 47) respondents who were professional nurses working in paediatric wards. The instrument used in this study was the FCCQ-R scale (Bruce & Ritchie, 1997). The researcher adhered to the scoring guidelines as outlined by the developer (Bruce & Ritchie, 1997). According to the scoring guidelines, a high score on the scales of the FCCQ-R indicates high representation of FCC in practice.

Data was analysed by nurses' perceptions on the necessary scale of the FCCQ-R using measures of central distribution (means and standard deviations) for the total questionnaire scores. The results of this process are summarised in **Table 4.2.**

Table 4.2 Means and standard deviations on the necessary scale of the FCCQ-R

Statements	Necessary scale	
	Means	Standard deviation
1. "Staff encourage parents and siblings to come and go at any time that meets the family's needs	**2.82**	1.64
2. Staff work with families to determine the level of participation in direct care and decision-making that suits the family's needs best	3.74	1.70
3. The family is the key decision maker in the care of the child	3.10	1.88
4. Staff determine the child's needs in consultation with the family and other health professionals	**4.18**	1.44
5. Parents contribute to the development and review of hospital policies and practices.	3.06	1.57
6. Parents and siblings are involved in staff orientation and continuing education programmes.	2.96	1.65
7. Educational programmes and written material convey the sense that families are key respondents in care.	3.70	1.45
8. The admission process is used as an opportunity to begin involving the family as members in the health care team.	3.82	1.67
9. Hospital facilities, policies, and procedures foster family choices for participation."	3.28	1.69
10. Interview with families are conducted in private location.	**4.24**	1.44
11. Staff are aware of and take approaches that address the fact that families take time to develop trust.	**4.00**	1.40
12. Staff discuss with the child and family what helps them deal with events during hospitalisation.	**4.00**	1.41
13. Staff assess the level of understanding and skills of the child and family before and after teaching."	**4.28**	1.51
14. Staff promote preadmission programmes which familiarise children and families with hospital staff, routines, and equipment prior to a scheduled admission.	3.86	1.47
15. Information is routinely communicated to help families understand each aspect of care that their child will experience such as anticipated	**4.18**	1.45

Table 4.2 continued

Statements	Necessary scale	
	Means	Standard deviation
16. Any family member significantly involved in the child's care is encouraged to discuss or chart information about the care of their child.	3.30	1.73
17. Staff coordinate the flow and sequence of information given to children and their families, ensuring that the child's information needs are a priority."	3.98	1.48
18. "Staff encourages parents to discuss concerns with other parents with similar experiences informally or in formal parent groups.	3.88	1.45
19. Staff provide programmes and support for parents, siblings and members of the extended family to assist families in managing needs.	**4.26**	1.26
20. Staff assess the needs and concerns of siblings	3.50	1.49
21. There is a designated comfortable are for parents to gather.	3.74	1.54
22. Staff help children and family stay in touch with their family and friends.	3.76	1.49
23. Direct care managers have adequate knowledge in child development to support hospital staff in the practice of family – centred care.	3.66	1.60
24. Hospital brochures accurately describe the health care experience for children and their families.	3.64	1.54
25. Staff maintain familiar routines for each child and family.	3.52	1.74
26. Staff assess the child's interaction with staff, peers and family.	3.48	1.97
27. When possible, the same staff members are assigned to care for the child and family.	3.68	1.62
28. Information and support are provided to help families understand the illness process and the impact on the child and family, choices and risks, services, and roles of various health professionals.	**4.22**	1.40
29. Staff recognises the financial strain on families and assist them in obtaining help.	**4.00**	1.48
30. During procedures, a staff member is designated to explain to the child and family exactly what is happening.	**4.30**	1.53
31. "Non -urgent outpatient services are available daily and in the evening.	3.32	1.66
32. All written material for families is available in English/Zulu/Afrikaans/Sotho/French versions.	3.70	1.67

Table 4.2 continued

Statements	Necessary scale	
	Means	Standard deviation
33. "Parent evaluation are considered reliable sources of information about how well the hospital meets their needs.	3.78	1.45
34. Staffing patterns are planned according to the developmental and psychosocial needs of children.	3.70	1.56
35. There are guidelines to assist staff in providing care during painful procedures such as: teaching children ways to cope with pain and post-procedural debriefing of the child.	3.94	1.57
36. Job descriptions and performance appraisal systems incorporate expectations of family-centred care such as: knowledge of family dynamics, skills and in collaboration, problem-solving and interventions that address family's needs.	3.90	1.40
37. Continuing education programmes provide opportunities for staff to learn to deal effectively with families.	**4.28**	1.37
38. The hospital recognises and rewards special knowledge and skills that are needed to care for children and families.	3.98	1.39
39. Staff are encouraged to identify, plan and evaluate new programmes, policies and procedures to improve the quality of patient and family care.	**4.18**	1.49
40. Staff can express confidentiality to those responsible for assuring quality care, their concerns related to those demands of providing care for children and families."	**4.14**	1.50

Table 4.2 presented these results. Items with a mean score equal to or greater than 4 were item numbers 10, 11, 12, 13, 15, 19, 28, 29, 30, 40, 42 and 43. These scores indicate that the respondents agreed that activities stated in these items were necessary practices for FCC. Of these items, number 30 had the highest mean score of 4.30 (SD 1.53). Here respondents agreed that "*during procedures, the presence of a designated staff member was essential to explain to the child and family exactly what is happening".*

Items with the lowest scores on the necessary scale of the FCCQ-R were item numbers 1 and 6. Item one had a mean score of 2.82 (SD 1.64) indicating respondents disagreed that parents and siblings should be encouraged by staff members to come and go at any time according to family needs. Item 6 had a mean score of 2.96 (SD 1.65) indicating respondents disagreed that *"parents and siblings be involved in staff orientation and continuing education programmes"*. These scores indicate that respondents did not consider these activities as necessary for FCC.

Each item on the questionnaire was categorised and placed into subscales for the topics outlined in the necessary scale related to FCC. **Table 4.3** provides an overview of this process.

Table 4.3 Subscale item numbers with a range of scores

Subscale	Items included	Range of Scores
"Family is the constant	#1, #2, #3	Minimum 3 Maximum 15
Parent-professional collaboration	#4, #5, #6, #7, #8, #9	Minimum 6 Maximum 30
Recognition of family individuality	#10, #11, #12, #13	Minimum 4 Maximum 20
Sharing information	#14, #15, #16, #17	Minimum 4 Maximum 20
Developmental needs	#18, #19, #20, #21	Minimum 4 Maximum 20
Emotional-financial support	#22, #23, #24, #25, #26	Minimum 5 Maximum 25
Parent-to-parent support	#27, #28, #29, #30	Minimum 4 Maximum 20
Design of health care system	#31, #32, #33, #34, #35, #36, #37	Minimum 7 Maximum 35
Emotional support for staff"	#38, #39, #40, #41, #42, #43	Minimum 6 Maximum 30

Key: # = item

Further, the total mean scores for the necessary scale were obtained for each respondent for questions 1 to 43. Total subscale scores for each subscale were also obtained by totalling respondents' scores on each subscale. Also, average subscale scores were computed for each to compare scores between subscales. **Tables 4.4** and **4.5** presents these results.

Table 4.4 Means and standard deviations on the necessary scale of the FCCQ-R

Subscale	Mean Score	SD	Range of Scores
"Family is the constant	8.53	4.98	3 - 15
Parent-professional collaboration	19.53	7.00	6- 30
Recognition of family individuality	16.64	3.74	4 – 20
Sharing information	14.60	5.03	4 – 20
Developmental needs	14.68	4.52	4 – 20
Emotional-financial support	16.94	5.90	5 – 25
Parent-to-parent support	16.21	4.50	4 – 20
Design of health care system	23.57	9.46	7 – 35
Emotional support for staff "	24.55	7.25	6 – 30
Total score	155.26	37.59	43 - 215

Table 4.4 shows means and standard deviations for the total scores and subscale scores as well as the average subscale scores. As presented in the table, the mean total score is 155.26 – note that possible scores range from 43 to 215. Total subscale scores are not commented on since each subscale contains a different number of items. Means and averages are presented and will indicate approximate scores.

Table 4.5 shows average subscale scores on the necessary scale of the FCCQ-R.

Table 4.5 Averages on the necessary scale of the FCCQ-R

Subscale	Mean	Standard Deviation
"Family is the constant	**3.22**	1.44
Parent-professional collaboration	3.50	1.26
Recognition of family individuality	**4.13**	1.26
Sharing information	3.83	1.25
Developmental needs	3.84	1.19
Emotional-financial support	3.61	1.23
Parent-to-parent support	4.05	1.32
Design of health care system	3.62	1.30
Emotional support for staff"	4.00	1.38

Table 4.5 presents these results. The highest mean average subscale score was obtained for "*recognition of family individuality*" (M = 4.13; SD 1.26). The lowest was obtained for *"family is the constant"* (M = 3.22; SD 1.44). There was little difference between the *"sharing information"* subscale (M = 3.83; SD 1.25) and "*development needs*" subscale (M = 3.83; SD 1.19). It is noteworthy that all the average scores were greater than 3, the neutral point on the Likert scale, therefore there was overall agreement on all items.

4.3.2.1 Open-ended Responses

To obtain an understanding of how professional nurses in the South African context define FCC, respondents were asked to define FCC as they perceived it, the methodology for this is explained in chapter 3 (*Appendix A - question 1 on page 92*). Family-centred care was founded in developed countries, making it important to understand the FCC definition in the South African context as it is a developing country. Summative content analysis as described by Hsieh and Shannon (2005) was used to summarise the findings. The data yielded eleven (11) categories.

Table 4.6 Categories for the definition of FCC

Theme	Frequency	Percentage
Family involvement	15	39.5%
Partnership with the family	8	21.1%
Family importance	3	7.9%
Care focused on patient and family	2	5.3%
Culture/language sensitivity	2	5.3%
Decision making	2	5.3%
Family inclusion	2	5.3%
Beneficial health care approach	1	2.6%
Family education	1	2.6%
Gauging parental/family knowledge on child's condition	1	2.6%
Promotion of health services	1	2.6%
	38	100.0%

The results show that most of the respondents described FCC as a form of care which involved the family (39.5%; n = 15), partnered with the family (21.1%; n = 8) and considering the family as important (n = 3, 7.9%; n = 3).

4.3.3 Section Three: Nurses perceptions on the current scale of FCCQ-R

In this section, data was analysed by nurses' perceptions on the current scale of the FCCQ-R using measures of central distribution (means and standard deviations) for the total questionnaire scores. The results of this process are summarised in **Table 4.7.**

Table 4.7 Means and Standard Deviations on the Current Scale of the FCCQ-R

Statements	Current scale	
	Means	Standard deviation
1. "Staff encourage parents and siblings to come and go at any time that meets the family's needs	2.50	1.46
2. Staff work with families to determine the level of participation in direct care and decision-making that suits the family's needs best	3.66	1.29
3. The family is the key decision maker in the care of the child	3.34	1.49
4. Staff determine the child's needs in consultation with the family and other health professionals."	**4.24**	1.02

Table 4.7 continued

Statements	Current scale	
	Means	Standard deviation
5. "Parents contribute to the development and review of hospital policies and practices.	2.26	1.50
6. Parents and siblings are involved in staff orientation and continuing education programmes.	2.52	1.52
7. Educational programmes and written material convey the sense that families are the families are key respondents in care.	3.22	1.43
8. The admission process is used as an opportunity to begin involving the family as members in the health care team.	3.74	1.23
9. Hospital facilities, policies, and procedures foster family choices for participation."	2.90	1.47
10. Interview with families are conducted in private location.	**4.06**	1.10
11. Staff are aware of and take approaches that address the fact that families take time to develop trust.	3.82	1.02
12. Staff discuss with the child and family what helps them deal with events during hospitalisation.	3.90	0.99
13. Staff assess the level of understanding and skills of the child and family before and after teaching.	**4.04**	1.14
14. Staff promote preadmission programmes which familiarise children and families with hospital staff, routines, and equipment prior to a scheduled admission.	3.00	1.51
15. Information is routinely communicated to help families understand each aspect of care that their child will experience such as anticipated	**4.00**	1.12
16. Any family member significantly involved in the child's care is encouraged to discuss or chart information about the care of their child.	3.12	1.52
17. Staff coordinate the flow and sequence of information given to children and their families, ensuring that the child's information needs are a priority.	3.74	1.31
18. Staff encourages parents to discuss concerns with other parents with similar experiences informally or in formal parent groups.	3.40	1.39
19. Staff provide programmes and support for parents, siblings and members of the extended family to assist families in managing needs.	3.70	1.27
20. Staff assess the needs and concerns of siblings	2.86	1.31
21. There is a designated comfortable are for parents to gather."	2.98	1.48

Table 4.7 continued

Statements	Current scale	
	Means	Standard deviation
22. "Staff help children and family stay in touch with their family and friends.	3.42	1.34
23. Direct care managers have adequate knowledge in child development to support hospital staff in the practice of family – centred care.	2.90	1.53
24. Hospital brochures accurately describe the health care experience for children and their families.	2.84	1.33
25. Staff maintain familiar routines for each child and family.	3.26	1.64
26. Staff assess the child's interaction with staff, peers and family.	3.66	1.42
27. When possible, the same staff are assigned to care for the child and family.	3.16	1.45
28. Information and support are provided to help families understand the illness process and the impact on the child and family, choices and risks, services, and roles of various health professionals.	3.84	1.33
29. Staff recognise the financial strain on families and assist them in obtaining help.	3.68	1.22
30. During procedures, a staff member is designated to explain to the child and family exactly what is happening.	**4.38**	1.03
31. Non -urgent outpatient services are available daily and in the evening.	2.98	1.39
32. All written material for families is available in English/Zulu/Afrikaans/Sotho/French versions.	2.68	1.42
33. A written summary of relevant information about the child is available in the primary official language of the family.	2.56	1.46
34. The physical layout of the unit is designed to meet the developmental and psychological needs of the child and family.	3.60	1.31
35. Resources exist to provide families with the appropriate support that they need at varying times.	3.30	1.15
36. Parent evaluation are considered reliable sources of information about how well the hospital meets their needs.	3.30	1.16
37. Staffing patterns are planned according to the developmental and psychosocial needs of children.	2.98	1.52
38. There are guidelines to assist staff in providing care during painful procedures such as: teaching children ways to cope with pain and post-procedural debriefing of the child."	3.38	1.46

Table 4.7 continued

Statements	Current scale	
	Means	Standard deviation
39. "Job descriptions and performance appraisal systems incorporate expectations of family-centred care such as: knowledge of family dynamics, skills and in collaboration, problem-solving and interventions that address family's needs.	3.06	1.41
40. Continuing education programmes provide opportunities for staff to learn to deal effectively with families.	3.72	1.18
41. The hospital recognises and rewards special knowledge and skills that are needed to care for children and families.	2.92	1.40
42. Staff are encouraged to identify, plan and evaluate new programmes, policies and procedures to improve the quality of patient and family care.	3.46	1.34
43. Staff can express confidentiality to those responsible for assuring quality care, their concerns related to those demands of providing care for children and families."	3.58	1.43

Table 4.7 presented these results. The items with a mean score equal to or greater than 4 were item numbers 4, 10, 13, 15 and 30. These scores indicate that respondents were in agreement that activities stated in these items were included in current practices for FCC. Of these items, number 30 had the highest mean score of 4.38 (SD 1.03). Here the respondents agreed that "*during procedures, the presence of a designated staff member was essential to explain to the child and family exactly what was happening"* was included in their current practice activities of FCC.

Items with the lowest scores on the current practice scale of the FCCQ-R were item numbers 1, 5, 6, 9, 20, 21, 23, 24, 31, 32, 33. 37 and 41. These scores indicated that respondents disagreed that activities stated in these items were included in current practices for FCC.

Total scores for the current practice scale were obtained for each respondent for questions 1 to 43. Total subscale scores for each subscale were obtained by totalling respondents' scores on each subscale. Also, average subscale scores were computed for each to compare scores between subscales. **Tables 4.8** and **4.9** presents these results.

Table 4.8 Means and standard deviations on the current scale of the FCCQ-R

Subscale	Mean Score	SD	Range of Scores
Family is the constant	6.89	4.13	3 - 15
Parent-professional collaboration	13.43	7.65	6- 30
Recognition of family individuality	13.43	4.90	4 – 20
Sharing information	10.79	5.72	4 – 20
Developmental needs	11.57	7.16	4 – 20
Emotional-financial support	8.60	6.04	5 – 25
Parent-to-parent support	12.62	4.53	4 – 20
Design of health care system	13.30	9.17	7 – 35
Emotional support for staff	13.83	8.62	6 – 30
Total	**104.43**	41.13	43 - 215

Table 4.8 shows means and standard deviations for the total scores and subscale scores as well as average subscale scores. As presented in the table, the mean total score is 104.43 – note that possible scores range from 43 to 215. Total subscale scores are not commented on since each subscale is based on a different number of items. Means and averages are presented and will indicate approximate scores.

Table 4.9 Averages on the current scale of the FCCQ-R

Subscale	Mean	Standard Deviation
"Family is the constant	3.16	1.06
Parent-professional collaboration	3.14	0.95
Recognition of family individuality	**3.95**	0.71
Sharing information	3.46	0.99
Developmental needs	3.23	1.02
Emotional-financial support	3.21	0.93

Parent-to-parent support	3.76	0.90
Design of health care system	**3.05**	0.86
Emotional support for staff “	3.35	0.88

Table 4.9 presented these results of the averages on the current scale of the FCCQ-R. The highest mean average subscale score was obtained for “*recognition of family individuality*” (M = 3.95; SD 0.71). The lowest was obtained for the “*design of the health care system*” (M = 3.05; SD 0.86). It is noteworthy that all the average scores were greater than 3, the neutral point on the Likert scale, therefore there was overall agreement on all items.

4.3.3.1 Open-ended responses

The instrument was developed based on activities reflective of FCC in developed countries. Seeing that South Africa is a developing country it is possible that FCC practices are not the same activities as those in developed countries, it was imperative to ask respondents to list FCC activities of their daily practice not listed on the questionnaire *(see Appendix A -question 2 on page 92)*. Summative content analysis as described by Hsieh and Shannon (2005) was used to summarise the findings. The data yielded five (5) categories. **Table 4.10** presents these results.

Table 4.10 Categories for practices reflective of FCC

Activities	Frequency	Percentage
Counselling support	9	**31.0%**
Keeping the family constant	9	**31.0%**
Sibling involvement and support	3	**10.4%**
Discharge management	5	17.2%
Family involvement	3	**10.4%**
Total	29	100.0%

The results found that counselling support and keeping the family constant were the most practised activities (31.0%; n = 9) in the respective wards. The least practised activities (10.4%; n = 3) were sibling and family involvement, which included sibling support.

4.3.4 Section Four: Comparisons between Current and Necessary Scales of the FCCQ-R

4.3.4.1 Distribution of the sample

The Shapiro Wilk test was used to determine whether the sample had a normal distribution and based on the small sample the test resulted in a small w-value which indicated that the sample that was *not normally distributed*.

4.3.4.2 Reliability analysis

Findings for the reliability analysis were based solely on the reliability coefficient, and no subscales of the FCCQ-R were omitted to maximise reliability of the coefficient alpha. These findings meet the standard 0.80 to 0.85 for reliability (Polit & Beck, 2008) and suggest a positive relationship exists between the variables of the subscale scores. This was described more in detail in Chapter 3 of this report.

Table 4.11 Paired t-test for comparison between parent and professional collaboration by current and necessary scales of the FCCQ-R

Variable	n	Mean	SD	CI	p-value
Current scale	47	3.26	0.14	2.99 – 3.54	0.000
Necessary scale	47	3.97	0.08	3.80 – 4.14	

(t = 5.13; df = 46; p = 0.000)

Table 4.11 presented these results. A statistically significant (p = 0.000) difference was found in the mean subscale scores for parent and professional collaboration between the two scales. The mean score for parent and professional collaboration on the necessary scale was statistically significantly higher than the mean score on the current scale (M = 3.97 vs M = 3.26). Meaning there is a difference in respondents' perceptions between these two scales.

4.3.4.3 Comparisons between current practice and necessary practice

Table 4.12 Medians for current practice and necessary practice by nine subscales and total scale scores

Subscales	Current scale				Necessary scale			
	n	%	Md	SD	n	%	Md	SD
Family as the constant	47	94.0%	8.00	4.13	45	90.0%	9.00	4.98
Parent/Professional Collaboration	47	94.0%	13.00	7.65	47	94.0%	**21.00**	7.00
Recognition family individuality	47	94.0%	14.00	4.90	47	94.0%	18.00	3.74
Sharing information	47	94.0%	12.00	5.72	47	94.0%	15.00	5.03
Developmental Needs	46	92.0%	12.00	7.16	47	94.0%	15.00	4.52
Parent to parent support	47	94.0%	9.00	6.04	47	94.0%	**18.00**	5.90
Emotional / financial support	46	92.0%	13.00	4.53	47	94.0%	18.00	4.50
Design of health care system	47	94.0%	12.00	9.17	46	92.0%	**26.00**	9.46
Emotional support for staff	47	94.0%	12.00	8.62	47	94.0%	**27.00**	7.25
Total Scores	47	94.0%	**111.00**	41.13	47	94.0%	**159.00**	37.59

Key: Md = Median

Table 4.12 presented these results. In this study, total scores on the necessary scale show a higher 159.00 median score compared to a lower 111.00 median score on the current scale. Similar findings are also observed in the subscales of both the current and necessary scales,

whereby all subscale median scores are higher in the necessary scale compared to the current scale. **Figure 4.1** provides a graphical representation of these results.

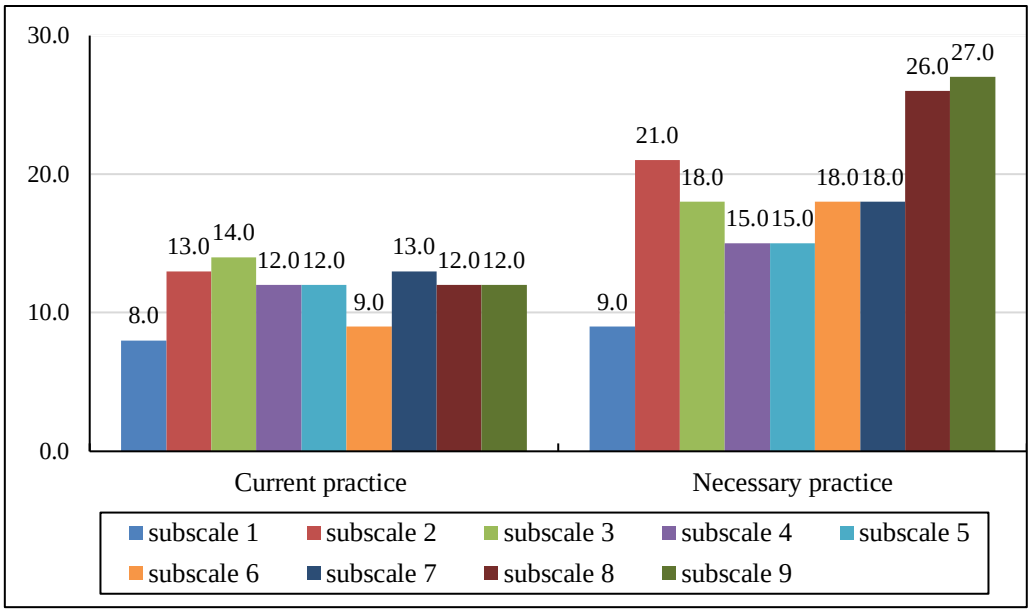


Figure 4.1 Comparison of median total scores for current practice and necessary practice by nine subscales

Based on the observed differences in the median subscale scores on both scales (**Table 4.12**), further testing was undertaken to determine congruency between these scales; the Wilcoxon signed ranks test was employed to provide the test statistic. According to Glantz (2012), the Wilcoxon Signed Ranks test is a non-parametric equivalent of the paired t-test, which is commonly used to test for difference in the mean (or median) of paired observations. In this study, a non-parametric Wilcoxon Signed Rank Test was employed in STATA because the researcher wanted to rank order importance of the paired subscales. **Table 4.13** presents these results.

Table 4.13 Summary statistics for the Wilcoxon signed rank test by FCCQ-R scales and subscales

Subscale	Sign	n	z statistic	p-value
"Recognising family individuality	Positive differences Negative differences Zero Total	2 34 10 46	z = -5.439	0.000*
Development needs	Positive differences Negative differences Zero Total	2 34 10 46	z = - 5.357	0.000*
Emotional support for staff	Positive differences Negative differences Zero Total	6 35 6 47	z = -5.039	0.000*
Health care design	Positive differences Negative differences Zero Total	6 33 7 46	z = -4.900	0.000*
Emotional and financial support for families	Positive differences Negative differences Zero Total	4 32 10 46	z = -4.805	0.000*
Parent and professional Collaboration	Positive differences Negative differences Zero Total	6 32 9 47	z = -4.500	0.000*
Parent –to-parent support	Positive differences Negative differences Zero Total	7 33 7 47	z = -4.327	0.000*
Sharing information with parents	Positive differences Negative differences Zero Total	8 32 7 47	z = -4.284	0.000*
Family is the constant"	Positive differences Negative differences Zero Total	6 27 12 45	z = -4.033	0.001*

Key: * = statistical significance

A Wilcoxen signed-ranks test indicated that "*recognising family individuality*" (Md = 18.0; SD = 3.74) was higher (ranked ordered 1) in the Necessary practice scale than the Current practice scale (Md = 14.00; SD = 4.90), Z = 5.439, p = 0.000. Similarly, "*development*

needs" (Md = 15.0; SD = 4.52) was higher (ranked ordered 2) in the Necessary Practice than Current practice (Md = 12.00; SD = 7.16), Z = 5.357; p = 0.000), and "*emotional support for staff*" (Md = 27.00; SD = 7.25) was higher (ranked ordered 3) in the Necessary practice scale than the Current practice scale (Md = 12.00; SD = 8.62), Z = 5.039, p = 0.000). Results of this process are displayed in **table 4.13**.

Data were then further explored based on the observed differences in the median scores a paired t-test was used to compute the t-statistic, confidence interval and significance. According to Grove, Burns and Grey (2013), computing a confidence interval (CI) is more appropriate as it provides the upper and lower ranges of the statistic. A p-value of 0.05 ($p<0.05$) was used to determine significance. **Table 4.14** presents these results.

Table 4.14 Summary statistics for paired t-test for comparison of current practice and necessary practice scales of the FCCQ-R

Variable	n	Mean	SD	CI	p-value
Current practice	47	**3.44**	**0.62**	**3.26 – 3.62**	0.000*
Necessary practice	47	4.16	0.44	4.03 – 4.29	

(t = - 6.96; df = 46)

These results indicated that there was a statistical difference for mean total scores between the current practice and necessary practice scales (t = -6.96; df = 46; p = 0.000). In other words, the necessary practice scale (M = 4.16) did have a statistically significant higher mean than the current practice scale (M = 3.44), implying that in terms of the mean scores the **current practice activities** of nurses **did not match** their perceptions of **activities necessary to provide family centred care.**

4.3.5 Relationships between Demographic Data and Mean Scores

4.3.5.1 Current Practice Scale of the FCCQ-R

Table 4.15 Summary of statistics from the Kruskal Wallis test by the current practice subscales of the FCCQ-R

Categorical variable	n	Median	Kruskal Wallis rank sum	Chi-squared $\chi 2$	p-value
Age					
<30 years	4	**3.80**	119.0	3.941	0.260
31 to 40 years	9	3.34	153.0		
41 to 50 years	15	3.41	323.0		
>50 years	17	3.60	440.0		
Years of experience					
<10 years	19	3.41	470.0	1.303	0.521
11 to 20 years	18	3.44	374.0		
>20 years	9	**3.68**	237.0		
Education level					
Postgraduate	29	3.54	573.0	2.838	0.092
Undergraduate	14	**3.75**	373.0		
Clinical setting					
Emergency care	2	3.28	28.0	5.575	0.134
Medical care	11	3.61	223.0		
Outpatient department	20	**3.67**	498.0		
Surgical care	8	3.06	112.0		

Table 4.15 presented these results. The relationship between nurses' demographic data and the level of current practice subscales was investigated using the Kruskal-Wallis test. Based on the results of this study, there was no statistically significant difference between current practice responses and demographic variables (age, years of experience, education level and clinical setting).

4.3.5.2 Necessary Practice Scale of the FCCQ-R

Table 4.16 Summary of statistics from the Kruskal Wallis test by necessary practice subscales of the FCCQ-R

Categorical variable	n	Median	Kruskal Wallis rank sum	Chi-squared $\chi 2$	p-value
Age					
<30 years	4	**4.60**	145.0	5.731	0.125
31 to 40 years	9	4.34	230.0		
41 to 50 years	15	3.96	290.0		
>50 years	17	4.18	370.0		
Years of experience					
<10 years	19	**4.38**	455.0	0.062	0.969
11 to 20 years	18	4.03	412.0		
>20 years	9	4.26	214.0		
Education level					
Postgraduate	29	4.27	654.0	0.172	0.678
Undergraduate	14	**4.32**	292.0		
Clinical setting					
Emergency care	2	3.92	20.0	3.147	0.369
Medical care	11	**4.38**	244.0		
Outpatient department	20	4.33	459.0		
Surgical care	8	4.04	137.5		

Table 4.16 presented these results. The relationship between nurses' demographic data and the level of current practice subscales was investigated using the Kruskal-Wallis test. Based on the results of this study, there was no statistical significant difference between necessary practice mean responses and demographic variables.

4.4 SUMMARY

This chapter described the process of data analysis. The descriptive and comparative statistics yielded from the data were presented in table and graph form. A brief description and interpretation of data was included. Generally, the nurses in this study viewed the FCC

elements (subscales) as important, yet this was not reflected in their current practice in their respective wards. The elements that they had reported as necessary in their practice were not ranked as the most important. Although no statistically significant association was found between any of the demographic data variables, respondents who were younger than thirty or had more than 15 years' experience, and were in possession of a post-graduate qualification, were found to be implementing the elements of FCC in their practice. It was interesting to note however that postgraduates younger than 30 years of age, but inexperienced, felt that the FCC elements identified were necessary for the adequate implementation of FCC in their practice. The findings will be discussed further in the next chapter**.**

CHAPTER FIVE

DISCUSSION OF STUDY FINDINGS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The final chapter of the study presents a summary of the study and discussion of the main findings as per the objectives. This will be followed by the limitations encountered during the study as well as the recommendations for clinical practice, nursing education and areas for further research.

5.2 SUMMARY OF THE STUDY

The purpose of this study was to describe FCC in the South African context by describing ~~investigating~~ the perceptions and practices of the professional nurses working in the paediatric wards at a tertiary academic hospital in Gauteng. With the objective to describe the perceptions and identify practices of professional nurses working in paediatric wards concerning elements of FCC as well as to make a comparison between their perceptions and practices. A quantitative, descriptive design with a self-administered survey was used to meet the purpose and objectives of the study. A questionnaire developed by Bruce and Ritchie (1997), the "*Family-Centred Care Questionnaire-Revised*" was used for data collection. The target population were professional nurses working in the paediatric wards of a tertiary academic hospital in Gauteng. The overall response rate for the study was 51.08%, and the STATA version 14 statistical software package was used for statistical analysis. The main findings are described in relation to the objectives of the study.

5.3 DISCUSSION OF MAIN FINDINGS

5.3.1 Demographic Characteristics of the Study

Of the 47 completed questionnaires received from respondents, more than one-third (37.8%; n = 17) were over 50 years old. This is consistent with the global challenge of an ageing nursing workforce (Sherman, Chiang-Hanisko and Koszalinski, 2013). A report by the United Nations stated that 57 countries are in crisis with regards to their health workforce, of which 36 were in sub-Saharan Africa (*United Nations Population Facts Health Workers, International Migration and Development*, 2006). Nurses under 30 were the least represented at 8.3% (n = 4) of the total sample. The findings concur with the Organisation for Economic Co-Operation and Development, which estimated that by 2015 there would be a higher ratio of retirees than young entrants to the workplace (Sherman et al., 2013).

More than one-quarter (26.1%; n = 12) of the respondents had less than five years' experience working in the paediatric wards. The least (15.2%; n = 7) respondents were spread out between nurses who had 6 to10 and 16 to 20 years of experience. Literature has shown that experience is not merely taken as working with patient's conditions and situations, but it also involves reflecting on the encounters in order to refine decision-making abilities at an intuitive level (McHugh and Lake, 2010). However, nurses with more working experience can generally perform more complex tasks than those with less experience (McHugh and Lake, 2010). From this, an assumption can be made that more years of experience working in the paediatric wards would result in better clinical acumen when dealing with children and their families.

A majority (67.8%; n = 29) of the respondents reported to having a postgraduate qualification. The post-graduate qualification encompasses specialities ranging from oncology, nephrology and orthopaedics, and includes paediatric nursing. Paediatric nursing in South Africa is a post-registration qualification that is registered as Child Nursing with SANC. The qualification is offered at both colleges and universities as a 1-year diploma and a 2-year master's degree respectively. Paediatric nurses are a scarce speciality in South Africa with their main role being to decrease the child mortality and morbidity rates in hospitals (Coetzee, 2014).

Another characteristic of the respondents was the clinical setting in which they currently practise. Twenty (n = 20; 48.8%) of the respondents work in the outpatient department (OPD). In this setting engagement with the child and their families is often short. Family-centred care in the OPD setting is relatively different to that offered in the short-term to long-term stay wards. The most common way of delivering FCC in the OPD setting is family inclusion and family psycho-education (Heru, 2015). Family inclusion goes beyond having the family present in the patient routine visit; it includes finding out about the psychosocial demands the illness has had on the family, assessing family interactions and functioning, and identifying any signs of caregiver burden (Heru, 2015). A minority (4.9%; n = 2) of the respondents would have engaged the family for a short period in the emergency department. The shortness of the encounter with families in the emergency department with health care professionals poses a challenge to creating an effective partnership with them (Dudley, Ackerman, Brown and Snow, 2015). Other challenges faced in the emergency department include family and children not being aware of their role as partners in care as well as having to limit family presence during invasive procedures or resuscitations (Dudley et al., 2015). Respondents working in the medical and

surgical wards made up 19.51% and 26.83% respectively. The children in these wards are usually admitted for longer periods as opposed to those seen in the OPD or emergency departments. This allows the child and their families to develop relationships, and to establish an effective partnership. Professional nurses in these wards have a longer period of engaging with the child and their family, allowing for more opportunities to provide care that is family-centred.

The main findings of the study are discussed below in accordance with the study's objectives.

5.3.2 Objective One: Describe the perceptions of professional nurses working in paediatric wards concerning elements of FCC

The first objective of the study was to describe the perceptions of professional nurses working in the paediatric wards concerning FCC. Results from the Necessary scale of the FCCQ-R guided these findings.

Perceptions as defined in this study refer to "the nurse's interpretation of any given aspect of family-centred care, as described by that nurse" (Follett, 2006). Respondents in this study had higher average scores on the Necessary scale for these three elements; "*recognising family individuality"* (M = 4.14; SD 1.26), *"parent-to-parent support* (M = 4.05; SD = 1.32) and *emotional support for staff* (M = 4.00; SD = 1.38) These findings concur with previous research by Bruce and Ritchie (1997), Peterson Cohen and Parsons (2004) and Coyne et al. (2013) which indicates that the nurses who responded found these elements necessary for the adequate implementation of FCC. Elements found to have the

lowest average scores were "*family is the constant" (M = 3.22; SD = 1.44), "parent and professional collaboration*" (M = 3.50; SD = 1.26) and *"design of the healthcare system* (M = 3.62; SD = 1.30*).* These findings are similar to those of previous research done which reported "*parent and professional collaboration"* as the lowest scored necessary element (Bruce and Ritchie, 1997; Coyne et al., 2013; Peterson et al., 2004).

In an open-ended question, participants were asked to define FCC as they perceive it. This was done to get an understanding of what FCC means to professional nurses in the South African context. Most of the respondents defined FCC as care that involves the family, where the healthcare professional and family work in partnership and where the family is recognised as being important to the child's care. This definition is similar to that of the Institute for Patient- and Family-Centred Care, which defines FCC as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families " ("Institute for Patient- and Family-Centred Care," 2017) This indicates that the professional nurses at this study site were aware of what FCC is and what it entails and therefore should be able to practise it adequately.

These findings also reinforced those reported by Coyne, O'Neil, Murphy, Costello and O'Shea (2011), who found family involvement and working in partnership with parents as components central to delivering FCC. Information sharing and decision making were reported to be aspects essential in involving the family in the care of the child (Coyne, O'Neill, Murphy, Costello and O'Shea, 2011). With regards to working in partnership with parents, the nurses saw their role as that to encourage and empower them to be able to fully participate in the delivery of non-medical care to their child (Coyne et al., 2011).

5.3.3 Objective Two: Identify practices of professional nurses working in paediatric wards reflective of the elements of FCC

The second objective was to identify practices of professional nurses in the paediatric wards reflective of FCC. Results from the Current scale of the FCCQ-R guided these findings.

Findings in this study revealed respondents had higher average scores for *"recognition of family individuality"* (M = 3.95; SD = 0.71), "*parent-to-parent support*" (M = 3.76; SD = 0.90) and "*sharing information*" (M = 3.46; SD = 0.99). Bruce and Ritchie (1997), Peterson Cohen and Parsons (2004) and Coyne et al. (2013) reported that respondents in their studies found the least likely practised elements to include *parent and professional collaboration, emotional support for staff* and *design of the health care system*. They also found that *respecting family individuality, providing families with emotional and financial support* and *regarding them as a constant in the child's life* were consistently practised (Bruce and Ritchie, 1997; Coyne et al., 2013; Peterson et al., 2004).

One finding from this study appears contrary to these studies as the respondents indicated that they are less likely to show an understanding that the "*family is the constant in the child's life*", whereby the average score was a low 3.16 (SD 1.06). The other findings reinforced the previous studies as the nurses reported that the facilities did not enable collaboration between parents and professionals (M = 3.14; SD 0.95) and that the overall "design of the healthcare system" (M = 3.05; SD = 0.86) was not conducive to the implementation of FCC. The nurses reported they were not given adequate emotional support (M = 3.35; SD 0.88) they needed to provide FCC. The nurses stated that they were

least likely to recognise the different developmental needs (M= 3.23; SD = 1.02) and provide them (families) with emotional and financial support (M = 3.21; SD = 0.93).

In order to get an understanding of which activities reflective of FCC are practiced in paediatric wards, the nurses were requested to list activities of their daily practice that were not included on the questionnaire. This was done as the data collection instrument used is based on research in developed countries, and as South Africa is a developing country, local practices may differ. Findings revealed that the most practised activities (31.0%; n = 9) included providing counselling and support to the families and keeping them a constant in the hospitalised child's life. The least-practiced activities (10.4%; n = 3) were those in which the siblings and family were involved in the child's care, which includes allowing sibling support.

It was interesting to find that keeping the family as a constant was listed as an activity practised in the wards, yet it had one of the lowest scores under the Necessary scale of FCCQ-R. This discrepancy may be because the nurses listed activities different to those on the instrument. The activities listed to demonstrate how the family is kept as a constant in the child's life included rooming –in/lodger facilities, allowing for the presence of mothers in the wards and allowing parents to visit their children from 12:00–17:00. All these aforementioned activities are part of the restrictive FCC policies currently in practice in South Africa (Irlam and Bruce, 2002).

5.3.4 Objective Three: Comparison between nurses' perceptions and their practice reflective of FCC in paediatric wards

The last objective of the study was to compare the nurses' perceptions of FCC-related activities with their actual practices.

Findings from this study revealed that the paired total mean scores of the nurses' perceptions were higher (M = 4.16; CI = 4.03 – 4.29) than their actual practice (M = 3.44; CI = 3.26 – 3.62), indicating a statistically (p = 0.000) significant difference between the respondent's perceptions and Current practice of FCC in their respective wards. These findings are consistent with those of Bruce and Ritchie (1997), Peterson Cohen and Parsons (2004) and Coyne et al. (2013), whom all reported a statistically significant difference between the nurse's perceptions and practice of FCC. These findings suggest a theory-practice gap with regards FCC in these paediatric wards. Meaning that nurses do have the theory related to FCC but may find it difficult to implement in clinical practice.

Literature indicates that the elements with the greatest discrepancies between the Necessary and Current scales are the *design of the health care system, information sharing* and *emotional support for staff* (Bruce and Ritchie, 1997; Coyne et al., 2013; Peterson et al., 2004). This study reinforced these findings, as the respondents reported the greatest difference in areas of *design of the healthcare system* and *emotional support for staff*. This indicates that the design of the health care system of the study site is not responsive to the needs of the hospitalised child and their family, nor are there adequate programmes and policies in place to provide for the emotional support of staff.

An interesting finding in this study was the results yielded for both the Current and Necessary scales. Though the nurses reported considering *family is the constant, parent/professional collaboration* and *design of healthcare system* as the least necessary elements of FCC, they ranked them higher than the elements they had reported as necessary. Similar to the Current scale, the elements most likely to be practised were not the highest-ranked. This could suggest that although the nurses consider these elements to be necessary and important, they do not necessarily practise them or ensure that they are performed.

Data was analysed to determine any association between the respondent's demographic variables and their responses on the Current and Necessary scales. There was insufficient evidence to show any association between the four demographic variables and the respondent's perceptions and practices. Significance values (p-values) of each demographic variable were found to be greater than 0.05, which indicates that the nurses' age, years of experience, educational level or clinical setting in which they work did not influence their Current or Necessary practices related to FCC.

This was contrary to the findings of Bruce and Ritchie (1997), who found that the nurses' practices varied with their ages and that their educational levels contributed to their perceptions and practices. Literature also showed that nurses' years of experience working in the paediatric wards contributed to predicting their perceptions and practice of FCC (Peterson et al., 2004). Coyne et al. (2013) found that nurses with a degree qualification had a better perception of the elements necessary for implementing FCC.

However, findings also demonstrated that respondents with less than five years' experience and working in the medical ward yielded the highest median scores for the Necessary scale. Under the Current scale, nurses with 16 or more years of experience and those working in the OPD had higher median scores compared to the other variables. Those nurses, who are over thirty years old and in possession of a postgraduate qualification, yielded higher median scores on both the Current and Necessary scales. This finding may be attributed to the focus on FCC in education and training over the past decades.

5.3.5 Conclusion of the Main Findings

The results of this study support previous research findings of a discrepancy between nurses' perceptions and practice of FCC. Nurses in this study claimed to find *recognising family individuality, emotional and financial support for families* and *emotional support for staff* as necessary elements for implementing FCC in the paediatric wards. They also reported consistently *recognising family individuality, providing families with emotional and financial support* and *regarding them as a constant in the children's lives*.

There was no statistical significance found between the demographic variables and the Current and Necessary scales, indicating that respondents' ages, years of experience, education levels and clinical work settings has no association with their perceptions and practices of FCC.

5.4 LIMITATIONS OF THE STUDY

The limitations to the study included a small sample size and types of additional qualifications held by the respondents.

Due to the low response rate from the total sample, findings from the study are specific to the sample and the context under which the study was done. Thus, the findings of the study cannot be generalised to the total population.

The answers given for the open-ended questions asked at the end of the questionnaire appear to have been influenced by the questions which were asked in the actual questionnaire.

The researcher did not question the type of qualification respondents held, such as degree/diploma, under the education level. There is a need to include this to gain insight into whether educational qualification types have a significant impact on the nurses' perceptions and practices of FCC. Previous studies have found that those with a baccalaureate qualification had higher scores for the necessary practice (Coyne et al., 2013).

The study did not include other healthcare professionals, such as doctors, enrolled nurses and enrolled nurse assistants who are also part of the team responsible for providing care to the child and their families.

5.5 RECOMMENDATIONS

Based on the findings of this study, the following recommendations for clinical practice, nursing education and research are made.

5.5.1 Clinical practice

Nurses from this study emphasised that the design of the healthcare system and the emotional support available for staff in their respective wards was not conducive for implementing FCC, highlighting the need for an improved healthcare system design and better emotional support for staff.

On-going workshops and in-service training for all staff on FCC and its implementation are recommended. This would raise awareness and sensitivity to children and their need for their families in the hospital setting as well as make sure that FCC is kept at the core of their practice.

Though FCC may be an adopted model of care in organisations, there is still a need to have dedicated resources such as policies and programmes available for delivering FCC to help facilitate its practice and to provide nurses with the emotional support they need to deliver FCC.

Nurses and children's families should be included in the development of evidenced-based policies and programmes aimed at delivering FCC. Furthermore, nurses should be encouraged to be research-oriented and use evidence-based practice in their daily clinical practice (Ajani and Moez, 2011).

5.5.2 Nursing education

Findings from this study showed that there is a theory gap between the nurse's perceptions and their practices of FCC. Though they may understand the FCC model of care, there remain discrepancies in its implementation. Therefore, in both the undergraduate and postgraduate courses that include a child health component, FCC should be taught as the core model of care to be delivered to both the child and their family.

Literature has highlighted that nurse educators should spend more time in clinical practice to gain an understanding of the current practices in the field (Ajani and Moez, 2011). Thus, they will be able to teach the theory content of the course in a manner which is applicable to the current clinical practice realities.

Child nursing component of the undergraduate programme as well as the Child nursing postgraduate programme should be aligned to the principles underpinning the policies and programmes in place in the work place (Ajani and Moez, 2011). This has been said to be an influence on changing and improving the clinical practice of nurses (Ajani and Moez, 2011).

Students should be encouraged to use research as a basis to make clinical judgements and decisions whilst in the clinical areas (Ajani and Moez, 2011).

5.5.3 Research

This research study was conducted at one institution; it should be conducted at other public and private sector institutions to validate the findings.

A quantitative method was used for this enquiry; however, to obtain a more in-depth understanding of the phenomenon, a qualitative approach could be used. Furthermore, more research should be conducted to investigate how FCC can be enhanced in the clinical setting.

To further understand the discrepancy that exists between the nurses' perceptions and practice, research should be done to investigate the factors that contribute to or reduce the nurses' ability to fully execute FCC.

5.6 CONCLUSION

This chapter provided a discussion of the findings from Chapter Four.

In conclusion, this study has highlighted the discrepancies that exist between theory and practice of FCC implementation in South African paediatric wards. The findings have confirmed similar findings in existing literature. Recommendations for clinical practice, nursing education and nursing research have been made based on the findings. It is hoped that the findings from this study can be used to help implement FCC in paediatric wards.

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APPENDIX A

FAMILY-CENTERED CARE IN AN ACADEMIC HOSPITAL IN GAUTENG: PERCEPTIONS AND PRACTICES OF NURSES WORKING IN THE PAEDIATRIC WARDS

DATA COLLECTION INTRUMENT

The instrument used in this study is the Family-Centered Care Questionnaire Revised (FCC-R) © by Beth Bruce (1993).

The following questions refer to your beliefs about what family-centered care is or is not. We are interested in knowing how well these items represent your practice and perceptions of family-centered care.

DIRECTIONS
Carefully think about each item with respect to the extent that you include this aspect of care in your current practice. Circle the most appropriate response under the **current practice scale (1)**.

Carefully think about each item with respect to whether you believe that this aspect of care is necessary for family-centered care to be provided. Circle the most appropriate response under the **necessary scale (2)**.

DEFINITIONS
For the purpose of this study, **staff** refers to any health professional who provides direct care for children and their families, for example: nursing manager, staff nurse, social worker, clergy, child life, psychologist, physician, etc. **Family** refers to parents, guardians, grandparents, and siblings, and any family friend who is significantly involved with the child's everyday life or care.

Key to rating scale:
Strongly agree = SA; Agree = A, Neutral = N; Disagree = D; Strongly disagree = SD

Statements		Scales									
		Current Practice (1)					Necessary Practice (2)				
1	Staff encourage parents and siblings to come and go any time that meets the family's needs	SA	A	N	D	SD	SA	A	N	D	SD
2	Staff work with families to determine the level of participation in direct care and decision-making that suits the family' needs best.	SA	A	N	D	SD	SA	A	N	D	SD
3	The family is the key decision maker in the care of the child	SA	A	N	D	SD	SA	A	N	D	SD
4	Staff determine the	SA	A	N	D	SD	SA	A	N	D	SD

	child's need in consultation with the family and other health professionals										
5	Parents contribute to the development and review of hospital policies and practices	SA	A	N	D	SD	SA	A	N	D	SD
6	Parents and siblings are involved in staff orientation and continuing education programmes	SA	A	N	D	SD	SA	A	N	D	SD
7	Educational programmes and written material convey the sense that families are key respondents in care	SA	A	N	D	SD	SA	A	N	D	SD
8	The admission process is used as an opportunity to begin involving the family as members in the health care team	SA	A	N	D	SD	SA	A	N	D	SD
9	Hospital facilities, policies and procedures foster family choices for participation	SA	A	N	D	SD	SA	A	N	D	SD
10	Interview with families are conducted in private location	SA	A	N	D	SD	SA	A	N	D	SD
11	Staff are aware of and take approaches that address the fact that families take time to develop trust	SA	A	N	D	SD	SA	A	N	D	SD
12	Staff discuss with the child and family what helps them deal with events during hospitalisation	SA	A	N	D	SD	SA	A	N	D	SD
13	Staff assess the level of understanding and skills of the child and family before and after teaching	SA	A	N	D	SD	SA	A	N	D	SD
14	Staff promote pre-admission programmes which familiarise children and families with hospital staff, routines, and equipment prior to a scheduled admission	SA	A	N	D	SD	SA	A	N	D	SD
15	Information is routinely communicated to help	SA	A	N	D	SD	SA	A	N	D	SD

	families understand each aspect of care that their child will experience such as anticipated										
16	Any family member significantly involved in the child's care is encouraged to discuss or chart information about their care of their child	SA	A	N	D	SD	SA	A	N	D	SD
17	Staff coordinate the flow and sequence of information and their families, ensuring that the child's information needs are a priority	SA	A	N	D	SD	SA	A	N	D	SD
18	Staff encourages parents to discuss concerns with other parents with similar experiences informally or in formal parent groups	SA	A	N	D	SD	SA	A	N	D	SD
19	Staff provide programmes and support for parents, siblings and members of the extended family to assist families in managing needs	SA	A	N	D	SD	SA	A	N	D	SD
20	Staff assess the needs and concerns of siblings	SA	A	N	D	SD	SA	A	N	D	SD
21	There is a designated comfortable area for parents to gather	SA	A	N	D	SD	SA	A	N	D	SD
22	Staff help children and family stay in touch with their family and friends	SA	A	N	D	SD	SA	A	N	D	SD
23	Direct care managers have an adequate knowledge in child development to support hospital staff in the practice of family centred care	SA	A	N	D	SD	SA	A	N	D	SD
24	Hospital brochures accurately describe the health care experiences for children and their families	SA	A	N	D	SD	SA	A	N	D	SD
25	Staff maintain familiar routines for each child and family	SA	A	N	D	SD	SA	A	N	D	SD
26	Staff assess the child's interaction with staff, peers and family	SA	A	N	D	SD	SA	A	N	D	SD
27	When possible, the same	SA	A	N	D	SD	SA	A	N	D	SD

	staff are assigned to care for the child and family										
28	Information and support are provided to help families understand the illness process and the impact on the child and family, choices and risks, services, and roles of various health professionals	SA	A	N	D	SD	SA	A	N	D	SD
29	Staff recognise the financial strain on families and assist them in obtaining help	SA	A	N	D	SD	SA	A	N	D	SD
30	During procedures, a staff member is designated to explain to the child and family exactly what is happening	SA	A	N	D	SD	SA	A	N	D	SD
31	Non-urgent outpatient services are available daily and in the evening	SA	A	N	D	SD	SA	A	N	D	SD
32	All written material for families is available in English / Zulu / Afrikaans / Sotho / French versions	SA	A	N	D	SD	SA	A	N	D	SD
33	A written summary of relevant information in the primary official language of the family	SA	A	N	D	SD	SA	A	N	D	SD
34	The physical layout of the unit is designed to meet the developmental and psychological needs of the child and family	SA	A	N	D	SD	SA	A	N	D	SD
35	Resources exist to provide families with the appropriate support that they need at varying times	SA	A	N	D	SD	SA	A	N	D	SD
37	Parent evaluation are considered reliable sources of information about how well the hospital meets their needs	SA	A	N	D	SD	SA	A	N	D	SD
38	There are guidelines to assist staff in providing care during painful procedures such as: teaching children ways to	SA	A	N	D	SD	SA	A	N	D	SD

	cope with pain and post-procedural debriefing of the child										
39	Job descriptions and performance appraisal systems incorporate expectations of family-centered care such as: knowledge of family dynamics and skills and in collaboration, problem solving and interventions that address family's needs	SA	A	N	D	SD	SA	A	N	D	SD
40	Continuing education programmes provide opportunities for staff to learn to deal effectively with families	SA	A	N	D	SD	SA	A	N	D	SD
41	The hospital recognises and rewards special knowledge and skills that are needed to care for children and families	SA	A	N	D	SD	SA	A	N	D	SD
42	Staff are encouraged to identify, plan and evaluate new programmes, policies and procedures to improve the quality of patient and family care	SA	A	N	D	SD	SA	A	N	D	SD
43	Staff are able to express confidentiality to those responsible for assuring quality care, their concerns related to those demands of providing care for children and families	SA	A	N	D	SD	SA	A	N	D	SD

OPEN ENDED QUESTIONS

1. <u>How would you define Family Centered Care?</u>

_____

_____

_____

_____

_____

2. Briefly list activities (not included on the questionnaire which represent Family Centered Care practised in your ward?

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

DEMOGRAPHIC SHEET CODE:_____

Please complete the following general information, where applicable mark with a "X".

1. AGE (years):		
2.YEARS OF EXPERIENCE IN PAEDIATRIC NURSING		
3. HIGHEST LEVEL OF EDUCATION	Undergraduate Qualification	
	Post Graduate Qualification	
4.CLINICAL SETTING	Medical care	
	Surgical care	
	Emergency care	
	Outpatient Department (OPD)	

APPENDIX B

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

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

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

18 July 2017
Person No: 553737
PAG

Miss TP Mosito
P O Box 516
Swartklip
0370
South Africa

Dear Miss Mosito

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Family centered care in an academic hospital in Gauteng: paediatric nurses' perceptions and practices* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX:C

R14/49 Ms Tshireletso Pascaline Mosito

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170459

NAME: (Principal Investigator)	Ms Tshireletso Pascaline Mosito
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Family Centred Care in an Academic Hospital in Gauteng: Paediatric Nurses Perceptions and Practises
DATE CONSIDERED:	05/05/2017
DECISION:	Approved
CONDITIONS:	Following GDoH Circular 10 of 2015 to GDoH Staff. It is the responsibility of the applicant to obtain written permission to to do the study from the study site CEO and Provincial Authorities.
SUPERVISOR:	Sizakele Khoza
APPROVED BY:	Prof P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/07/2017

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX D

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
31 August 2017

Ms. Tshireletso Pascalline Mosito
University of the Witwatersrand
Department of Nursing Education
Faculty of the Health Sciences
NHRD REF : GP_2017RP31_148

Dear. Ms. Tshireletso Pascalline Mosito

RE: "Family Centered Care in an Academic Hospital in Gauteng: Paediatric Nurses Perceptions and practices"

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

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

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

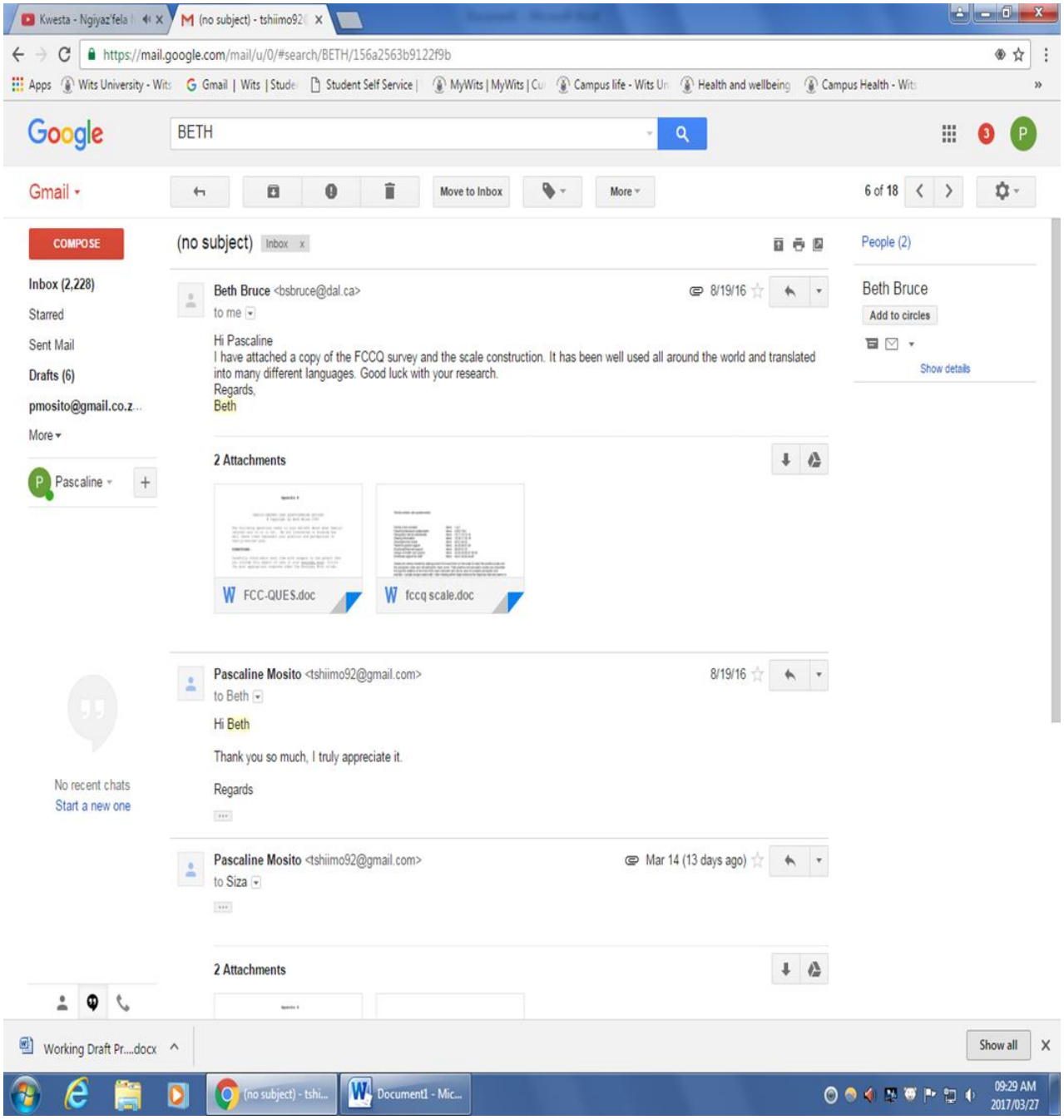
Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~
Ms. M.M Pule
Nursing Director
Date: 31/08/2017

~~Approved~~ / not approved
Ms. G. Bogoshi
Chief Executive Officer
07.09.2017

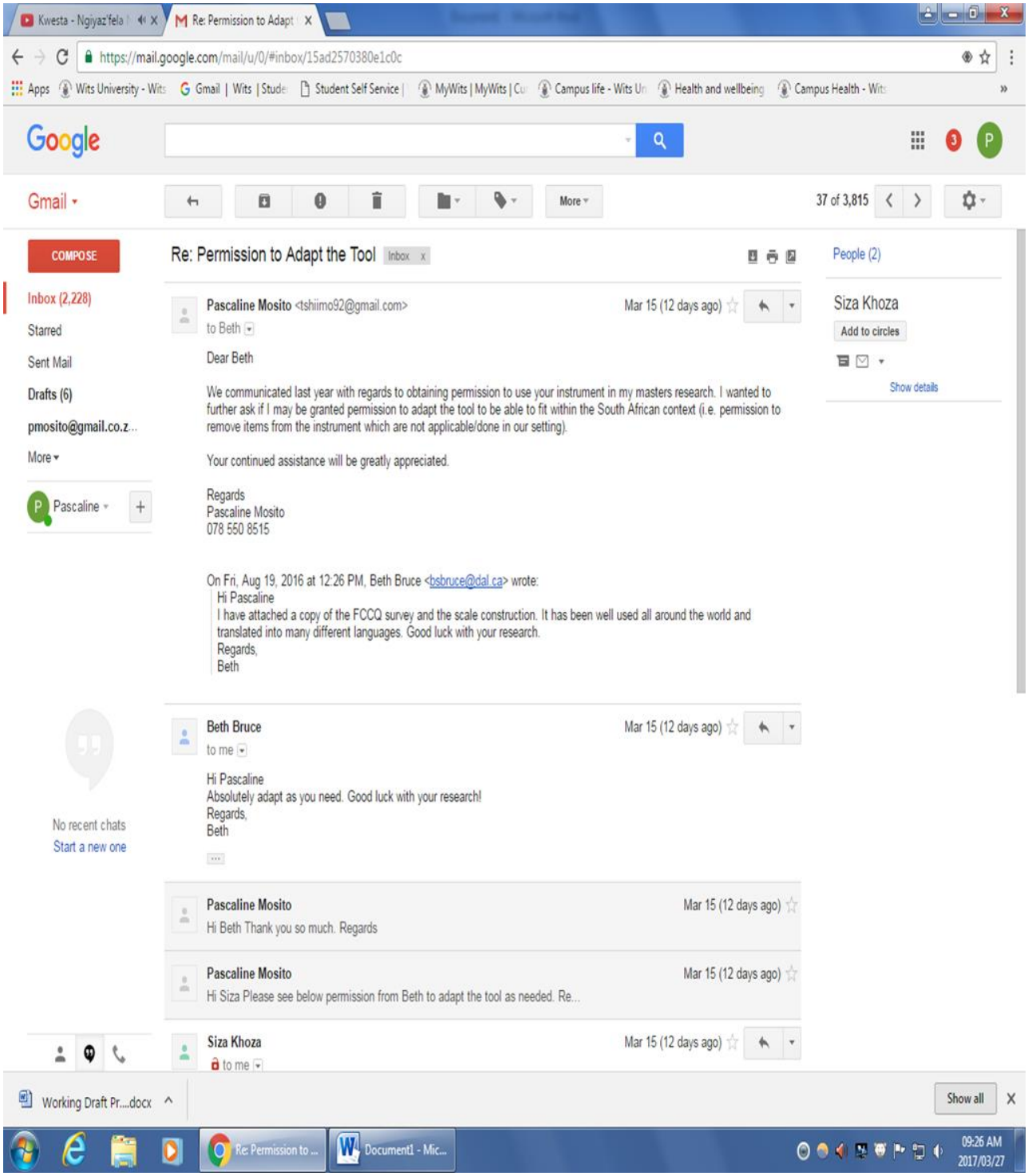
APPENDIX E

PERMISSION TO USE DATA COLLECTION INSTRUMENT



APPENDIX F

PERMISSION TO MAKE CHANGES ON DATA COLLECTION INSTRUMENT



APPENDIX G

INFORMATION LETTER

Family centered care in an academic hospital in Gauteng: Perceptions and practices of nurses working in the paediatric wards

Dear Colleague

My name is Pascaline Mosito, and I am presently studying towards a Master's Degree in Nursing Science at the University of the Witwatersrand. I am conducting a research study on the paediatric nurses' perceptions and practices of family centred care and would like to invite you to participate in the study.

The study is aimed at defining the concept of family centred care in the South African context by describing the perspectives and practices of the professional nurses working in the paediatric wards. The information will help with the development of policies and guidelines regarding family centred care.

Should you agree to participate in the study you will be required to complete the Family Centred Care Revised Questionnaire which consists of 45 closed ended questions which will take you approximately 20 minutes to complete. On completion of the questionnaire kindly place it in the marked box by the nurses' station. Please would you complete the consent form provided which will be collected separately from the questionnaire so as to maintain anonymity. Participation in the study is completely voluntary and you may withdraw from the study at any point with no penalty to you. To ensure anonymity please do not write your name on the questionnaire. All information obtained from you will be kept in the strictest confidence. You are requested to please refrain from writing any identifying information on your questionnaire (i.e. ward number, name etc.).

It should be noted that there are no benefits or forms of remuneration for participating in the study, however participating in the study will give you the opportunity to make your understanding of family centred care known which will in turn help define what family centred care means to South African nurses.

If you have any questions regarding the study, please feel free to contact me at:
Email:553737@students.wits.ac.za Telephonically: (078) 550 8515

Thank you for taking the time to read this information letter. Your participation in this research is valuable and appreciated.

Yours Sincerely

_____

Pascaline Mosito (Ms)

APPENDIX H

RESPONDENTS SIGNED CONSENT:

Family-centered care in an academic hospital in Gauteng: Perceptions and practices of nurses working in the paediatric wards

I, _____ agree to participate in the research study assessing needs of families of infants hospitalized in the neonatal intensive care unit and high care unit at an academic hospital in Johannesburg.

I have read and understood the information sheet. I also understand that my participation is voluntary and I can withdraw at any given time without any consequences.

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

Signature:
_____

Date:
_____

Editing Certificate

To:

The Department of Nursing Education,

Faculty of Health Sciences, University of the Witwatersrand

I certify that I have edited the following

MSc Research Report

to the standard required by

the Wits Department of Nursing Education:

Family-Centred Care in an Academic Hospital in Gauteng: Paediatric Nurses' Perceptions and Practices

by Tshireletso Pascaline Mosito

Nicky Nagy

Independent editing and publishing professional

29 March 2018