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PRIMARY CARE GIVERS' EXPERIENCES OF FAMILY CENTRED CARE IN A PAEDIATRIC HOSPITAL IN GAUTENG

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

2022

DECLARATION

I, PRETTY MASHISHI, declare that this Research Report is my own work, that all the sources quoted have been indicated and acknowledged by means of complete references and that it is being submitted for the degree of Master of Science in Nursing. This report has not been submitted for any other degree at any other institution.

Signature: ……P.Q Mashishi……..……

On this …23…day of …June……2022

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

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- Nelson Mandela Children Hospital: thank you for the chance you gave me to go to university; the financial assistance that you provided is highly appreciated.
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- My lovely husband who supported me through thick and thin with everything I needed to finish this research, those sleepless night you had with me are highly appreciated.

ABSTRACT

Family Centred Care (FCC) is an approach to the planning, delivery and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families and health care professionals (Johnson and Abraham, 2012). When nursing patients their loved ones are involved and a holistic approach is applied. The benefits of FCC are well documented and include shorter hospital stays, improved preparedness for discharge and less emotional stress for both families and patients (Johns Hopkins Children's Center, 2018).Most nurses acknowledge the importance of FCC and are practising it to some extent however, unsuccessful implementations of FCC are known to exist in various clinical practice settings (Almaze and De Beer, 2017).

The experiences of Primary Care Givers (PCGs) in paediatric care are important to understand because according to Hill, Knafl, and Santacroce, 2018 parents are the voice, advocates and care givers for their children including during critical paediatric illness (Hill et al., 2018). Therefore, it is important to know what families actually need as opposed to what healthcare professionals assume they need (Jordan, 2018).

The purpose of this research was to determine the primary care givers experience of Family Centred Care in a paediatric hospital in Gauteng. Knowing the positive and negative experiences of FCC by PCGs assists health care providers to gain insight into how to involve PCGs and improve the practice of FCC.

A sample of participants was selected using purposeful sampling from Primary Care Givers who were lodging at the hospital. A qualitative descriptive design was used in this research. Interviews with semi-structured questions were used to collect data. Questions were based on four key elements of FCC, as identified by Conway et al(2006) and were used as a template design for the questions.

Data was analysed using a latent content analysis approach. The findings were described using themes formed from the interview questions in relation to the core concepts of FCC.

The findings of this study reveal that primary caregivers encounter both positive and negative experiences when core concepts of FCC are implemented. Regarding

participation, primary caregivers are willing to engage in care with health care professionals as the enabling factor. Respect and dignity are primarily conveyed through human and professional courtesies. These professional and friendly courtesies also facilitate information sharing. The severity of the condition of a child is a key limiting factor for participation but primary caregivers place trust in the knowledge of health care professionals. PCGs place total trust in the knowledge of health care providers. Collaboration was not present in terms of the Institute for Patient and Family-Centred Care (IPFCC) definition as there was no evidence of involvement in policy and program development.

Recommendations

Health care professionals must be acquainted with the core concepts of FCC and how their actions can impact the experiences of primary caregivers through efforts to act professionally and kindly so that the care environment is conducive for primary caregivers. It is also recommended to educate primary caregivers regarding coping with their hospitalised child and also regarding FCC. Finally, the hospital should develop policies for FCC regarding training, implementation and regular evaluation.

DEDICATION

I would like to thank my Almighty God who gave me strength to finish this paper even though it was a tough journey.

I dedicate this research to my late mother, Sbongile Mkhize, who was part of this journey and left me when I needed her most. She was my pillar of strength and pushed me hard to get the best education and to be a hard worker in everything I do. She taught me values of life and to always be humble. It is well, God's will always prevails.

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CHAPTER 1: AN OVERVIEW OF THE STUDY

1.1 Introduction

Family Centred Care (FCC) is an approach to the planning, delivery and evaluation of health care that is grounded in a mutually beneficial partnership among families, patients and health care professionals (Johnson and Abraham, 2012). Patients are nursed using a holistic approach while involving their loved ones. The benefits of FCC are well documented and include shorter hospital stays, improved preparedness for discharge and less emotional stress for both families and patients (Johns Hopkins Children's Center, 2018). Most nurses acknowledge the importance of FCC and are practising it to some extent, however, unsuccessful implementations of FCC are known to exist in various clinical practice settings (Almaze and De Beer, 2017).

Family centred care (FCC) is increasingly a recommended care practice that is being used to deal with specific issues of hospitalised children and their families (Hill, Knafl and Santacroce, 2018). The hospitalisation of a child is a challenging issue to families and care givers. According to Canga et al (2020), sick children suffer post-traumatic stress disorder (PTSD) as a result of hospitalisation, while parents are traumatised by their children's admission. The need for FCC was recognised as far back as 1956 by the Platt Committee, which was set up to make a special study of the arrangements made in hospitals for the welfare of sick children (Swanwick ,1983, cited by (Irlam and Bruce, 2002). In subsequent years, these findings have been confirmed, and it is recognised that FCC recognises and prioritises the health requirements of both the ill child and the family (Ohene, Power and Raghu, 2019). FCC is beneficial to parents as care givers. Parents regard FCC as significant for their child's well-being because they are more knowledgeable about the child, which is central to the quality of the care that is given (Terp, Weis and Lundqvist, 2021).

The experiences of Primary Care Givers (PCGs) are important to understand in paediatric care because, according to Hill, Knafl, and Santacroce, during critical paediatric illness, parents are care givers, voice and advocates for their children (Hill et al., 2018).

Parents have critical responsibilities to assist children to adjust to new clinical settings. Throughout the process, they endure significant levels of stress as a result of unmet information demands, interpersonal connections with physicians and concerns about the condition of their child and recovery progression (Ohene et al.,2019). Families who accompany their loved ones are usually unprepared for the turmoil that comes with the experience, and rely on health care professionals to help them get through it. To assist a patient's family members to adapt, health care practitioners must use relational and participative family-centred techniques (Emmamally and Brysiewicz, 2018). Evaluating features of FCC from the parents' perspectives might assist us to identify the need for further development of FCC in a Neonatal Intensive Care Unit (NICU) (Raiskila et al., 2016). Parents' perspectives have an influence in areas such as the conceptual evolution of FCC, the varied terminology that has formed within different components of the concept and its prevalence in paediatric care (Ohene et al., 2019).

There is significant confusion over what behaviours constitute FCC at both the provider and patient levels. Some providers say FCC gives families more responsibility for care and decision-making than they want. Families want more collaboration and shared decision-making, but not necessarily more responsibility and autonomy (Kuo et al., 2011). Families, on the other hand, may not be aware of what they may and should expect from an FCC partnership (Jordan, 2018). Therefore, to gain a better understanding of FCC, care givers need to be given a larger role in defining its key aspects.

Hill et al (2018) noted in an Integrative review conducted in the United States that health care professionals' experiences and viewpoints have been more researched unlike those of parents. Jordan states that “it is important to note what families actually need as opposed to what health care professionals assume they need” (Jordan, 2018).

1.2 **History of Family Centred Care**

FCC started after World War II when nursing, which was then fundamentally paternalistic, had become asynchronous with changing social expectations for the treatment of hospitalised children (Jolleyand Shields, 2009). In the second part of the twentieth century, there was widespread international recognition and endorsement of the key principles of FCC. Anne Casey, in the early 1990s, developed a model called Partnership-in-care whereby parents had a right to be with their child at all times (Jolley and Shields, 2009.)One of the new aspects of care was that parents were allowed to contribute to decision making regarding the care of a child. (Arabiat et al., 2018.) The positive results were immediately evident, and parents and children reported increased satisfaction with their care.

FCC has been widely implemented in developed countries such as Sweden, Canada, Japan, United States, Italy, and Australia (Maria, Litch and Stepanchak, 2021). Consequently, most studies on FCC practice come from developed countries. FCC practice is not widely implemented in developing countries, although pilot studies about FCC have been conducted in South Africa (Maria et al., 2021). The use of FCC differs, depending partially on social situation. Experts agree that cultural differences in values are important variables in shaping FCC practice and implementation across the world (Ohene et al., 2019). Irlam and Bruce (2002) stated that families have evolved differently in developed and culturally distinctive societies such as the USA or the UK in comparison to South Africa, which compromises families representing both first and third world.

1.3 **Constructs within Family Centred Care**

FCC has been adapted globally to specific environments. The original model had the following eight dimensions: respect for patients' preferences and values, emotional support, physical comfort, information, communication and education, continuity and transition in care, coordination of care, the involvement of family and friends, and access to care (Conway et al., 2006).

The constructs of FCC have continually evolved in an attempt to provide a model of ideal care. In 2006, Conway cited respect and dignity, information sharing, participation in care and decision making, and collaboration as the four essential elements fundamental to the success of FCC (Conway et al., 2006). These core concepts have been used to guide this research.

Dignity and Respect: Health care professionals have to listen to and honour patients' and families' perspectives and choices. Patient's and family's knowledge, values, beliefs and cultural background are integrated into the planning and delivery of care (Johnson and Abraham, 2012).

Information Sharing: The capacity of health care professionals to exchange information freely with primary care givers, thereby enabling families to voice their concerns, is critical to optimal patient care (Griffin, 2003).

Participation: Patients and primary care givers (PCGs) are encouraged to take part in care and decision making at the level of their choice.

Collaboration: "Families, patients, health care professionals and hospital leaders work together in policy and program development and implementation, and evaluation of programs ranging from health care facility design to professional education, as well as the delivery of care" (Conway et al., 2006).

1.4 Benefits of Family Centred Care

Studies have shown that practising FCC has benefit to the child, PCGs and the health care system. The benefits of FCC have been well documented and include: improved working relationship between health care professionals and families, shorter hospital stays, prevention of medical errors and confidence to continue care at home.

Improved working relationship between health care professionals and families: The Institute for Family-Centred Care explains that this is achieved because families feel that they are part of their children's care rather than merely visitors.

Shorter hospital stays: FCC leads to shorter stays of patients, resulting in savings in hospital resources and budget. Segers et al (2019) carried out a review and found substantial evidence that FCC reduces patients' duration of hospitalisation when parents participate in care for their new-born in a Neonatal Intensive Care unit (NICU).

Prevention of medical errors: Due to the increased presence of PCGs patients' safety improved because the family are more likely to notice errors in care.

Confidence to continue care at home: Hill et al (2018) explained that parents are often responsible for caring for their children after discharge. A study by Siems (2007) about chronically ill patients emphasised that through constant education and information given about the condition anxiety was allayed and the family become empowered.

1.5 **Challenges in implementing Family Centred Care**

Although the benefits of FCC are evident the implementation of such a model is challenging. The following are some of the challenges that have been identified: rigid visiting policies, lack of adequate resources, lack of communication, lack of nurses' skills.

Rigid visiting policies: The Institute for Family Centred care highlighted that many hospitals and health systems have outdated visiting policies that separate families during hospital stays. This is a problem because the strategies for family engagement include daily communication, regular family meetings and flexible family presence including on rounds (Coyne et al., 2013). Coyne (2015) discussed that children want their parents to stay with them and they valued parents' constant presence and help.

Lack of adequate resources: The study done by Coyne in Ireland explained that nurses ended up relying more on primary care givers (PCGs) due to staff shortages. Coyne (2015) explained that staffing levels, patient-nurse ratios and skill mix must show that nurses need to provide care for both the child and the family. A study undertaken in the Eastern Cape revealed that a lack of adequate resources increased administrative work due to fear of litigation, and unprofessional behaviour of nursing staff are some of the factors that hinder patient-centred care (Jardien et al., 2016).

The Johns Hopkins Academic Hospital in Boston provides comprehensive care and support services to all families whether they come from the neighbourhood or they are from far (Shapiro, 2016). The ideal that FCC is about serving everyone equally is upheld. The Johns Hopkins Hospital is recognised as a well-resourced institution with adequate space that serves everyone equally. South African hospitals do not accommodate all PCGs, they follow certain criteria for lodging PCGs.

Lack of communication: Latour et al (2011) emphasised that PCGs appreciate honesty, even if they are not fully told everything. Updating them about any uncertainty on a patient's condition leads them to trust the health care professionals more and feel secure. In the Irish study it was shown that lack of communication resulted in lack of clarity in identifying the roles between the PCGs and the nurses (Coyne, 2015).

Lack of nurses' skill: Foster et al (2010); Power and Franck (2008) (as cited in Coyne et al., 2013) explained that health care professionals suggested that delivery of FCC is hindered by a lack of knowledge, skills, time, or available resources.

1.6 **Family Centred Care in the context of South Africa**

South Africa is a developing state with a multicultural population. In order for FCC to succeed in this environment, there needs to be a clear definition of the social-cultural domain. There is evidence that many South African health care institutions are failing to meet basic standards of care and patient expectations, and therefore failing to implement a successful model of FCC (Maphumulo and Bhengu, 2019). However, there is little local literature available that looks at primary care givers' experiences of FCC practice in paediatric settings (Pretorius, 2019 and Emmamally and Brysiewicz, 2018). South Africa carries a high burden of disease yet has few resources available to tackle this burden. The practice of FCC has been shown to decrease costs while improving outcomes, both financial and satisfaction (Pretorius, 2019 and Emmamally and Brysiewicz, 2018). Much of the existing literature on FCC has focussed on the need for FCC in the South African setting (Ndlovu, 2017).

According to an integrative literature review done by Irlam and Bruce (2002) engaging and advocating for FCC contributes to positive health outcomes for the patient because

the inclusion of the parents results in continuity of good care for the child after discharge. Roets, Rowe-Rowe and Nel (2012) argued for encouragement of parental presence for hospitalised children since doing so can lessen anxiety in both the children and the parents.

Doorenbos et al (2012) reinforced the idea further by suggesting that allowing parents whose children are hospitalised to stay with their children would result in emotional stability and good bonding for both the child and the parents.

The South African Children's Act 2005 (Government Gazette: Republic of South Africa, 2006) states that "if it is in the best interests of the child, the child's family must be given the opportunity to express their views in any matter concerning the child." Furthermore, "a child, having regard to his or her age, maturity and stage of development, and a person who has parental responsibilities and rights in respect of that child, where appropriate, must be informed of any action or decision in a matter concerning the child which significantly affects the child." The Act's provisions create a solid framework for FCC practice in South Africa since they clearly identify the role of the family in maintaining the child's well-being while also strengthening the child's health in partnership with the health care team.

FCC is also seen to be helpful for post-discharge care because it supports the parental role and improves family functioning by ensuring PCGs have the skills needed to care for the child at home (Terp et al., 2021). This is important in the South African context as many families travel long distances to get health care.

This gap in research necessitates further studies of FCC among parents as primary care givers of hospitalised children in the South African setting. Such studies are key to the improvement and management of family experiences but also the advancement of FCC in paediatric care settings.

The South African health setting is resource poor and socially complex. There is little knowledge of the actual experiences of PCGs as they experience FCC in its various hybrid forms as practised by different hospitals.

As Jordan stated in a South African study, it is important to know what families actually need in order to deliver an effective model of FCC (Jordan, 2018).

1.7 **Problem Statement**

FCC is practiced in both developed and developing countries. However, its success is more evident in high resource settings and appears to be more challenging to achieve in low resource environments. There is evidence that FCC practiced in paediatric settings improves clinical outcomes for hospitalised children and their families (Ohene et al., 2019).

There is also evidence that parents need to be fully integrated in the care of their child in order to be capable of caring for the child both during hospitalisation and post-discharge (Terp et al., 2021). A one-size-fits-all implementation approach to FCC does not work because of the variation of cultural norms and social practices across different local settings and differing clinical conditions (Ohene et al., 2019). Most studies have focussed on health care professionals' experiences rather than those of parents. This may result in a one-sided perception of the efficacy of FCC.

The majority of studies on FCC have been carried out in developed countries yet culture and resources have an impact on the effective implementation of FCC. Furthermore, there is no evidence of research that has focused on the experiences of the lodger primary care giver who experiences FCC 24 hours per day while fulfilling their caring role. The role of the PCG is pivotal to the successful implementation of FCC. This study will inform policy development related to the management of primary care givers regarding FCC when their child is admitted in a specialised paediatric hospital in urban Gauteng.

1.8 **Research Question**

What are the primary care givers experiences of Family Centred Care in a Paediatric hospital in Gauteng?

1.9 **Purpose**

The purpose of this research is to determine the primary care givers experiences of family centred care in a paediatric hospital in Gauteng.

1.10 **Objective**

To explore and describe primary care givers experiences regarding Family Centred Care in a paediatric hospital in Gauteng.

1.11 **Definition of Key Concepts**

The key concepts that have been used throughout this study are defined below.

Primary Care Giver

A primary caregiver is a person or parent with whom a child is permanently residing and has the right to care for that child and supervise his or her daily life (Department of Social Development, 2008). In this study a primary caregiver is a person or parent who has a close, meaningful relationship with the sick child and provides care to that child.

Experience

Experience refers to the way that a phenomenon happens and how it makes one feel (Oxford Learner's Dictionaries, 2022). In this study, experience means the way that FCC happens and how it is perceived by the PCGs.

Patient and Family Centred Care

Patient- and family-centred care is 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. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care and in all health care settings (IPFCC, 2016). In this study, patient and family centred care means a partnership approach to health care decision making and delivery of care between a family and health care professionals.

Specialised Paediatric Hospital

A specialised paediatric hospital is a hospital that provides medical care to children from birth to the age of 16. A specialised paediatric hospital is defined in this study as a state-of-the-art, 200-bed specialist paediatric referral hospital that provides a compassionate, child- and family-centred environment to treat and assist critically sick children.

Ronald McDonald

Ronald McDonald is a lodging place that provides families with accommodation and compassionate care at little or no cost. The 27-bedroom house is located at the top of the specialised paediatric hospital in Johannesburg. The house includes a kitchen, dining room, library, meditation room, kid's playroom, TV room and lounges. It is part of a worldwide network of such facilities.

Lodging place

Lodging place means a place or facility used for temporally stay.

1.12 **Organisation of chapters**

The research study encompasses five chapters structured as follows:

Chapter One: Overview of the study

Chapter Two: Literature review

Chapter Three: Research design and methods

Chapter Four: Discussion of findings

Chapter Five: Conclusion, limitations and recommendations.

1.13 **Summary**

This chapter introduced the topic and gave an overview of how primary care givers should experience Family-Centred Care when their child is admitted in a specialised paediatric

hospital. It included an introduction and background to the study, the problem statement, study aim and objectives, definitions of concepts, research methods and population. The data collection, data analysis, trustworthiness and ethical considerations were discussed. Chapter two focuses on the literature review.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Chapter 1 presented a background and introduction to the study and some key definitions for the study. This chapter presents a literature review of FCC. The scope of the literature review is the history and framework of family centred care, the importance of FCC and its implementation challenges. Finally, the experiences of primary care givers regarding FCC is discussed, using local and international studies. The importance of PCGs in FCC and why their experiences matter is also discussed.

2.2 History of Family Centred Care in Paediatric Health Care

Understanding the FCC concept today necessitates a review of historic events. FCC is believed to have begun after World War II, which was a catalyst for change to the care of children in hospital (Jolley and Shields, 2009). Previously, families of hospitalised children only served a role of a visitor or attendant (Kuo et al., 2011). The war changed the way children were cared for in hospitals and had a profound effect on nursing as it led to the evolution and development of various models of care, such as parent participation, care-by-parent, partnership-in-care, and FCC (Jolley and Shields, 2009). Two British scholars, John Bowlby and James Robertson were influential in the evolution of FCC (Jolley and Shields, 2009). Their work, together with other scholars such as Renee Spitz, a USA researcher, showed that the separation of parent and child due to hospital admission had significant negative psychological effects, such as emotional trauma to the parents (Jolley &Shields, 2009).

In the mid-twentieth century, there was a greater recognition of child/family separation trauma in the inpatient setting in places like the United States and Europe, so hospital policies were changed to allow for rooming-in, open visiting hours, sibling visits, and accompanying children to surgeries (Kuo et al., 2011).Family advocates were crucial in transforming hospital-based treatment for children and their families, as well as in

advocating for the deinstitutionalisation of children with intellectual and other impairments in their communities (Kuo et al., 2011).). In the United States, family advocates were instrumental in the passage of the first special education law, Early Intervention, in 1975, as well as the first Katie Beckett Home and Community-Based Medicaid Waiver in 1982, which allowed many children and adults with disabilities and chronic conditions to receive care at home (Kuo et al., 2011). Concept of Family Centred Care

The term Family-centred care (FCC) has no standard universal definition and lends itself to wide interpretation for implementation and measurement. Consequently, there is no consensus definition of FCC practices and actions (Raiskila et al., 2016). FCC has often been associated with terms such as “partnership,” “collaboration,” and families as “experts” to describe the process of care delivery (Kuo et al., 2011). Family Voices, the Maternal and Child Health Bureau (MCHB), the American Academy of Paediatrics (AAP), and the Institute for Patient- and Family-Centred Care have all reached significant agreement on FCC principles (Jolley and Shields, 2009).

The concept of FCC is often related to developed world because literature regarding FCC originates from developed countries (Ohene et al., 2019). However, as new studies from developing Asian and Eastern European countries have emerged, it has been argued that FCC principles may not fit for children in every situation, due to wide differences in clinical conditions, social practices and cultural norms across different local settings (Ohene et al., 2019). Therefore, cultural differences and clinical manifestations of health problems have a worldwide impact on FCC adaptation.

FCC is a partnership approach that promotes collaboration efforts between families and health care professionals in providing care for a sick child. Both the children and families experience positive outcomes from such collaborative efforts (Arabiat et al., 2018). As a result, the FCC concept emerged to assure successful management of family experiences in paediatric care settings (Ohene et al., 2019).

According to Conway et al (2006), the original FCC model had the following eight principles:

- Respect for patients' preferences and value
- Emotional support
- Physical comfort
- Information, communication and education
- Continuity and transition in care
- Coordination of care
- The involvement of family and friends
- Access to care

According to the Institute for Family Centred Care, FCC is based on the recognition that patients and families are important partners for quality and safety of the patients (Conway et al., 2006). When health care professionals are in direct care interactions with patients, they need to apply FCC concepts for quality improvement, safety initiatives, education of health professionals, research, facility design and policy development (Conway et al., 2006). The IFCC organisation emphasises the significance of these four FCC basic principles:

- Respect and dignity
- Information sharing
- Participation
- Collaboration.

2.2.1 Respect and Dignity

Health care professionals have to listen to and honour patients' and families' perspectives and choices. The patients' rights charter stipulates that every patient has the right to be treated with respect and dignity, and to be informed about his/her health care status and treatment (Republic of South Africa, Act No 108 of 1996). This is confirmed by the South African Nursing (SANC) Act no. 33 of 2005 (South African Government Nursing Act 33 of 2005). It is critical to incorporate patient and family expertise, values, beliefs, and cultural background into treatment planning and delivery (Johnson & Abraham, 2012). When treating people with respect and dignity it gives them a sense of acknowledgement because their opinions matter and are important. Families and patients must be treated with respect as individuals.

2.2.2 Information Sharing

The Institute for Family Centred Care (IFCC) stipulates that, for active engagement of families in patient care and decision making, health care practitioners must be honest when interacting with families and patients (Conway et al., 2006). Health care providers need to be welcoming and friendly so that PCGs can trust them to not withhold any important information.

According to studies, the capacity of health care providers to exchange information freely by enabling families to voice their concerns is critical to providing optimal patient care (Griffin, 2003). Griffin went on to say that if information is not communicated appropriately or is insufficient, main care givers feel unappreciated in their child's care.

2.2.3 Participation

Principles of ethics include autonomy, which is the right of patients to make decisions about their medical care (Armstrong et al., 2013). Health care professionals have to educate PCG about their child's condition and management so that PCGs are able to participate in making decisions about their child's care. Systematic review of qualitative studies confirmed that "parents wish to participate in their hospitalised child's care, however, the nature and extent of this involvement has to be negotiated on an individual family basis" (Watts et al., 2014).

It has been reported that in paediatric environments parents' experiences indicate that the implementation of FCC requires much work to be done in areas of participation in decision-making and person-centred communication (Terp et al., 2021). It is also known that parents' perspectives and expectations of their children's hospitalisation have influenced the improvement of FCC in some clinical settings (Hill et al., 2018). The Institute of Family Centred Care encourages PCGs to participate in care and decision making at the level of their choice (Conway et al., 2006).

2.2.4 Collaboration

Collaboration is defined as the working together of patients, families, health care professionals and hospital leaders in the delivery of care. They also work together in formulating policy, program development, implementation and evaluation of programs

ranging from health care facility design to professional education (Conway et al., 2006).Research conducted in Canada by MacKean, Thurston, and Scott (2005) explains that FCC does not suggest that the obligations of caring for children should be handed to PCGs, but rather that health care practitioners must collaborate with PCGs to identify the roles of PCGs to the children.

The Children's Act 38 of 2005 stipulates that the role of PCGs is to care for the child, to keep contact with the child, to act as a guardian of a child and to contribute to the maintenance of a child, which is the provision of food, clothing medical care and education (Government Gazette: Republic of South Africa, 2006). PCGs must continue attending to child basic care while the child is hospitalised. Delivery of care includes performing basic care like bathing, feeding, comforting the child. It is safe to assume that not all PCGs are as interested in their child's care as others.

2.3 **Benefits of Family Centred Care**

2.3.1 Improving working relationship between health **care professionals and families**

Family cantered care allows families and health care professionals to work together. Families spend considerable time in hospital observing health care workers' routines while their children are in hospital (Coyne, 2015). Families assist health care workers by attending to their child's basic needs. Health care professionals have to rely on families to get more information about their child. Families and health care professionals work together and this interaction enhances the working relationship between families and health care professionals. When families are included in their child's care, they feel fulfilled. The Institute for Family-Centred Care explains that this is achieved because families feel that they are part of their children's care rather than visitors.

2.3.2 Shorter hospital stays

The practice of FCC has a good impact on families and their children's health, mental health and wellbeing. FCC leads to shorter stay for patients resulting in savings on hospital resources and budget. Segers et al (2019) carried out a review and found substantial evidence that FCC reduces patients' duration of hospitalisation when parents participate in care for their new-born in a NICU, but parents' satisfaction was moderate.

2.3.3 Prevention of medical errors

Patient safety is improved due to the presence of PCGs. PCGs are more likely to notice errors in care that may occur because when they are with their child, and they receive education on child management (Johns Hopkins Children's Center, 2018). PCGs are educated on the medication given to their child, therefore, if health care professionals give different medication PCGs are likely to identify it before the child takes it (Johns Hopkins Children's Center, 2018).

2.3.4 Confidence to continue care at home

Hill et al (2018) explained that parents are often responsible for caring for their children after discharge. A study conducted by Siems (2007) on chronically ill patients emphasised that through constant education and providing information anxiety is allayed and the family becomes empowered to continue taking care of the child at home.

2.4 Challenges in implementing FCC

2.4.1 Visiting time

The Institute for Family Centred Care highlighted that many hospitals and health systems have outdated visiting policies that separate families during hospital stays. This is a concern since family involvement plans require daily contact, regular family gatherings and flexible family presence, even during rounds (Coyne et al., 2013). Coyne (2015) discussed that the children want their parents to stay with them and they valued parents' constant presence and help. In South African hospitals visiting times differ according to institutional policy and standards and infection prevention and control standards. Visiting times differs from hospital to hospital.

2.4.2 Lack of adequate resources

Human resource is a challenge and is a barrier for the effective practice of FCC. FCC includes taking care of a child and their PCGs. In order for health care professionals to render total nursing care to patients and their families more nursing staff is needed. The study done by Coyne (2015) in Ireland explained that nurses ended up relying more on PCGs due to staff shortages. Coyne further explained that staffing levels, patient-nurse

ratio and skill mix must show that nurses need to provide care for both child and family (Coyne 2015).

Research in the Eastern Cape discovered that the impediments to patient-centred care were a lack of suitable resources, increased administrative work owing to lawsuit fear, and unprofessional behaviour of nursing personnel (Jardien-Baboo et al., 2016).

2.4.3 Lack of communication and role clarity

Latour et al (2011) emphasised that PCGs appreciate honesty, even if they are not fully told everything. Updating them about any uncertainty on the patient's condition makes them trust the health care professionals more and feel secure. A study carried out in Ireland revealed no communication clarifying roles between PCGs and nurses (Coyne, 2015). If roles are not clarified between PCGs and health care professionals that might lead to confusion and disorganisation. Some basic needs might be omitted, like feeding of patient - nurses might think a child has been fed by PCGs only to find that the PCGs thought it was the nurse's duty.

2.4.4 Lack of nurses' skills

Foster et al (2010) and Power and Franck (2008) (as cited in Coyne et al., 2013) explained that health care professionals suggested that delivery of FCC is hindered by a lack of knowledge, skills, time or available resources. In his study, Coyne (2015) found that nurses require skills training, proper resources, and management support in order to address the requirements of families adequately. Families, too, require clear advice, knowledge, and support in order to assist with the care of their child. The results of a study done in Bloemfontein emphasised that "Competencies of nurse practitioners and other staff involved must be improved" (Roets, Rowe-Rowe and Nel 2012). It therefore seems evident that some training is required before nursing staff can be expected to implement FCC effectively.

2.4.5 Lack of infrastructure

Johns Hopkins academic hospital provides comprehensive care and support services to all families, whether they come from the neighbourhood or are from afar (Shapiro, 2016). FCC is about serving everyone equally. The infrastructure of many hospitals in South

Africa does not allow for the accommodation of PCGs in the Paediatric unit. This is a challenge for FCC practice as PCGs rely on a place to lodge in the hospital premises in order to be close to their sick child (Mol, Argent and Morrow, 2018).

2.5 **Impact of not practising FCC**

Hospitals that do not use the FCC approach cause families to spend a lot of money on transport when PCGs travel to see their child in hospital.

Commodari (2010) found that care givers' stress levels increase when their children are hospitalised, and if FCC is not practised. Rokach (2016) explains that children see hospital as a foreign place. Children take time to adapt to hospital routine and environment due to the unfamiliar, technologically advanced, clinical environment. Children may regress in their milestone developmental if familiar primary care givers are not present (Rokach, 2016). If PCGs are not able to practice FCC in hospital they may not be able to continue caring for their child at home. Therefore, continuity of care is broken and patients might relapse, resulting in recurrence of hospitalisation.

2.6 Importance of Primary Care Givers in Family Centred Care and why their experiences matter

Parents have critical responsibilities in assisting children to adjust to new clinical settings. Throughout the process they endure significant levels of stress as a result of unmet information demands, interpersonal connections with physicians and concerns about their child's condition and progress toward recovery (Ohene et al., 2019). Family members, especially parents, are natural advocates for the neonatal patient for whom the emotional, social and developmental needs are serious and urgent (Jordan, 2018). Families who accompany their loved ones are usually unprepared for the turmoil that comes with the experience and rely on health care professionals to help them get through it. To assist a patient's family members to adapt, health care practitioners must use relational and participative family-centred techniques (Emmamally and Brysiewicz, 2018).

Evaluating features of FCC from the parents' perspectives might assist us in identifying the need for further development of FCC in NICUs (Raiskila et al., 2016). According to the research, the perspectives of parents influence conceptual evolution of FCC, its prevalence in paediatric care discourse, and the varied terminology that have formed within different strands of the concept (Ohene et al., 2019).

Exploring the experiences of PCGs are significant because they contribute to a better understanding of Family Centred Care (Kuo et al., 2012). At both provider and patient levels there is still ambiguity on what exact behaviours constitute FCC. Some providers believe that FCC delegates more responsibility for care and decision making to families than families desire (Kuo et al., 2012).

Families express a desire for collaboration and shared decision making, but not necessarily for increased responsibility and autonomy (Kuo et al., 2012). Families, on the other hand, may be unaware of what they may and should expect from a relationship (Jordan, 2018). As a result, in order to obtain a better grasp of FCC, care givers must have a bigger part in defining its main characteristics.

More studies need to be done to collect data on family centred care in scenarios arising from existing models of care, in which family centred care is considered to be an inherent

component yet leaves families with little or no help in caring for sick children (Shields, Pratt and Hunter, 2006).

According to Saleeba, (2008), parents are specialists in their child's care and know more about their child than any assessment could possibly teach us. The family is also a child's primary source of support, giving stability at what may be a stressful moment in a child's life. The presence of family members during medical procedures can greatly lessen both the child's and parents' anxiety. Reduced worry from the patient and family reduces stress on health care staff, thereby improving their capacity to offer treatment (Saleeba, 2008). The best ways for children to learn and develop are via everyday play and interactions with their parents, carers, and relatives. When one helps families acquire skills, knowledge, and confidence for these interactions, one is also helping to provide the ideal environment for children's health, development, and well-being (Saleeba, 2008).

2.7 **FCC in the context of South Africa**

FCC is relevant and important for paediatric care in South Africa. The Children's Act 38 of 2005, recognises that the views of a family are important on matters concerning the child (Child Act 38 of 2005, Chapter 2, Section 6, Government Gazette: Republic of South Africa, 2006). The Act also mandates that guardians who are the primary care givers be notified of every action or decision affecting the child (Child Act 38 of 2005, Chapter 2, Section 6, Government Gazette: Republic of South Africa, 2006). These statements clearly indicate that FCC is applicable in the South African setting.

In South Africa, only a few studies have been conducted regarding FCC. The study done by Irlam and Bruce (2002) concluded that "many nursing and medical personnel in South Africa have either not taken cognisance of the published research or have alternatively, not been convinced of its relevance". The same study also indicates that South African hospital design is not child friendly, unlike in developed countries and that make it challenging to practice FCC.

Roets, Rowe-Rowe, and Nel (2012) argued for encouragement of parental presence for hospitalised children, since doing so can lessen anxiety in both the children and the parents. Doorenbos et al (2012) reinforced the idea further by suggesting that allowing

parents whose children are hospitalised to stay with their children would result in emotional stability and good bonding for both the child and the parents.

The results of a quantitative study that was conducted in four emergency departments in KwaZulu-Natal by Almaze and De Beer (2017) show that a majority of nurses acknowledge the importance of FCC and are practising FCC. Family members were continuously provided with information and the nurses had the necessary skills to provide FCC. The same study also shows that practising FCC has some challenges for nurses if they are not fully skilled about this approach. The health care providers also need to understand a family's cultural belief system and their languages to convey information.

A mixed methods study was conducted by Pretorius (2019) to investigate and characterise nurses', health care professionals', and family members' perspectives of FCC in an intensive care unit. Pretorius (2019) discovered that to overcome discrepancies in views of family-cantered care, the implementation of family centred care should engage all stakeholders in the intensive care unit (Pretorius, 2019).

Similarly, Ndlovu (2017) discovered that respondents are generally satisfied with family centred care in two paediatric wards in a quantitative study that attempted to examine parents' perspectives on FCC in two general paediatric medical wards of an academic hospital. The respondents from both wards in the study did not differ significantly in terms of FCC views, as portrayed by the Family Centred Care Scale (Ndlovu, 2017). Both Ndlovu (2017) and Pretorius (2019) acknowledge that FCC is unresearched in South Africa. The author notes that these studies are mixed methods and quantitative. Therefore, a qualitative study is an important contribution to filling the gap in research on FCC in South Africa.

2.8 **Summary**

The literature has shown that the FCC model has many benefits to the health care system, families and patients, if practised correctly. There are challenges to practise it in developing countries like South Africa. Globally, health care institutions are striving towards the improvement of quality of care. FCC has been shown to be essential in the promotion of quality patient care through the recognition of family needs (Kokorelias et

al., 2019). Studies indicate that it is not possible to deliver FCC in a one-size-fits-all approach (Richards et al., 2017).

The complexities of parental experiences were described by Latour and are relevant to the SA setting which is recognised as complex. Understanding and meeting of parental needs and experiences are linked to improved clinical outcomes (Latour et al., 2011). The literature demonstrates the significance of PCGs' experiences in FCC. Parents have critical responsibilities in assisting children to adjust to new clinical settings. Throughout the process they endure significant levels of stress as a result of unmet information, demands, interpersonal connections with physicians, and concerns about the child's condition and progress toward recovery (Ohene et al., 2019). PCGs and their experiences are significant because they contribute to a better understanding of FCC.

Despite the limited literature from South Africa, Family Centred Care is being practised in hybrid forms. Improving the experiences of PCGs is vital to ensuring the success of FCC, both in hospital and post-hospital settings. The South African context is recognised as being complex, both politically and socially. FCC in South Africa can be improved by broadening what is known about the experiences of PCGs.

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

CHAPTER 3: RESEARCH METHOD AND DESIGN

3.1 Introduction

This chapter presents a detailed description of the research methodology and design used to explore and describe the experiences of primary care givers about FCC when their child is admitted in a specialised paediatric hospital. Research design, population and sampling strategy, interview strategy and data analysis is explained. Measures used to ensure trustworthiness and ethical considerations are also discussed.

3.2 Research method

The methodological choices of this study were based on the practicality and suitability of the research strategy and method in meeting the objectives of the study. A qualitative descriptive design was deemed appropriate to generate new knowledge, since little was known about the experiences of PCGs regarding FCC when a child is admitted in a specialised paediatric hospital.

A qualitative research aims to describe life experiences from the perspective of research participants (Grove et al., 2017). It lends significance to subjective human experience while data collection usually requires personal contact with the participants (Polit and Beck 2017). Qualitative research falls within a naturalistic holistic framework and allows the researcher to explore depth, richness and complex characteristics in the lives of human beings (Nieswiadomy and Bailey, 2018).

3.3 Study Setting

The study was conducted at a specialised paediatric hospital in urban Gauteng. Three (3) units in the hospital were used for data collection; the details are tabled below.

Table 3-1: Details of units used for data collection

Unit type	No of beds	Average length of stay	Average age of patient
PICU	8	2 weeks	1 month-16 years
NICU	10	3 weeks	Birth-1 month
General ward	29	10 days	1 month-16 years

Patients in the PICU and NICU ward are critically ill and require specialised health care. PCGs may not be allowed to attend to basic needs of their child due to the critical illness of their child.

In the general ward PCGs are fully involved in their child's care since the illness of their child is not critical and PCGs are being prepared for the discharge of their child.

3.4 **Research design**

Research design is a master plan that guides the planning and implementation of a study to ensure validity of the study findings (Creswell and Creswell, 2018). The function of a research design is to enable a researcher to anticipate what the appropriate research decision should be to maximise the validity of the eventual results. In this study, the researcher sought to explore and describe the experiences of PCGs. There are two research designs in the study: Exploratory research design and descriptive research design.

Exploratory research helps to gain new insight, discover new ideas and increase knowledge of the phenomenon (Burns and Groove, 2001). The study attempts to explore the experiences of PCGs regarding FCC when their child is admitted in a specialised paediatric hospital. This design will assist to have a better understanding of PCGs experiences regarding FCC.

Descriptive research seeks to learn more about features within a certain field of study and to paint a picture of conditions as they occur in the real world. The goal of descriptive research is to investigate and characterise events in real-life circumstances (Creswell and Creswell, 2018). The data that emerges from a qualitative study is descriptive, that is data is reported primarily in a participant's words (Creswell and Creswell, 2018). This study was therefore descriptive, as the researcher systematically described aspects related to FCC as experienced and explained by PCGs at the hospital.

3.5 **Population**

The population is the total collection of objects or individuals in which a researcher is interested (Nieswiadomy and Bailey, 2018). The population for this study was PCGs of patients receiving treatment in the PICU, NICU and General wards who were lodging in the hospital. The lodging facility accommodates 20 primary care givers and these twenty PCGs formed the population. The target population was PCGs who were willing and consented to participate in the research.

3.6 **Sample and sampling method**

A sample is defined as a representative part of the population that is used to conduct a study (Korstjens and Moser 2017). To choose the sample for this study, the researcher employed a non-probability purposive sampling approach. Purposive sampling is the selection of specific participants based on the researchers' opinion of which possible volunteers will be most informative for the study (Grove et al., 2017). This sampling method was used because it was a suitable method to select PCGs who met the inclusion criteria and with sufficient knowledge and exposure to the phenomenon under study.

A purposive sample of PCGs were selected to participate in individual semi-structured interviews at the specialised paediatric hospital in Gauteng. After conducting 11 interviews, data was saturated as no new information was added and at this point the researcher stopped data collection. Data saturation is the point at which the major themes have been identified and no new information can be added to the list of themes or to the detail of existing themes (Creswell and Creswell, 2018).

3.7 **Inclusion and Exclusion criteria**

The inclusion criteria of the participants were as follows:

- PCGs, both male or female, who were lodging at the lodger house full time while their child was admitted in the PICU, NICU or the General ward. They will be more knowledgeable about what is happening with their child. They will also be able to explain their experiences of FCC when they are rooming-in as FCC is about being with your child all the time.
- PCGs who were in their second week or more of stay at the hospital.
- PCGs who were able to speak and understand English language to do the interviews.
- PCGs who were willing to participate and consented to participate in the study.

The exclusion criteria were:

- PCGs who were not lodging at the lodger house full time.
- PCGs who were in their first week of stay at the hospital.
- PCGs who could not do an interview in English language.
- Foreign PCGs that could not speak English.
- PCGs who were not willing to participate and consent to partake in the study.

This sampling process enabled the researcher to select PCGs who had rich information and were familiar with the hospital routine.

3.8 **Data Collection**

Data collection is a means of acquiring relevant data needed to carry out research and attain objectives (Grove et al., 2017). Individual semi-structured interviews were used to obtain data for this research. Semi-structured interviews, according to Polit and Beck (2017), are organised around certain topics of interest while retaining some breadth and depth flexibility. In this study, questions for the interviews were developed from the existing core concepts of FCC according to the Institute for Family-Centred Care.

The PCGs were asked to describe their experiences of FCC by answering questions that were designed around the four core elements of FCC as described by Conway. The interview questions that were asked are provided in 0 All PCGs were asked the same basic questions in the same order. The questions were worded in an open-ended format. According to Patton, open-ended inquiries elicit detailed comments on participants' experiences, views, opinions, feelings and knowledge (Patton, 2015). The PCGs answered the same questions, and the data was completed for each PCG on the topics addressed. This reduces researcher bias and allows for evaluation of the instrument used (Patton, 2015).

3.8.1 Data collection process

Data collection commenced after ethical approval from the University of the Witwatersrand and permission from the hospital was obtained (0 and 0). The researcher fully disclosed the purpose and objectives of the study to the participants (0).

The participants were informed that their participation was voluntary and that they could withdraw at any time if they wished to do so without any consequences. This initial interaction built a rapport with the participants and provided an opportunity for the prospective participants to ask questions or raise any concerns, before volunteering and providing informed consent to participate in the study and have their interview audio recorded (0 and 0).

The duration of the interviews ranged from 25 to 45 minutes. The researcher displayed respect, friendliness, a non-judgmental attitude and positive affirmation to create a placid environment that allowed individuals to express themselves freely. During the interview, the researcher took field notes to strengthen the trustworthiness of the data acquired. The interviews were audio-recorded with the participants' agreement, and the information was transcribed verbatim thereafter (annexure 6). Accurate verbatim accounts of the experiences of the participants were provided by recording the interviews.

In this qualitative study, the researcher conducted the interviews and served as the primary research instrument (Creswell and Creswell, 2018). The researcher was actively involved in providing a favourable environment for the PCGs to convey their experiences.

The participants were interviewed in their comfortable quiet area where they were lodging.
The time to start interviews was conveniently chosen by participants
The researcher stuck to the time stipulated in the consent form.
The researcher also employed probing communication strategies to gain more information, allowing for a more in-depth examination of the data (Murphy and Dillon, 2011).The probes were directed by four elements of FCC and the questionnaire guide was followed.

3.9 **Data Analysis**

In qualitative research, data analysis is done concurrently with data collection (Korstjens and Moser 2017). Data collection and data analysis complement each other to build a comprehensible interpretation of the data (Creswell and Creswell, 2018). The researcher transcribed the data verbatim from a voice recorder after each interview. The interview data, together with the field notes, were then analysed using latent content analysis to identify meaning in the experiences of the PCGs conveyed in the text. Latent content was chosen because of the language skills of the participants, for many of whom English was not their first language. Therefore, it was appropriate to analyse the words used rather than deeper meanings.

Latent content analysis is type of qualitative content analysis that involves interpretation of the text rather than deeper meanings (Kleinheksel et al., 2019). In this data analysis method, the role of the researcher is to discover the implicit meaning of the text because meaning is not readily apparent on the surface (Kleinheksel et al., 2019). The researcher is directly involved in the analytical process and utilises mental schema, theories and lenses to interpret and understand the data (Kondracki, Wellman and Amundson, 2002). The analysis of the content uses codes to identify themes, and patterns within and among these themes (Korstjens and Moser 2017). Therefore, the researcher was directly involved and sought to discover the implicit meaning of the text which expressed the PCGs' experiences.

To become acquainted with the data, the recordings were listened to repeatedly by the researcher, read through all the transcripts, and took notes as part of the data analysis protocol.

The researcher then identified units of meaning and assigned codes to each question that was asked of the PCGs. In other words, themes emerged from the questions that were asked.

Then the researcher took note of the words that were used and how often they were used and later provided a commentary with the supporting literature (Kleinheksel et al., 2019). This is discussed in CHAPTER 4:.

3.10 **Trustworthiness**

Trustworthiness ensures rigor in the research (Korstjens and Moser, 2017). In this study, the researcher used the following four criteria of trustworthiness as defined by Lincoln and Guba, (1985): credibility, transferability, dependability, and confirmability.

3.10.1 Credibility

Credibility is explained by Polit and Beck (2017) as a strategy for establishing the extent to which the findings of the study are a true reflection of the reality. In this study, credibility was maintained through the use of in-depth interviews. Audio recordings of the participants during the in-depth interviews and verbatim transcribing of the interviews was done. Clear and accurate records of the research process was maintained and are available should they be required for audit purposes.

3.10.2 Transferability

Transferability deals with the extent that findings could be replicated in another other settings or groups (Polit and Beck, 2017). In this study, a detailed description of the research design, method and settings of the study were provided by the researcher.

3.10.3 Dependability

Dependability is a technique for assuring the consistency of results throughout time and across environments (Korstjens and Moser, 2017). In this work an audit trail was used to

establish dependability. The research steps performed from the beginning to the finish of the study were outlined in detail by the researcher.

3.10.4 Confirmability

Confirmability refers to the objectivity of the study. It is concerned with ensuring that the data obtained, as well as the interpretations of the data reflect the information provided by the participants and not fuelled by the researcher's imagination (Brink et al.,2018).

To ensure confirmability, the findings of the data in this study are reported truthfully and fairly. All documents used in data analysis are kept safely in a sealed envelope and locked in the Nursing department and will be made available on request, to validate the results of the study. Literature has been consulted to substantiate the results.

3.11 Ethical Considerations

The researcher adhered to all relevant ethical guidelines in carrying out this research. The researcher received ethical clearances and permission to do the study (0). The researcher also followed the ethical principles of respect for persons, beneficence and non-maleficence, and justice (Grove et al., 2017).

3.11.1 Ethical clearance and permissions

The proposal was submitted to the University of the Witwatersrand's Post Graduate Assessors Committee for quality and feasibility and it was approved (Annexure 2).

Clearance from the Human Research Ethics Committee of the Witwatersrand University to do the study was sought and granted (Annexure 3).

Permission was also obtained from Nursing Director, Head of Department and the Unit Managers of the PICU, NICU, and General ward at the specialised paediatric hospital prior to conducting the study.

3.11.2 Respect for persons

The ethical principle of respect for persons gives recognition to a person as an autonomous individual. It also compels one to recognise that each person has the right to self-determination and dignity (Brink et al., 2018). In this study, the researcher

acknowledged and respected participants as autonomous individuals. Participants were provided with full written information of the study (0). The participants were informed that participation was voluntary and that they had a right to participate or decline participation in the study. Answers to questions posed by participants regarding the study were provided. The participants were also informed that they had a right to withdraw from the study without any penalty.

Participants were asked to provide informed consent before participation and for the interview to be audio recorded. The collected data was handled anonymously and confidentiality was maintained. The data collected was used for this research report purpose only. All research materials and data are stored safely in a sealed envelope and locked in the Nursing department.

3.11.3 Beneficence and non-malefice

The ethical principle of beneficence and non-malefice is about doing good and avoiding harm to research participants (Brink et al., 2018). The researcher believes that the findings of this study will help to improve clinical outcomes for hospitalised children and increase levels of satisfaction for the families caring for these children and improve their experiences. The researcher anticipated that the research might cause some discomfort to the participants because having a hospitalised child is a worrisome event and recollecting the experiences can cause discomfort. The participants were asked to suggest a suitable time convenient for them to do the interviews. The interviews were conducted on the second week of participants' stay because conducting the interviews in the first week was a potentially stressful time for the PCGs. The social worker of the hospital was informed of the research and she was available in case the participants required support if they experienced any discomfort.

3.11.4 Justice

The ethical principle of justice is about fairness and equal distribution of benefits and risks of participation in a research study (Brink et al., 2018). In this study, purposive sampling was used to select participants. The participants were informed prior to the research, that participation is voluntary.

3.12 **Summary**

The research design and method were introduced and detailed in depth in this chapter. To elicit detailed information from the individuals, the researcher used a qualitative descriptive approach. Strategies for establishing trustworthiness were discussed. The fourth chapter summarises and analyses the study's findings in terms of themes and supporting literature.

CHAPTER 4: FINDINGS AND DISCUSSION

4.1 Introduction

This chapter presents the findings of the semi structured interviews that were conducted with the participants of the study. The interviews aimed to explore and describe the experiences of PCGs towards FCC when their child was admitted in a specialised paediatric hospital. Participants provided their responses in relation to their experiences in the paediatric hospital with regards to FCC. The initial opening question to the participants was “Tell me about your involvement in your child’s treatment and care” then several probes followed. The study attempted to answer the main research question, which was “What are the primary care givers experiences of Family Centred Care in a Paediatric hospital in Gauteng?”

The data was analysed using latent content analysis. The themes that formed from the questions followed by sub-themes that have emerged from the findings and supporting participants’ responses are presented in

Table 4-1: Summary of findings

Theme	Sub-Theme	Supporting response
1. Participation: The act of taking part in an activity or event (Oxford Learner’s dictionary, 2022) Primary caregiver involvement in child’s care (IPFCC, 2016)	1.1 Care giving	*‘Every time I’m there, I am taking care of my child I’m feeding him I change her nappy, I feed her’*
	1.2 Presence	*‘I stay with my child from morning I go outside for a short break just to refresh myself’*

Theme	Sub-Theme	Supporting response
	1.3 Decision making	*'Before they make any decisions, they always ask me like if they want to do an operation they ask if I am ok with it.'* *'Some of the decisions I can't make it for myself because it depends on the problem about the child. They used to talk to me and I asked questions where I don't understand. But I can't take decisions. It depends on the situation how is the child'.*
2. Support from health care providers: To help or encourage somebody/ something by saying or showing that you agree with them/ it (Oxford Learner's dictionary, 2022) According to this study , it is when health care giver are helping primary care givers to provide quality care to their child	2.1 Respect	*'They are respecting me* *They address you well'*
	2.2 Individualism	*'They talk to me like I am at home* *They will ask you how are you doing'*
	2.3 Friendliness	*'They are friendly* *Greet you with the smile'*

Theme	Sub-Theme	Supporting response
3. Challenges and Limitations Challenge is a new or difficult task that test someone's ability and skill (Oxford Learner's dictionary, 2022) Limitation is a fact or situation that allows only some actions and makes others impossible (Oxford Learner's dictionary, 2022) According to this study challenges refers to difficulties primary care givers faced in hospital regarding FCC Limitation refers to obstacles that prevent primary care givers to provide quality care to their child	3.1 Interpretation of information	*'Some of the information is new I'm am still processing'* *'Nurses don't give out information at all they will say ask your doctor'*
	3.2 Overwhelming clinical situation	*'I was scared because it my first time here'* *'You can't do that because the situation of the patient doesn't allow'*

Theme	Sub-Theme	Supporting response
	3.2 Inconsistency of staff applying FCC principle	*'Day staff is better but night staff is bad they will expect you to bath your child not helping you they do not ask if you will manage on your own.....'* *'We working good with doctors but sometimes with nurses something you need to do it ourselves while it is their job to it in this child'*

4.2 **Participation**

4.2.1 Care giving

The PCGs who were lodging at the specialist hospital were physically present, actively involved and willing to provide care to their children. The PCGs performed various parental care roles such as feeding, bathing, cleaning and comforting the child. This was enabled by receiving some form of support from the health care professionals. They were concerned with their child's well-being and experienced some emotions when unable to provide care.

The study's findings are reflected in the literature. Being present and participating in the child's care emerged as a theme in a study conducted by Ames, Rennick and Baillargeon (2011) to explore parents' perceptions of the parental role in a tertiary care Canadian university-affiliated hospital's paediatric intensive care unit (PICU), where parents expressed the importance of caring and comforting the child at his/her bedside. (Ames et al., 2011; Hill et al., 2018 and Ohene et al., 2019).

4.2.2 Presence

This current study indicated that parental presence, active involvement and willingness to provide care to their children is influenced by emotions and feeling concerned for the wellbeing of the child. In the study PCGs conveyed being present by staying with their child the whole day. Being by bedside of the child is fulfilling to the PCGs and comforting. These findings are reflected in research conducted in the Sub-Saharan context where the results showed that the condition of the hospitalised child is a basis for parents' heightened emotions, and support from health care professionals provides reassurance (Ohene, et al., 2019). Furthermore, it has also been observed in the FCC literature that being unable to participate and involved in care for the child, due to the nature of the condition, contributes to feelings of fear, helplessness and stress (Hill et al., 2018).

4.2.3 Decision making

The PCGs appeared to experience giving consent as part of contribution in decision making. There was some satisfaction with the decisions that health care professionals make. It also appeared that there is a level of trust in the health care professionals regarding their decisions on treating the child. This trust somewhat makes primary care givers limit themselves in participating in decision making. The complexity of the problem or condition of the child also limits the participation of primary care givers in decision making.

The findings of this current study are also partly reflected in the participation component of FCC. According to the IPFCC, participation entails that "patients and families are encouraged and supported in participating in care and decision-making at any level they choose" (IPFCC, 2012). In this current study there is evidence that participation of PCGs is made possible whenever there is support from health care professionals at the facility permitting them to do so.

The willingness of the health care professionals to facilitate the primary care givers in being involved provides evidence that the participation concept of FCC is being followed

at the facility where the study was done, thus giving the primary care givers some positive experiences.

4.3 **Support from health care providers**

4.3.1 Friendliness

This study demonstrates that the support from health care providers was conveyed by friendly courtesies of health care professionals towards PCGs. Actions such as health care professionals properly responding to PCGs, respecting, greeting them, calling them by name, welcoming them and being friendly showed support to PCGs, These actions are important in practice of FCC as they contribute to the positive experiences of PCGs. Similar findings exist in the literature (Levin et al., 2015 & Hill et al., 2018). According to Levin et al (2015), respect is considered by parents as showing good manners such as doctors introducing themselves and addressing parents directly (Levin et al., 2015). Hill et al (2018) argue that the PICU environment impacts parents' experiences. In relation to this current study, it can be noted that a friendly environment creates a safe environment for PCGs to feel comfortable to communicate hence contributing to positive experiences.

The behaviours in this research indicate important actions that parents experience as respectful and dignified. Similar findings exist in the literature (Meyer, 2006; Cantwell-Bartl and Tibballs, 2013 and Terp, Weis, and Lundqvist, 2021). According to Meyer (2006), professional attitudes and listening without judgement conveys respect to parents. Similarly, compassion, kindness, and caring nurses also convey respect (Cantwell-Bartl and Tibballs, 2013). Terp et al (2021) found that when parents are treated with empathy and respect, and when assistance is offered for both the child and the parents, the relationship between health care team and parents grows. The findings of Terp et al (2021) are significant to this study in the sense that there is a concurrence of evidence which indicates that in the implementation of FCC, parents will be satisfied when they experience actions of compassion and support from health care professionals.

4.3.2 Individualism

This study found that addressing PCGs concerns individually, being compassionate and non-judgemental, being friendly, providing assurances and showing respect to PCGs during their stay at the health care facility, conveyed support of health care professionals. In this current study, it can be seen that PCGs are concerned for the wellbeing of the child and experience some emotions, but it takes the support of health care professionals to give reassurance and enable parental involvement. These findings are similar to a study done in Ghana by Ohene et al (2019) who found that the condition of the hospitalised child was the basis for parents' heightened emotions and receiving support from health care professionals provided reassurance.

4.3.3 Respect

In a study by Terp et al (2021) it was found that the relationship between parents and health care team strengthens when parents are treated with empathy and respect, and support was provided for the child and the parents (Terp et al, 2021). This implies that FCC as a successful partnership is dependent on the extent of support and treatment that is given to family members.

In this study, lack of respect was viewed when there was lack of friendly courtesies and support among some health care professionals, which gave the PCGs negative experiences and they expressed their dissatisfaction. These negative experiences are felt when PCGs do not receive attention from health care professionals, when they are disregarded or when not attended to. Similar findings whereby parents expressed their dissatisfaction due to lack of respect from health care professionals is also found in the in the literature (Hill et al., 2018). It has been observed that a perceived lack of compassion, callous communication and inappropriate body language are behaviours that do not convey respect and dignity to families (Hill et al., 2018). This means that PCGs notice when health care professionals convey respect or not.

Therefore, health care professionals should not only focus on technical skills but also behaviours that are consistent with respect and dignity. This is more important in the South African context, since black culture emphasises respect.

4.4 Challenges and limitations

4.4.1 Interpretation of information

Some of the PCGs had active communication with health care professionals at the health care facility and received various types of information. However, some of the participants report their experience with lack of information or help in interpreting information from some health care professionals. Some health care workers, like nurses, were obstructive with information and were not willing to share information. As a result, PCGs were unable to voice their concern for fear their child would not receive the requisite care they need but felt they needed to be given information.

Some PCGs expressed dissatisfaction with lack of information and did expect clear communication from health care professionals. A study by Terp, Weis and Lundqvist (2021) discovered that information exchange gave parents a sense of security, addressed their needs, and decreased stress and worry.

The PCGs acknowledged the usefulness of receiving information from health care professionals to prepare for home care. They reported to be ready to provide care. They also pointed out feeling concerned about the child, dealing with emotions such as fear, anxiety and panicking and difficulties with understanding or processing the information. These appear to be the limiting factors that affect the PCGs readiness to continue home care.

It has been found in the literature that the rate at which information is presented impacts how effectively the knowledge is received, taking into account what parents feel in terms of stress, weariness, and emotions (Hill et al., 2018). Language is another factor that can determine how well information is absorbed. Use of medical jargon cannot always be understood by parents (Abib El Halal et al., 2013). It is possible these could also be indirectly contributing to the experiences of PCGs in interpreting information from some health care professionals. Furthermore, a study by Terp et al., 2021) found that information sharing provides a sense of security among the parents addresses their needs and reduces levels of stress and anxiety. These could also be indirectly

contributing to the experiences of PCGs in interpreting information from some health care professionals.

4.4.2 Overwhelming clinical situation

Some PCGs reported that there were some factors that limited their involvement in providing care to their children. These factors were the severity of the condition of the child and policies. Two PCGs wished for the hospital to allow them to sleep with their children at night.

It has been observed in the literature that the nature of the condition may prevent families from being involved and participating in caring for the child; this results in feelings of helplessness, fear and stress (Colville et al., 2009; Jee et al., 2012; Smith da Nobrega Moraisand Geraldo da Costa, 2009 as cited in Hill et al., 2018). Furthermore, it is important to have a shared understanding between primary care givers and health care professionals concerning when, how, and the level of participation each parent wishes (Hill et al., 2018). It is therefore important that the health care facility develops, Implements and educates primary care givers on how and when can they be involved.

4.4.3 Inconsistency of staff applying FCC principles

Some health care providers were helpful like doctors. Nursing staff was a challenge they were not willing to help PCGs. This is conveyed by day staff is better but night staff is bad. It is clear that PCGs this inconsistency of care is a challenge in this health care facility The PCGs experienced lack of help or support from some health care professionals. These negative experiences appear to paint a picture of the kinds of working relationships the PCGs had with different nurses. However, poor communication appears to be a contributing factor. These findings are similar to those of Terp et al (2021), who discovered that a lack of collaboration was caused by health care professionals providing care based on the diagnosis and the department's guidelines for care organisation rather than tailoring care to the individual needs of the child and his/her family.

4.5 **Summary of Findings and Discussion**

This research described the experiences of primary care givers as they lodge in the hospital facilities and involve themselves in their child's care. The findings show that primary care givers are willing to participate in the care of their child by being physically present, making decisions and giving care to their child through performing various parental duties, like feeding, bathing and comforting the child. Primary care givers participate because they are concerned for the well-being of the child. Participation of primary care givers is made possible whenever there is support from health care professionals at the facility permitting them to do so. Therefore, the willingness of health care professionals to facilitate the primary care givers in being involved provides evidence that the participation concept of FCC is being followed at the facility where the study was done thus giving the primary care givers some positive experience. PCGs experienced various emotions like fear, anxiety and stress. Support from health care professionals at the facility plays a pivotal role in helping PCGs to deal with these emotions.

According to the concept of support from health care provider, this research found that health care professionals' actions of respect, individualism and friendliness gave the primary care givers a feeling of being supported. Respect in this case is conveyed through common courtesies such as health care professionals addressing PCGs well, properly responding to primary care givers, greeting them, welcoming them and being friendly. Due to these courtesies, primary care givers had a safe environment for them to feel comfortable to communicate. PCGs also felt supported when health care providers were individualising their care. This is conveyed when health care providers talk to PCGs like they were at home. Also when health care providers make time for PCGs to find out how they were doing.

This research found that PCGs acknowledged receiving useful information from health care professionals but sometimes the information was complicated to process. It is unclear what really caused difficulty to process the information. However, there are elements of panicking or feeling scared that seem to contribute. Perhaps stress, fatigue, emotions or language could also indirectly contribute to the experiences of PCGs' challenges in interpreting information from some health care professionals.

Dissatisfaction was expressed when primary care givers did not get all the necessary information and were fearful to ask despite expressing the need to be given information. The use of medical terms could also be the limiting factor for the PCGs to interpret the information given. Therefore, it is important for health care facilities to have guidelines that direct the use of understandable language to primary care givers to maximise comprehension.

This research also found that PCGs experience some limiting factors that affect their participation and involvement in their child's care while heightening their emotions. These limiting factors include the condition of the child and hospital policy. The severity of the condition of a child is a key limiting factor for participation but primary caregivers place trust in the knowledge of health care professionals. PCGs place total trust in the knowledge of health care providers

For some of the experiences uncovered in this study there seems to be a limited understanding between some of the primary care givers and health care professionals regarding how or when the primary care giver can participate. Consequently, some PCGs felt denied an opportunity to participate. However, evidence shows that some PCGs appeared to understand the validity of the reasons why in certain circumstances they could not participate. In this research it seems such understanding is limited thus the negative experiences. Therefore, noting that support from health care workers is an important enabling factor for primary care givers participation, it is necessary that health care facilities develop plans for guiding primary care givers participation and best measures to offer continued support.

PCGs felt supported when health care givers showed friendliness. Friendliness is conveyed when health care givers greet the PCGs with the smile and when they are friendly.

Some challenges PCGs experienced was clinical environment that was overwhelming because it was their first time in hospital. Also the child condition and being in ICU was limiting PCGs to provide care and be with their child as they wish due to hospital policy.

Some PCGs noticed inconsistency of staff in applying FCC principles. Some health care professionals were not giving them attention, felt disregarded or were not attended to. In addition, poor staff attitude created a non-safe environment for the primary care givers to express themselves and they became fearful that their child would not receive proper care. Inconsistency of staff is conveyed when PCGs says day staff is better but night staff is bad. Also when they say doctors are more helpful than nurses. This indicates that unprofessional conduct and lack of common courtesy creates negative experiences for primary care givers in terms of how are treated. It is important that health care professionals prioritise in demonstrating professional behaviours and common human courtesies for continued positive experiences for primary care givers.

CHAPTER 5: LIMITATIONS RECOMMENDATIONS AND CONCLUSION

5.1 Introduction

This chapter presents the limitations of this study. It also presents suitable recommendations for FCC regarding practice, research, education and management. Direction of future research is suggested and the chapter ends with a conclusion for the study.

5.2 Summary

This chapter has presented the limitations of this study. It has also presented suitable recommendations for FCC regarding practice, research, education and management. Direction of future research has been suggested and it has been concluded that primary care givers encounter both positive and negative experiences when core concepts of FCC are implemented.

The findings of this study provide knowledge for understanding the experiences of PCGs regarding FCC when their child is admitted in a specialised paediatric hospital. The findings may inform policy and practice to assist health care professionals and health institutions to improve the delivery of FCC, which may improve PCGs' experiences, satisfaction and patient outcomes.

5.3 Limitations of the study

This study was limited to a specific region of South Africa and a specific hospital. Furthermore, only English-speaking participants were selected. The setting is a relatively well-resourced hospital. It would be interesting to have included non-English speaking primary care givers and a limited resource setting. Therefore, the results cannot be generalised to other hospital settings that may have different management policies.

There were no foreign English speaking parents lodging at the time of the study. The hospital serves people from all over Africa who can be English and non English speaking. The study was based on participants who can understand English and speak English because there was no interpreter on standby.

Another limitation is that the study was conducted by a novice researcher and it is probable that not enough probing during the interviews was done to gain more information from the participants. However, the findings from the study provide an insight into how primary care givers experienced Family Centred Care when their child was admitted to this specialised paediatric hospital. It also serves as a benchmark for the development of further research exploring various perspectives of primary care givers regarding FCC.

5.4 **Recommendations for Practice, Research, Education, and Management**

This study has shown that despite operating on the principle of family-centred care in the paediatric care environment, primary care givers' experiences reveal shortcomings that prevent full implementation of FCC as per its core concepts. Therefore, the author makes the following recommendations.

5.4.1 Practice

It is recommended that the findings of this study be shared with health care professionals within the specialised paediatric hospital. This may raise awareness on the extent that FCC core concepts are met or unmet. This will assist to identify gaps that exist regarding FCC and the development of improvement strategies.

It is also recommended that health care professionals must make deliberate efforts to act professionally and kindly so that the care environment is conducive for primary care givers.

5.4.2 Education

It is recommended that health care professionals should undergo orientation and education on the core concepts of FCC.

It is also recommended to educate primary care givers regarding coping with their hospitalised child and regarding FCC.

The concept of FCC in medical, nursing, physiotherapy, speech therapy, and occupational therapy student training is also recommended to improve family capacity to play a significant part in their loved one's care and positive perceptions about receiving care.

5.4.3 Management

It is recommended that the hospital develop policies for FCC regarding training, implementation and regular evaluation.

It is recommended that the Hospital develop clear written protocols for the involvement of parents/family in the care of the in-patient child and this should be communicated through induction to the institution.

5.5 Future research

There is a need for further research to identify specific actions that primary care givers associate with FCC. These actions may be used for benchmarking and quality improvement purposes.

Further research in this setting is required to determine the knowledge levels of health care professionals regarding FCC. This might help to understand the success factors of implementation of FCC and the root of any shortcomings. When there are shortfalls in implementation of the FCC core concepts reported by families, health care professionals and the institution should determine whether these perceptions are attributed to lack of institutional support or lack of determination and understanding.

Further research is also needed to generate evidence about FCC in situations arising from modern models of care where the parents attend daily and do not lodge on site. This will also enhance the validity and generalizability of research in family centred care.

5.6 **Conclusion**

The purpose of this study was to explore the experiences of primary care givers regarding FCC when their child is admitted to a specialised paediatric hospital in Gauteng. These experiences demonstrate the extent to which FCC core concepts, as outlined by the Institute of Patient and Family Centred Care (IPFCC), are implemented within this specialised paediatric hospital. However, the partnership between the PCGs and the health care professionals is inadequate because there are areas that emerged that need improvement. The needs of both Health Care Professionals and PCGs are needed in the delivery of FCC because they all work towards the common goal of the patient. Therefore, clear policy guidelines that remove ambiguities on what specific actions constitute FCC, should be frequently reviewed to address the needs of both Health care professionals and PCGs.

The findings of this study reveal that primary care givers encounter both negative and positive in terms of the implementation of core concepts of FCC. In terms of participation, primary care givers are willing to engage in care and health care professionals are the enabling factor. Without the willingness of Health care professionals to encourage involvement, FCC cannot be practised. PCGs' presence is because they are concerned with the well-being of the patient. Therefore, parental presence without full involvement in the care of the patient should not be misconstrued or described as FCC. Respect and dignity are primarily conveyed through human and professional courtesies. These professional and friendly courtesies also facilitate information sharing. The severity of the condition of the child is a key limiting factor for participation but primary care givers place more trust in the knowledge of health care professionals. Open communication and availability of information to PCGs gives primary care givers the satisfaction of a positive experience, but they also expressed dissatisfaction when there was a lack of information sharing. Collaboration was not present in terms of the IPFCC definition as there was no evidence of involvement in policy and program development. The PCGs were not familiar with inclusion and collaboration in FCC because they were used to the fact that in South Africa Health care professionals play an authoritative role and PCGs just follow.

The nursing staff in particular, has more influence over FCC because of frequent contact with both patients and PCGs. It is the nurses who instruct the PCGs on the procedures and care that would be carried out during hospitalisation and post discharge. This implies that if you have a nurse that is willing to include the PCGs, then the FCC element will be seen to be implemented. Therefore, health care professionals' attitudes towards FCC core concepts can have an impact on the experiences of primary care givers.

It should be noted that most of the experiences in this study are positive. However, one should keep in mind that the PCGs would have been cautious to complain because their children were still in the hospital. The PCGs could have feared that their sick child would not receive good care if they expressed their negative experiences. Furthermore, some of the PCGs knew that the researcher was a Health Care Provider, and they probably would have felt uncomfortable to level criticism. Therefore, it should be noted that lack of negative experiences may not necessarily mean success in FCC delivery, but could be because the PCGs were in a vulnerable position and unlikely to express negative experiences or criticism.

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ANNEXURES

Approval of title

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

28 August 2019
Person No: 0403409G
PAG

Mrs PQ Mashishi
483 Maputo Street
Meyersig Estate
Alberton
1449
South Africa

Dear Mrs Pretty Mashishi

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Primary care givers experiences of family centred care in a Paediatric Hospital in Gauteng* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Assessors' feedback



School of Therapeutic Sciences

Faculty of Health Sciences · Private Bag 3, Wits, 2050, South Africa
Tel: +27 11 717 2083/4 · Fax: 27 11 717 2066/086 553 5964 · E-mail: irene.janse-van-noordwyk@wits.ac.za · www.wits.ac.za

SUMMARY OF ASSESSORS FEEDBACK

Date of Assessor Group Meeting : 17 July 2019

Assessor Group : Group 2

Student Number : 0403409G

Student Name : P. MASHISHI

		Yes	No
i.	Revision of the protocol to the Supervisor / Head of Department: (**Candidates**: x1 copy of protocol, list of corrections (x1), supervisor's approval letter (x1) - submit to: Mrs I Janse van Noordwyk, Room 4B02, Level 4, Medical School)	X	
ii.	Revision of the protocol to the satisfaction of the Assessor Group: (**Candidates**: copies of protocol (x2), list of corrections (x2), supervisor approval letter (x2) - submit to: Mrs I Janse van Noordwyk, Room 4B02, Level 4, Medical School)		
iii.	Revision of the protocol and resubmission of the revised protocol to the next Assessor Group Meeting: (**Candidates**: as per the guidelines for submission to an assessors meeting - submit to: Mrs I Janse van Noordwyk, Room 4B02, Level 4, Medical School)		
iv.	Candidate goes ahead		

Name and Signature of Chair of Assessor Group:

Sonti Pillay

Clearance certificate from Human Research Ethics Committee

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms P Mashishi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M190934

NAME: (Principal Investigator)	Ms P Mashishi
DEPARTMENT:	School of Therapeutic Sciences Department of Nursing Education Nelson Mandela Children's Hospital
PROJECT TITLE:	Primary care givers experiences of family centred care in a paediatric hospital in Gauteng
DATE CONSIDERED:	2019/09/27
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Mesdames C Bracher and L Engelbrecht
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2019/11/12

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 on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
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 submit details to the Committee. I **agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore reports and re-certification will be due early in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

Approval from the hospital as a study setting

Nelson Mandela Children's Hospital
A family dedicated to care

LETTER CONFIRMING KNOWLEDGE OF NON-CLINICAL TRIAL RESEARCH TO BE CONDUCTED AT NELSON MANDELA CHILDREN'S HOSPITAL (NMCH)

04 September 2019

Dear Pretty Mashishi,

Re: Primary Care Givers Experiences of Family Centred Care.

We hereby confirm knowledge of the above-named research application to be made to the Nelson Mandela Children's Hospital (NMCH) Executive Committee and in principle agree to the research application, subject to the following:

1. Data collection may not commence prior to the receipt of Ethics Final Approval;
2. A copy of the research will be provided to NMCH Executive Committee once it is finally approved by the tertiary institution, or once complete;
3. NMCH has the right to implement any Best Practice recommendations from the research;
4. NMCH reserves the right to withdraw the approval for research at any time during the process, should the research prove detrimental to the subjects/ NMCH or should the researcher not comply with the conditions of approval.

We wish you success in your research.

Yours faithfully,

Jayson Gopiechand
Nursing Director

NPC Registration No: 2011/000134/08
Web address: http://www.nelsonmandelachildrenshospital.org
P.O. Box 797, Highlands North, 2037. 6 Jubilee Road, Parktown 2193. Tel: (+27 10) 133-0600

Directors
Phethuxma Nhleko (Chairperson) • Terence Carter • Moses Kgosana • Richard Lebotho • Jacko Maree • Sibongile Mkhabela
Sam Mokgokong • Kgomotso Moroka • Moss Ngoasheng • Victor Sakoane • Joe Seabane • Sithembiso Velaphi • Martin Vuller

Consent form for participants



PARTICIPANT CONSENT SHEET

Primary Care Givers Experiences of Family Centred Care in a Paediatric Hospital in Gauteng

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Pretty Mashishi, MSc Child Nursing student, Principal investigator, Cell: 073 861 8376
Email: 0403409g@students.wits.ac.za

Mrs Claire Bracher,Supervisor, Cell no. 082 077 1942, e-mail: claire.bracher@wits.ac.zaLinette Engelbrecht, Supervisor, e-mail:Linette.engelbrecht@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by: _____

Name of Witness: _____

Signature: _____

Date: _____

Consent form for audio recording of participants' interview



CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

Primary Care Givers Experiences of Family Centred Care in a Paediatric Hospital in Gauteng

I hereby consent to audio recording of the interview; the recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.

- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research

I understand that:

- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Study information document



STUDY INFORMATION DOCUMENT

Study title: **Primary Care Givers Experiences of Family Centred Care in a Paediatric Hospital in Gauteng**

Good day

Introduction: I Pretty Mashishi am a student in MSc in Child Nursing from the University of Witwatersrand. As part of the degree, I am required to conduct a research study and hereby invite you to participate in the study. The purpose of the research is to describe primary care givers (PCGs) experiences regarding Family Centred Care (FCC). The results of the study will be used to inform health education and policies around FCC which will in turn ensure better practice of FCC.

Invitation to Participate: I am inviting you to take part in a research study

What is involved in the study? The design for the study is qualitative descriptive design using semi structured questions. Participation into the study means taking part in an interview whereby you will be asked to describe your experiences of family centred care. The interview will take 20 to 30minutes. Interviews will be audio recorded to ensure reliability and accuracy during data analysis.

Risks of being involved in the study: There are no known risks associated with participation

Benefits of being in the study: There is no direct benefit to the Participant.

Participation is voluntary, your participation in this interview is voluntary. Refusal to answer any questions that make you uncomfortable is permitted, and withdrawal from the interview may be taken without penalty or loss and it will not interfere with the medical or nursing care given to your child.

Reimbursements for "out of pocket" expenses: you will not receive any payments or other incentives for your participation.

Confidentiality: Your real name will not be used during the interview and the recordings will only be accessed by the researcher and the supervisor. Interviews will be recorded and destroyed after the study or publication. If the results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Support: The social worker of the hospital is informed of the research and she is available in case the participants require support if participants experience any discomfort. The social worker's office is easily accessible on the ground floor of the hospital and she is always available for any assistance.

Contact details of researcher: Pretty Mashishi, MSc Child Nursing student cell: 073 861 8376 Email: 0403409g@students.wits.ac.za

Mrs Claire Bracher, Supervisor, Cell no. 082 077 1942, e-mail: claire.bracher@wits.ac.zaLinette Engelbrecht, Supervisor, e-mail:Linette.engelbrecht@wits.ac.za

Contact details of HREC administrator and chair – for reporting of complaints / problems.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Dr Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The

telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

DATE: September 2019

Interview questions

Socio-demographic information

- **How old are you? below 20 20-29 30-39 above 40**
- **How many children do you have? less than 3 more than 3**
- **What is your Home language? ----------**
- **What is your marital status? Single Married Divorced Widowed**
- **How are you related to the patient ----------**
- **Who does child live with Both parents Mother Father**
- **Other (specify) ----------**
- **What is your highest level of education? ----------**
- **Are you working? Yes or No Pensioner**
- **If yes what is your occupation ----------**
- **Does your child get support grant? Yes or No**
- **If no specify the reasons ----------**

- **Long questions**

  Tell me about your involvement in your child's treatment and care

  Probes include:

- **How did the staff show you respect?----------**
- **How were you addressed when health care professionals were talking to you and your child? ----------**
- **How comfortable did you feel in expressing your concerns about your child's care?**

- **How did you contribute in making decisions for your child care? ----------**

- **What information did you get from health care professional? ----------**

- **How useful has the information you have received regarding your child's care been in preparing you for home care?----------**

- **How did you work together with health care professionals? ----------**

- **How were you included in treatment planning and delivery of care to the child?**

- **What were the limitations you experienced in your involvement with your child?**

