PARENTS' VIEWS OF FAMILY CENTRED CARE IN A SOUTH AFRICAN ACADEMIC HOSPITAL IN GAUTENG

A RESEARCH REPORT

BY

Mathoto Sinnah Ndlovu

Student Number: 324514

MASTER OF SCIENCE IN NURSING

SUPERVISORS:

PROF CHRISTA VAN DER WALT AND

DR. SUE ARMSTRONG

2017

DECLARATION

I, Mathoto Sinnah Lazarus Ndlovu, declare that this research report is my own work. It is being submitted for Master of Science (in Nursing) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature ……………………………………..

……………………………day of ……………………..2017

Protocol Number M160680

DEDICATION

Colossians 3:17 "And whatever you do, in word or deed, do everything in the name of the Lord Jesus, giving thanks to God the Father through Him."

Praise to God Almighty, who has given me the strength and wisdom to persevere through all.

ACKNOWLEDGEMENTS

I would like to thank my Heavenly Father for the wisdom He has imparted on me, without Him, I would not be.

I would like to thank the following special people in my accomplishment:

To the woman who birthed me, my mom, Pulane Josinah Manala, thank you so much for your encouragement throughout the trials and tribulations. Your strength is one of the reasons I see the world in a different view.

To my loving husband, Sifiso Wellington Ndlovu, thank you so much for your support, and always seeing the best in me when I did not. Thank you for being such an awesome father to our gorgeous daughters.

To my gorgeous princesses, Minenhle, Mbalenhle, and Zinhle, you have given me the reason to live life to the fullest, you are one of the reasons I persuaded this degree.

To my supervisors, Professor Christa van der Walt and Dr. Sue Armstrong, thank you for sharing your knowledge, and guiding me throughout this project.

To Professor Lize Maree, thank you for your encouragement and making me push through even when I felt like throwing in the towel. Please continue being the best Head of Department, not only for your staff, but for your students too.

To the research participants, I pray that God continue to give you strength to be there for your children. Through it all, God is the living King of Kings, continue putting your trust in Him. May He protect you and your loved ones.

ABSTRACT

Introduction Admission of a child in hospital is a stressful situation for the child, parents and family. According to the American National Centre for Family/Professional Development (2009) Family Centred Care is important as this can improve patient and family outcomes, improve the patient's and family's experience, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs, and lead to more effective use of health care resources. Hence, there is a need for Family Centred Care and this should be standard practice in health care institutions. While Family Centred Care is known to be beneficial, the approach has not received specific attention in most hospitals in South Africa. Little is also known about the parental views on family centred care in the South African context.

Purpose and objectives The purpose of the study was to describe parents' views on Family Centred Care in two general paediatric medical wards of an academic hospital with a view to develop to improve Family Centred Care in the future. The objectives are to describe parents' views regarding Family Centred Care with the use of Family Centred Care Scale and to compare parents' views in the two paediatric medical wards.

Method This study was conducted using a quantitative design with a descriptive, cross-sectional, non-experimental survey, using a researcher-administered assessment validated tool entitled Family Centred Care Scale (FCCS) with a 5-point Likert scale (Curley, Hunsberger, and Harris, 2013). The total population N=161 parents of the total sum of children's parents admitted in the two medical wards of a particular month were asked to participate in the survey if they met the inclusion criteria.

Results The results from the matched p scores ($p<0.05$) from the importance and consistency subscales show that the parents expectations of the nurses' actions are being fulfilled with regard to Family Centred care. The match scores were all above 50% however, the item "nurses help me feel welcomed" rated the lowest. This could be because of the rigid and short visiting hours. There was no statistically difference in the match scores of Ward A and Ward B.

Conclusion There is general satisfaction of family-centred care in the two paediatric wards from the respondents. The respondents from both wards in the study did not differ significantly in terms of family-centred care views, as portrayed by the Family-Centred Care Scale. There is a need to replicate this study on parents whose children have been discharged but meanwhile attention to the rigid visiting hours appears to be warranted.

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

LIST OF FIGURES

Figure

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 Introduction

In this chapter, the reader will be introduced to the overview of the study, which is Parents' Views on Family-Centred Care in a South African Academic Hospital in Gauteng. In the introductory chapter, the background, problem statement, purpose, objectives, significance and definitions of study operational terms will be outlined. Lastly, the framework of the research methodology, the reliability and validity of the study and ethical considerations will be presented.

1.1 Background

Admission of a child into hospital is a stressful situation for the child, parents and family. Evidence from studies conducted by Rees, Gledhill, Garralda, & Nadel (2004), and Morrison & McMill (2004) showed the children developed post-traumatic distress disorder (PTSD) due to hospitalisation, and the parents were traumatised by the experience of their children being admitted.

In their study, Morrison & McMill (2004) discovered that the families sampled were affected by their children's hospitalisation, resulting in them being traumatised from the experience of their children being admitted. To address this problem, it was recommended that participation by families in their child's care would promote normality of the family unit, continue the normal routines of the child's life within the limitations of the hospital setting and reduce the emotional stress for the child.

One study showed that the caregivers desire more participation in the care of their child and are often made to feel as though they are required to surrender their parenting role to healthcare providers when their child is admitted in hospital (Graham, Pemstein, & Curley, 2009). This involvement of parents in their child's care is one of the principles of family-centred care.

Family-centred care is "an innovative approach to the planning, delivery and evaluation of healthcare, which is grounded in a mutually beneficial partnership among patients, families and providers, and which recognises the importance of the family in the patient's life" (American Academy of Pediatrics, 2012). The American National Center for Family/Professional Partnerships (2009) stated that through practising family-centred care, health care policies and programmes are modelled to better relationships between patients, families, and healthcare workers.

The importance of family-centred care is seen as vital as it has the potential of helping to bring about enhancement of both the patient's and his/her family's outcomes, their outlook on life, and to further strengthen the relationships they have with each other. Family-centred care can also benefit the healthcare institutions as it can help in lowering costs, in turn optimising costs for other health-promoting and sickness-preventing measures (American National Center for Family/Professional Partnerships (2009). These mentioned benefits advocate for the need for family-centred care and this should be standard practice in healthcare institutions.

Views of the nurses regarding FCC were mentioned in an Irish study by Coyne (2013), where it was stated that paediatric nurses welcomed the model of FCC both at a national and international level, as well as in government policies in the Ireland and in England. However, the challenge that was faced by the nurses was the process of implementation of the FCC model. Challenges included having inadequate knowledge and skills, and the stress associated with the roles that the nurse and parent should play which, in turn, arises from a failure to negotiate with each other.

In the South African Children's Act 38 of 2005 (2005: Chapter 2, Section 3), it is stated, "if it is 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." The Act further states that, "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 taken in a matter concerning the child which significantly affects the child" (Child Act 38 of 2005, 2005: Chapter 2, Section 6). These statements further strengthen the relevance of family-centred care in the South African setting, as it brings together the onus of the family in the wellbeing of the child, therefore bettering and enhancing the child's health in collaboration with the healthcare team.

To date, no study has been found in literature for the South African setting regarding parental views on family-centred care, although a few studies have been conducted to show the need for family-centred care in the South African setting (Coetzee, Britton & Clow, 2005; Neal, Frost, Kuhn, Green & Grance-Cleveland, 2007).

1.2 Problem statement

In the hospital of the research setting's paediatric department, the environment is often challenging for staff and patients due to the high acuity levels and rapid turnover rate of patients. During the month of March 2016, there were 458 admissions, with medical wards contributing 35% of these. This can lead to a deficit in 'soft skills' or interpersonal interaction skills by nurses. As a paediatric nurse, the researcher has witnessed the distress that parents often face when having to leave their children during hospitalization due to nurses not communication effectively to the parents and in turn not making them feel welcomed. This further raises anxiety and stress for both the child and the family, on top of the distress already present caused by concern about the medical ailment for which the child is admitted.

While family-centred care is known to be beneficial (American Academy of Pediatrics, 2012; American National Center for Family/Professional Partnerships, 2009), the approach has not received specific attention in most hospitals in South Africa.

In South Africa, only a few studies have been conducted regarding family-centred care. An integrative literature review conducted by Bruce and Irlam (2002) elicited information that by including and advocating for family-centred care, positive outcomes for the child's health would result. This is due to the fact that the parents are involved, and would continue to take care of the child even after discharge. There is, therefore, a need to investigate parents' views on family-centred care in South Africa.

The development of an evidence-based programme to improve family-centred care in the South African setting might be considered as a result of the findings of this study.

1.3 Research question

What are parents' views regarding family-centred care in an academic, hospital in Gauteng?

1.4 Purpose of the study

To describe parents' views on family-centred care in two general paediatric medical wards of an academic hospital, with a view to improve family-centred care in this setting.

1.5 Objectives of Study

- To investigate parents' views regarding family-centred care with the use of a Family-Centred Care Scale
- To compare parents' views in the two paediatric medical wards in an academic hospital.

1.6 Significance of the study

The worth of investigating parents' views on family-centred care is to improve the principles of family-centred care in the medical paediatric units in the hospital. In the literature initially reviewed by the researcher it was found that parents might feel less stressed and have less anxiety over their children's admissions if the principles of family-centred care are practiced (Kristjansottir, 1995; Shields, 2001; and Shields & Kristensson-Hallstrom, 2004). The researcher has come across instances whereby parents do not know the reasons for their children being hospitalised and children crying inconsolably, wanting their parents who can only visit at times set out in the wards. Studies by Slade (2005), and Fonagy and Target (2005), further emphasise that panic can set in when children are stressed, but parents can help alleviate stress and anxiety levels merely by being present.

It is hoped that the outcome of this research study will help in improving family-centred care principles and raise awareness thereof to the patients, parents and the healthcare providers in the medical wards of the academic hospital.

1.7 Definition of operational terms

Parent: “Is it a person who is a mother or father to a child” (Merrian-Webster Dictionary, 2015).

Views: “An opinion or a way of thinking about something” (Merrian-Webster Dictionary, 2015).

Family-centred care: “An innovative approach to the planning, delivery and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognises the importance of the family in the patient’s life.” (American Academy of Pediatrics, 2012).

Nurse practitioner: “Any person registered under section 31(1) of the nursing act, Act no. 33 of 2005.” (SANC, 2005).

Academic Hospital: “A teaching, referral hospital that provides services that are generally of high cost and low volume…it requires high technology and/or multidisciplinary teams of people with scarce skills to provide sustained care of high quality.” (Cullinan, 2006)

1.8 Summary

In this chapter, an overview of the study was presented. As the introductory chapter, the background, problem statement, purpose, objectives, significance and definitions of the study operational terms were outlined. Lastly, the framework of the research methodology, the reliability and validity of the study and the ethical considerations were presented.

In the following chapter, the literature review will be presented.

CHAPTER TWO

LITERATURE REVIEW

In this chapter, the literature review and the framework of family-centred care will be outlined, the history will be discussed in conjunction with a definition and an explanation of its importance and lastly, international and local studies will be discussed to show the advances in family-centred care in the literature.

2.0 Introduction

Hospitalisation of a child is a stressful event to both the child and family, especially the parents (Commodari, 2010; Shields, 2001). Studies conducted by Rees, Gledhill, Garralda and Nadel (2004) revealed parents experience symptoms of post-traumatic stress disorder, 27% and 7% in Paediatric Intensive Care (PICU) and general wards, respectively, due to their children being in hospital.

There have been numerous models developed in the paediatric setting trying to alleviate the stress parents encounter with the hospitalisation of their children. These models are the ‘care-by-parent units,’ whereby the family moves into a setting, which portrays a home within the hospital resulting in most of the care being rendered by the parents. In ‘partnership-in-care,’ there is a discussion between the healthcare providers and the family to establish the level of involvement the parent wants, in other words the parent(s) can choose how much they want to be involved in the care of their child. Lastly, there is ‘family-centred care,’ whereby the whole family is seen as a unit, not just the child or the parent(s). Family-centred care model is the one model with good outcomes as it structures the parents’ involvement in their child’s hospitalisation, both in developed and developing countries, and it also reduces stress in parents during that period

(Coyne, 2013; Mortensen, Simonsen, Eriksen, Skovby, Dall & Elklit, 2014).

2.1 History of Family-centred care

Child nursing originates prior the First World War, when there was greater concentration on the emotional wellbeing of the child. Nursing care then acknowledged the child’s social as well psychological wellbeing (Jolley & Shields, 2009). Unfortunately, as industrialisation developed, hospitals became unwelcoming for children (Jolley, 2007), mainly because ward routines put the healthcare workers first rather than the children and parents unfortunately had to surrender all their parental powers to the hospital’s healthcare workers (Shields and Nixon, 1998). According to literature, the reason why parents were barred from hospitals during their children’s hospitalisation was due to high rates of cross-infection in the 1920s and at the end of World War II (Aubuchon, 1958). Little to no contact was optimised for children and their parents whilst hospitalised because of the absence of antibiotics. Ultimately, emotional wellbeing had to take little to no priority during the child’s hospitalisation (Lomax, 1996).

The concepts of family-centred care were first studied in the 1950s by United Kingdom researcher, Bowlby (Bowlby, 1952, 1953, 1960; Bowlby, Robertson, and Rosenbuth, 1952), who noticed the effects of hospitalisation on children and their parents. During that same era another researcher, Sir Harry Platt, developed the Platt Report (England Ministry of Health, 1959) in which he stated the children underwent protest, despair and detachment while the mothers experienced ‘maternal deprivation.’ He suggested in the report that there should be more presence and visitation allowed from the parents, and they should be more involved in the care of their children during hospitalisation. In the 1980s, American researchers Shelton, Jepson, and Johnson

(1987) brought to light eight key elements of family-centred care, namely acknowledging that the family is a constant structure in the child's existence, collaboration of the parents and health care providers, information sharing, policies, respect, independence, parent-to-parent support, and relevantly planned healthcare delivery services. The principles were additionally amalgamated in the '80s and '90s in the Ottawa Charter for Health Promotion (World Health Organization, 1986), the United Nations Convention on the Rights of the Child (Hogg, 1996), the State of the World's Children (United Nations General Assembly, 1989). More recently, non-profit organisations in the United States of America, such as the Institute of Family-Centered Care and the National Center for Family Professional Partnerships, endorsed the ideas of family-centred care by supporting the parents, families and healthcare providers in rendering family-centred care development.

2.2 The Importance of Family-centred care

Family-centred care is "an innovative approach to the planning, delivery and evaluation of healthcare, which is grounded in a mutually beneficial partnership among patients, families and providers, and which recognises the importance of the family in the patient's life" (American Academy of Pediatrics, 2012). The American National Center for Family/Professional Partnerships (2009) stated that through practising family-centred care, health care policies and programmes are modelled to better relationships between patients, families, and healthcare workers.

The importance of family-centred care is seen as vital as it has the potential of helping to bring about enhancement of both the patient's and his/her family's outcomes, their outlook on life, and to further strengthen the relationships they have with each other. Family-centred care can also benefit the healthcare institutions as it can help in lowering costs, in turn optimising costs for other health-promoting and sickness-preventing measures (American National Center for Family/Professional Development (2009). Lastly, it focuses on the family after discharge as the involvement of families in the care of their hospitalized children is important to help with continued care at home (Irlam & Bruce, 2002). These mentioned benefits advocate for the need for family-centred care and this should be standard practice in healthcare institutions.

Family-centred care appears to contain three core principles, which include partnership, participation and protection (Franck & Callery, 2004). Firstly, partnership means the relationships between the triad, i.e. the child, family and the healthcare provider, which are grounded on truthfulness, trust, equality and respect, and mutual agreement between these parties. The second principle of participation is where the family or child (if of the age or maturity to do so) selects the extent of participation with which they want to be involved. Lastly, protection is supporting and advocating for the rights of the child and parent so that they obtain the best care in all aspects (Corlett & Twycross, 2006).

It is evident that due to these three principles, anything that happens to the child has an impact on the parents and the family, in particular hospitalisation. This means healthcare providers should have decent communication and interaction with the parents of the children as they (child and parents) may be emotionally unstable (Shields, Pratt & Hunter, 2006).

2.3 International studies of Family-centred care

In a study conducted by Morrison & McMill (2004), the families sampled were affected, as they were traumatised by the experience of their children being admitted to hospital.

It was advised that the family to return its normal functional state to lessen the emotional anxiety experienced by the child. (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2005). In addition, one study highlighted the parental needs during a child's hospitalisation; they yearn to be involved in their child's care and often feel as though they are expected to surrender their parenting role to healthcare providers (Graham, Pemstein, & Curley, 2009). This can lead to role confusion.

Corlett & Tywcross (2006) stated that parents felt disempowered and deskilled if they were not involved in their children's care. They further mentioned that for family-centred care to be successfully implemented, there should be effective communication and role clarification between nurses and parents. The researchers suggested that parents should be involved in the process of making decisions.

2.4 South African context in Family-centred care

Academic hospitals in South Africa are overwhelmed with the influx of the number of patients due to urbanisation. According to the Gauteng Department of Health's Annual Performance Plan (2016), Gauteng is an over-populated urban province as it has 13.2 million people living in an area of 18 179 km^2. This is astounding as the whole country has an average of 42 per km^2. Of the country's population, 24% reside in this province, out of the nine provinces in the country, further showing uneven distribution of the population. The Department has been plagued by high vacancy rates by the health care professionals, including nurses, so the current inability to grow an understaffed department in line with the population it serves is a big challenge (Gauteng Department of Health, 2016).

In South Africa, only a few studies have been conducted regarding family-centred care. An integrative literature review conducted by Irlam & Bruce (2002) elicited that including and advocating family-centred care would bring about positive outcomes for the child’s health, as the parents are involved, and would continue to take care of the child even after discharge. Irlam & Bruce (2002) mentioned that family-centred care is the care driven by the parent and the nurse, whom, as part of the multidisciplinary team, has to act as a facilitator to nurture an open and transparent communication with the family and the rest of the multidisciplinary team. This is because the family know more about the child and this should be respected.

The presence of parents to render basic activities of daily living to their children can alleviate the burden on the nursing members, as they could then take care of the essential medical aspects during hospitalisation. Stuart & Melling (2014) found the parents sampled in their study opted to continue with the basic activities of daily living (ADLs) they did at home before their child’s hospitalisation; this can also help in role clarification as mentioned by Corlett & Tywcross (2006).

In another South African study by Roets, Rowe-Rowe and Nel (2012), the researchers stated there should be advocacy for parents to stay with their hospitalised children as this can reduce anxiety experienced by both parties. Doorenbos, Lindhorst, Starks, Aisenberg, Curtis & Hays (2012) further supported the notion by stating that endorsing ‘rooming-in’ of the parents whose child was hospitalised, would lead to emotional security and positive attachment to both the child and the parents. This is in line with the ideas of Bowlby and Platt (Bowlby, 1960; England Ministry of Health, 1959), who stated that “parents should be allowed to visit as much they can and to help in the care of their own child.”

The visitation times (15h00-17h00) in the research setting limit the parents having time to room in with their children. According to the hospital, only parents of babies who are breastfed are allow to room in, whereas those who are not breastfed are only allowed in the ward during the stipulated visiting times. Only in the Neonatal/Paediatric ICU are parents allowed visitation outside the stipulated hospital hours. The hospital seems to cater for the physical needs of the child, as it has state of art facilities such MRIs and CT scans, however neglecting the psychological needs as the children can suffer from separation anxiety.

The South African Children's Act (38 of 2005, Chapter 2 section 3) states, "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." The Act further states that, "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 taken in a matter concerning the child which significantly affects the child." These statements further strengthen the relevance of family-centred care in the South African context, as it brings together the role of the family in the wellbeing of the child, therefore bettering and enhancing the child's health in collaboration with the healthcare team. There is currently extensive legislation that protects the child in the country, however, the voices of the children and parents remain silent (Irlam & Bruce, 2002).

2.5 Parental views on Family-centred care

There have been numerous studies published in the literature regarding parental views on family-centred. In a study by Corlett and Twycross (2006), it was found that parents felt less empowered when they were excluded in the care of their child. It should be mentioned that there are certain activities that parents can do, called activities of daily living (ADLs), while the child is in hospital. This finding by Coyne (2015) suggests that for parents to feel more empowered they can render care such as bathing and feeding of their hospitalised children.

It is noted in the literature that not all parents are for family-centred care as there is lack of role clarification and expectation from the nurses. Research by Darbyshire (1994) showed that some parents felt overwhelmed and unsure of the roles they should assume whilst their children were hospitalised. The parents stated that as much they wanted to be advocates for their sick child, they had other siblings to take care of at home, family responsibilities and work commitments. The parents further stated in Coyne's (2008) study that they felt the nurses were over-reliant on them. The nurses in the study did mention that due to hectic schedules in the wards, this could result in being too dependent on the parents, in turn making the parents feel neglected and stressed.

Communication is the key point in role clarification and expectations from both parents and nurses (Helen & Gavey 2002). In a study by MacKean, Thurston, & Scott (2005), it was found that parents preferred to advocate for their children by being more involved in their delivery of care. However, Kawik (1996) stated that this involvement is at the discretion of the nurse nursing the child and more through convenience rather than purposefully negotiating the involvement. It was found that lack of communication resulted in the parents feeling they needed to be present with their children to prevent errors being committed, as the nurses were seen as being unable to care for their children consistently, and sometimes the parents having to update the nurses about the child's care whilst in hospital. It seems there is some ambiguity in the literature as nurses expect the parents to stay with their children and help with the child's basic and some nursing care (Coyne, 2015).

Being overly dependent on parents as well as lack of communication and negotiation meant family-centred care was not ideal. MacKean et al. (2005) stated that unfortunately it seems as though family-centred care is about shifting responsibility rather than collaboration. It was recommended in a study by Coyne (2015) that to facilitate communication better, having an appropriate way of documenting discussions with parents regarding what care and procedures they could do could help. It was further specifically suggested that a daily diary, where parents and staff could record discussions about roles and care procedures, could help with collaboration and communication. This highlighted the central elements in family-centred care being parental participation and role negotiation (Corlett & Twycross, 2006).

2.6 Summary

The importance of family-centred care has been studied extensively in literature, showing the benefits to both the child and the family, especially the parents. The child does not exist in isolation hence the family will always be an integral part of him/her. As mentioned in the literature reviewed, parents have a role to play especially regarding decision making, participation and collaboration, and the researcher concurs with this notion. Parental presence has greater positive aspects for the child, with the healthcare user and the parent as an ongoing supportive system. Literature was reviewed to understand the international phenomenon of family-centred care and to contextualise it in the South African setting. It can be deduced that a gap exists regarding the views of parents regarding family-centred care being practiced in South

African hospitals, hence the question arose “What are Parents’ views on Family-Centred Care in an academic hospital, in Johannesburg?”

In the following chapter, the research methodology will be discussed.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

In this chapter, the reader will be taken through the research methodology of the research. The research design, setting, and the sampling method will be discussed, the data collection and analysis processes will be described as well as the reliability and validity of the data and lastly, ethical considerations will be outlined towards the end of the chapter.

3.1 Research Design

The ideas of Botma, Greeff, Mulaudzi & Wright (2015) define research design as the typical skeleton of a study, as it gives the body of the study through the relevant methods and decisions on the type of designs to be used.

In this research study, a quantitative approach with a descriptive, cross-sectional, non-experimental survey was chosen.

3.1.1 Quantitative design

Quantitative research refers to the investigation of phenomena that lend themselves to precise measurement and quantification (Polit & Beck, 2014). In this study, measurement and quantification was achieved with the aid of a questionnaire, which will be explained later in the chapter.

3.1.2 Cross-sectional study

A cross-sectional study is defined as research that collects data on participants at one point in time (Brink, van der Walt & van Rensburg, 2012). Data was collected at one occasion, i.e. the child's admission obtained from different parents.

3.1.3 Comparative descriptive design

Comparative descriptive research design investigates the differences between or among two or more groups in terms of the variable of interest (Botma et al., 2015). In this study, the comparison will be described between parental views on family-centred care in two paediatric medical units.

3.2 Research setting

The research setting is defined as the geographical place where data collection took place (Polit & Beck, 2014).

The study was performed at an academic, tertiary hospital situated in an urban area of Johannesburg, Gauteng. Two paediatric medical units were chosen. The first medical unit admits children up until the age of 6 years, and is also an infectious disease medical unit; the second medical unit admits children from 7 years until 16 years of age. These units were chosen as they are where most ill children stay for long periods (more than two days) to receive care. Children who are referred from primary healthcare clinics because they are very ill and those discharged from the Paediatric Intensive Care Unit (PICU), as they have improved but still require High Care monitoring, are admitted in these units. Parents are allowed in the wards only at certain times, except for those who are breastfeeding who are allowed to stay with their babies throughout their hospitalisation. Exceptions are also made for critically ill children for whom care will not be escalated to the Paediatric Intensive Care Unit (PICU). This can be a challenge for the parents with regard to transitioning from PICU, as they had unlimited access to their children during the day compared to the medical units. At the time of the conducting of this study, visitation hours in the medical units are restricted to 15h00 to 17h00, further impeding the values of family-centred care (Appendix J).

3.3 Population

Grove, Burns & Gray (2013) defined population as all elements (individuals, objects, events, or substances) that meet the sample criteria for inclusion in a study, or the ‘target population.’ In this study, the target population were the parents of the children admitted in these two paediatric medical units. A preliminary audit was carried out in a particular month to ascertain the total number of admissions that take place in the two units. According to the audit, a total of 161 children, (90+61), were admitted to the two units (N=161), hence the population was predetermined prior to data collection.

3.4 Sample and sampling method

During this research study, a convenience sample technique, which is a non-probability sampling method whereby a smaller group of the population is selected based on availability (Brink et al., 2012), was used to obtain the sample. This sampling method was utilised as the parents of the children were readily available in the wards, although not always at the same time. A total sample was used on all the parents, therefore n=161.

3.4.1 Inclusion criteria for the parents:

- Parents who are 18 years old and above

- The primary caregiver of the child
- Parents who are physically present in the unit with the child

3.4.2 Exclusion criteria for parents:

- Parents who were in too much distress
- Parents who have lost a child due to death

3.5 Data collection

According to Grove et al. (2013), data collection is the precise, systemic gathering of information. A researcher-administered questionnaire was used for data collection purposes in this research study.

3.5.1 Instrument

Data was collected using a researcher-administered Family-Centred Care Scale (FCCS) tool developed by Martha Curley between 2002 and 2003 and validated in 2009 (Curley, Hunsberger & Harris, 2013). The questionnaire was the preferred method of collecting data recommended by Brink et al. (2012:152), who stated that "this technique may be used when the researchers' objective is to gather factual information about the respondents; the purpose of the questions is to determine what are their thoughts, perceptions, attitudes, beliefs..." Hence, for this study parental opinions were being investigated with the use of the questionnaire to find out their views on family-centred care in the different units. The FCCS tool uses a five (5) point Likert scale, it was developed in English and takes 10 to 15 minutes to complete (Appendix D). The questionnaire is divided in two sections:

Section A

In this section, the demographic characteristics of the parents were requested. This included the gender, age category, highest education level, marital status, and employment status.

Section B

Seven statements used to elicit the actions that should be executed by nurses to render family-centred care. Section B was further divided into two parts; Part 1 was how parents rated the *importance* of nurses to involve them during their children's hospitalisation and Part 2 was the *consistency* regarding how often the nurses engage and involve the parents during their children's hospitalisation. These actions were numbered as statements about nurses. Below the statements was an additional comments section for parents who needed to comment on other issues that were not mentioned in the questionnaire but were part of family-centred care.

There were two modifications done to the original FCCS questionnaire. Firstly, the exclusion of some of the demographic details of the parents, the type of unit to which the child was admitted, as only parents of children in medical units were used unlike in the original research which had surgical, cardiovascular and neurosurgery units, and information about the children's ages was excluded as the units are categorised according to age i.e. Ward A (Infectious Diseases) admits children 6 to 16 years and Ward B admits children 0 to 5 years of age. Secondly, the addition of the 'additional comments' section, as was advised from the lecturers, i.e. the Head of Department as well as Paediatric lecturer, during internal presentation of the tool in the nursing department. This is content validity.

3.5.2 Validity and reliability of the instrument

Validity is defined as the degree to which an instrument measures what it is intended to measure (Polit & Beck, 2014).

The instrument was developed and appraised in three phases by the original researcher.

Phase 1

The instrument was designed to study nursing interventions, which showed similarities between the parents' and nurses' association (Hunsberger, 2000). In the first phase, 18 items were developed. The items were focused on the actions of nurses, and parents were asked to indicate (a) the importance of each item and (b) the consistency with which nurses behaved in that way throughout their child's hospital stay. Based on these items, a pilot study was done.

Phase 2

After the pilot study, there were two more items to be included to the instrument, which were: (a) ''Nurses help my child feel well-cared-for'' and (b) ''Nurses help me feel well-cared-for,'' giving a sum of twenty items for psychometric testing.

Phase 3

Once testing in the second phase was completed, it was further shortened to seven items. The shortened version was further tested for validity in the third phase. All the three phases of the data collection were studied and appraised by the Human Subjects' Committee of the respective professional bodies from the two hospitals were data collection took place (Curley et al., 2013).

Content and face validity was ensured by the researcher in this research study by means of an expert review consisting of nurse researchers with a combination of knowledge of research and knowledge of family centred care in the South Africa context. In order to address a concern by the experts that parents may want to elaborate on care their children received in hospital, a section of “Additional Comments” was added to the questionnaire.

3.6 Reliability

The principles of Cronbach’s alpha were utilised to assess the degree to which the chosen set of items measures a single one-dimensional latent construct, internal consistency or scale reliability of the research instrument’s items (Cronbach, 1951). Reliability is defined as the extent of how dependable and consistent an instrument is (Polit & Beck, 2014).

The internal consistency of the FCCS questionnaire was analysed by Curley et al. (2013) during psychometric evaluation and yielded Cronbach alpha coefficients of 0.78 and 0.92 on importance and consistency items, respectively. This was good internal consistency as both items are >0.70.

3.7 Data management and analyses

After the data was collected, the data from the questionnaires were entered into Microsoft Excel programme and this programme was used for data entry. Descriptive and inferential statistics were used to analyse data. Hypothesis testing was done. Principal Component Analyses was used for data reduction. Multivariate analyses presented inferential statistics in the form of t-tests, followed by multivariate regression analysis. Data was analysed using STATA version 14 (STATA, 2014) at 95% confidence interval.

3.7.1 Descriptive statistics

The purpose of descriptive statistics is to give a precise picture of the variables that are being studied. They provide results in the form of frequency tables for each variable in the study. Summary tables of statistics for each sub dimension were produced, and displayed mean scores (between 0 and 1), standard deviations, standard errors, maximum, minimum, skewness and kurtosis (Gould, 1991; Acock, 2014).

The arithmetic mean is the most widely used measure of central tendency across observations. The standard error gives some idea about the variability possible in the statistics. The median splits the distribution in such a way that half of all values are above this value, and half are below (Hamilton, 2013; Acock, 2014).

3.7.2 Chi-square testing

Chi-square test (X2) is a non-parametric statistical test that is used to compare sets of data that are in a form of frequencies of percentages (Brink, et al, 2012). This test will be used to find statically significant values ($p < 0.05$).

3.7.3 Principal component analysis

Principal component analysis (PCA) is a statistical technique used to reduce the data (STATA, 2014; Acock, 2014). The objective of PCA is to find unit-length linear combinations of the variables with the greatest variance.

3.7.3.1 Assumptions of PCA

PCA thus conceived is just a linear transformation of the data. It does not assume that the data satisfies a specific statistical model, though it does require that the data be interval-level data, otherwise taking linear combinations is meaningless (STATA, 2014; Acock, 2014). The other assumption is that both the principal components and the principal scores are uncorrelated (orthogonal) amongst each other. To run a PCA, there should be inter item correlations above 0.3 (moderate) and above for most of the factors (Hamilton, 2013; Acock, 2014)

3.8 Data collection procedure

Upon receipt of ethical and scientific approval from the academic, ethical, professional and hospital committees, data collection commenced.

A pilot study was conducted in both paediatric medical units. The consent form, information sheet about the study and the FCCS questionnaire were handed out to five parents, two in the medical unit that admits children from 0 to 5 years (Ward B) of age and three to parents of children who were in the medical unit that admits children from 6 to16 years of age (Ward A). Polit & Beck (2014) advise that it is vital the researcher ensures the questionnaires are pretested on respondents to establish whether they can understand the questions. For this reason, a pilot study was carried out to establish the feasibility of the study, and to verify face and content validity of the questionnaire from the parental side. Face and content validity was good from the parents’ perspective as they were impressed on how short the questions were, although verbalising some meant asking the same thing twice. Clarity was confirmed, as one parent asked about the meaning of consistency in Part 2 of Section B of the questionnaire.

Parents, who fit the requirements to participate in the study i.e. inclusion criteria, were asked to partake in the study after it was explained, and the purpose and objectives outlined. This was done alongside the shift leader to exclude parents who seemed overly distressed or whom had lost a child. After those parents in the exclusion criteria were excluded, the nursing personnel were also asked to excuse the researcher during the approaching of the parents, who met the inclusion criteria, so that they would not feel intimidated.

The parents were told that partaking in the study was voluntary, that anonymity would always be upheld and that they could withdraw from the study at any time without prejudice to them or their child. They were given a chance to ask questions, which were answered. On average, the parents took 12 minutes to complete the questionnaire. Three of the five parents felt they needed to give the questionnaires back to the researcher personally, and not leave them in the research box at the nursing station, as they might be taken. This was considered as making the parents feel that anonymity and confidentiality were being upheld. Generally, it was a good response from the pilot study group. The findings from the pilot study were not included in the study.

The actual data collection commenced a week after the pilot study. The researcher collected data alone on different days and no one else had access to the questionnaires. The parents who met the inclusion criteria were asked to participate in the study.

The researcher went to the specific medical wards and asked permission from the shift leader to collect data. Once the shift leader had given permission, the researcher entered each cubicle where parents were present during visiting hours. This maximised the chances of parents being available. The researcher explained the study topic, defined FCC and outlined the purpose and objectives of the study. Parents who the shift-leader deemed to be overly distressed were excluded and the reasons explained to them.

Ethical considerations were practiced by assuring the parents that the questionnaires would be handled anonymously and confidential. All parents were assessed that no one who wished not to participate in the research study would not be prejudiced and their lack of participation would not affect the treatment of their child or themselves. The parents who indicated they were willing to participate were first given information sheets, and, if they were still willing, were handed a copy of the FCCS questionnaire inside an envelope. After completion, the envelopes were sealed by the parent and taken by the researcher, and stored at the researcher's home for data capturing.

3.9 Ethical considerations

"Ethics are a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal, and social obligations" (Polit & Beck, 2014:717). The authors further stated that when humans are used in research studies as participants, it is vital their rights as human beings are protected (Polit & Beck, 2014).

Permission and ethical clearance to conduct the study was requested from the School of Therapeutic Sciences' Postgraduate Research Committee as well as the Human Research Ethics Committee (HREC); both approved the study (Appendix E and

Appendix F). Clearance certificate number M160680 was granted (Appendix G). Permission from the hospital management was also requested, i.e. CEO, Clinical Director, Nursing Manager and the Head of Department, as well as the Operational Managers of the relevant units, and granted by the hospital CEO (Appendix H).

Verbal and written informed consent was administered to the parents, in which there was an explanation of the researcher's name, the purpose of study and contact details (Appendix A). The parents were also given a form whereby they consented to participation (Appendix B), which included that they could exit at any given time from the study.

The ideas of Botma et al. (2015) stated that three principles, respect for people, justice and beneficence, are relevant in the phase of data collection in a research study.

3.9.1 Respect for people

3.9.1.1 Anonymity and confidentiality

In this study, respect for people was followed, as there was anonymity and confidentiality. The researcher maintained anonymity as she elaborated to the parents that no names should be put on the returned FCCS questionnaires.

Confidentiality was maintained, as all returned FCCS tools were allocated codes according to the type of unit and the FCCS tool number, e.g. for first Medical Unit, MI 1 would be for the first assessment tool, etc.

3.9.2 Justice

The researcher adhered to the information that was provided in the protocol and the information that was given to the parents prior to them answering the questionnaire. No new interventions, procedures or techniques were used other than the ones outlined in the protocol and the information sheet for the parents. The time that was stated for the parents to complete the questionnaire was the same as mentioned in the information sheet. The parents were given contact numbers of the university's Human Research Ethics Committee to lodge complaints if they felt their rights had been violated.

3.9.3 Beneficence

It was mentioned to the parents that the research study might not benefit them directly, however long term, other parents whose children are admitted in these medical units may benefit. Indirectly, some parents benefited as the researcher administered the questionnaires and upon completion, they engaged with the researcher about their experiences in the units. Appropriate referral was done in liaison with the unit social worker.

3.10 Summary

In this chapter, the research methodology was comprehensively outlined. The research design and setting were stated, the population, sample and sampling methods were elaborated, and data collection was explained regarding the instrument used, the validity and reliability of the instrument as well as the procedure that transpired to collect the data. Lastly, the ethical considerations were mentioned, with specific consideration on respect for people by adhering to anonymity and confidentiality, justice and beneficence.

In the succeeding chapter, the researcher will mention and discuss the findings.

CHAPTER FOUR

RESULTS AND INTERPRETATION

4.0 Introduction

This chapter presents the findings of the survey of the views of parents of children in two paediatric medical wards, of the quality of family centred care received in those wards.

Firstly, the demographic characteristics of the parents who participated in the survey are described. Thereafter follows the descriptive analysis of the frequency of each question, split into importance and consistency of the action by nurses; the percentages of these results were converted to the first decimal point to simplify interpretation. This is followed by comparison of the parental views on importance and consistency of the nurses' actions on FCC between the two medical paediatric wards. The Family Centred Centred Scale (FCCS) score matches will be outlined as well as comparing the finding in the two wards. The Principal Analysis Component (PCA) will be used to reduce the data and lastly internal consistency results will be presented.

The findings will be discussed in chapter 5.

4.1 Approach to data analysis

The total number of questionnaires entered for data analysis was 115. The 161 comprised of 51 participants from Ward A, and 64 participants from Ward B. This gave a response rate of 71.4%. After the data was collected, the data from the questionnaires were entered into Microsoft Excel programme and this programme was used for data entry. Descriptive and inferential statistics were used to analyse data. Principal Component Analyses (PCA) was used for data reduction. Data was analysed using STATA version 14 (STATA, 2014) at a 95% confidence interval.

4.2 Results

4.2.1 Section A: Demographic characteristics

This section describes the respondents' demographic characteristics in terms of gender, age, ethnicity, marital status, highest education level and employment status.

Table 4.1 Parents' demographics characteristics

	Ward A n=51		**Ward B n=64**	
Characteristic	Frequency	Valid Percent	Frequency	Valid Percent
Gender				
Female	44	86.3	56	87.5
Male	7	13.7	8	12.5
Total	51	100.0	64	100.0
Age				
18-24 years old	9	17.6	15	23.4
25-34 years old	27	52.9	36	56.3
35-44 years old	12	23.5	10	15.6
45-54 years old	2	3.9	3	4.7
55+ years old	1	2.0	0	0

Total	51	100.0	64	100.0
Ethnicity				
Black	46	90.2	61	95.3
White	3	5.9	1	1.6
Coloured	2	3.9	2	3.1
Total	51	100.0	64	100.0
Marital Status				
Single (never married)	23	45.1	35	54.7
Co-habitation (staying together out of marriage)	10	19.6	14	21.9
Married	14	27.5	11	17.2
Separated	4	7.8	4	6.3
Total	51	100.0	64	100.0
Education Level				
No schooling	1	2.0	1	1.6
Primary School (Grade 1-7)	5	9.8	1	1.6
High School (Grade 8-11)	14	27.5	22	34.4
Matric (Grade 12)	16	31.4	23	35.9
Diploma Certificate	10	19.6	10	15.6
Bachelor’s Degree	4	7.8	6	9.4
Other	1	2.0	1	1.6
Total	51	100.0	64	100.0
Employment Status				
Unemployed	19	37.3	36	56.3
Student	5	9.8	5	7.8
Self-employed	6	11.8	8	12.5
Employed	18	35.3	15	23.4
Other	3	5.9	0	0
Total	51	100.0	64	100.0

The demographic characteristics shown in Table 4.1 indicate the majority of the respondents in both wards were female (>85%), and more than half were between the age of 25 and 34 years old. The ethnic group with most respondents was Black persons (90.2% in Ward A and 95.3% in Ward B). The respondents from the sample in Wards A and B were mostly single, i.e. never married, as evidenced by the percentages 45.1% and 54.7% respectively. Just fewer than 10% of the respondents in both wards were separated from their partners (7.8% in Ward A and 6.3% in Ward B). The highest educational level of respondents in Wards A and B was Matric (Grade 12), which as expected, and 37.3% and 56.3% of the respondents in Wards A and B, respectively, were unemployed.

4.2.2 Section B: Family-Centred Care

This section describes the respondents' views on family-centred care in the wards of an academic hospital, where their children were hospitalised, at the time of the survey. The Family-Centred Care Scale (FCCS) tool results reflect their perceptions on how important it was for nurses to perform an action, and how consistently the action was performed. The analysis compares respondents' views in the two paediatric medical wards**.** The FCCS Tool is a 5-point Likert Scale, consisting of seven items, with two parts. Part 1 asks how important is it for the nurses to give family-centred care and Part 2 asks about the consistency of the nurses' actions.

Table 4.2 FCCS Tool Descriptive data set

	WARD A				WARD B			
Items	N	Importance/Consistency	Frequency	Percentage	N	Importance/Consistency	Frequency	Percentage
1. “Nurses help me feel welcomed”	N=51	Not important	1	1.96%	N=63	Not important	5	7.9%
		Neutral	3	5.88%		Neutral	3	4.8%
		Important	47	*92.16%*		Important	55	*87.3%*
	N=51	Not consistent	5	9.8%	N=64	Not consistent	11	17.2%
		Neutral	11	21.6%		Neutral	13	20.3%
		Consistent	35	*68.6%*		Consistent	40	*62.5%*
2. “Nurses help me feel important in my child’s care”	N=51	Not important	1	1.96%	N=63	Not important	4	6.4%
		Neutral	1	1.96%		Neutral	5	7.9%
		Important	49	*96.08%*		Important	54	85.7%
	N=50	Not consistent	5	10%	N=62	Not consistent	10	16.1%
		Neutral	5	10%		Neutral	6	9.7%

		Consistent	40	80%		Consistent	46	74.2%
3. "Nurses treat me as a valued team member when planning my child's nursing care"	N=51	Not important	3	5.9%	N=64	Not important	6	9.4%
		Neutral	0	0%		Neutral	8	12.5%
		Important	48	94.1%		Important	50	78.1%
	N=50	Not consistent	9	18%	N=62	Not consistent	9	14.5%
		Neutral	4	8%		Neutral	12	19.4%
		Consistent	37	*74%*		Consistent	41	66.1%
4. "Nurses give explanations about the nursing care that they provide"	N=51	Not important	2	3.9%	N=64	Not important	9	14.1%
		Neutral	2	3.9%		Neutral	9	14.1%
		Important	47	*92.2%*		Important	46	71.8%
	N=51	Not consistent	8	15.7%	N=64	Not consistent	16	25%
		Neutral	9	17.6%		Neutral	15	23.4%
		Consistent	34	66.7%		Consistent	33	51.6%
	N=51	Not important	2	3.9%	N=64	Not important	15	23.4%

5. “Nurses explain about the changes I could expect in my child’s condition”		Neutral	0	0%		Neutral	8	12.5%
		Important	49	96.1%		Important	41	64.1%
	N=51	Not consistent	9	17.7%	N=64	Not consistent	16	25%
		Neutral	4	7.8%		Neutral	15	23.4%
		Consistent	38	74.5%		Consistent	33	51.6%
6. “Nurses help my child feel well-cared-for”	N=51	Not important	1	1.95%	N=64	Not important	7	10.9
		Neutral	1	1.95%		Neutral	4	6.3
		Important	49	96.1%		Important	53	82.8%
	N=51	Not consistent	4	7.8%	N=64	Not consistent	8	12.5%
		Neutral	2	3.9%		Neutral	10	15.6%
		Consistent	45	88.3%		Consistent	46	71.9%
7. “Nurses help me to feel well-cared-for”	N=51	Not important	1	2%	N=64	Not important	11	17.2%
		Neutral	4	7.8%		Neutral	8	12.5%
		Important	46	90.2%		Important	45	70.3%

	N=51	Not consistent	7	13.7%	N=64	Not consistent	16	25%
		Neutral	7	13.7%		Neutral	10	15.6%
		Consistent	37	72.6%		Consistent	38	59.4%

The results from the items of the questionnaire will be explained.

Respondents from both wards indicated that nurses helping them feel ‘welcome’ was important, as evidenced by 92.16% and 87.3% of the respondents’ choices, in Ward A and Ward B, respectively. Even though a higher percentage the respondents from Ward A and Ward B said it was very important for nurses to help them feel welcomed, only 6 (68.6%) respondents in Ward A and 62.5% in Ward B reported it was done consistently. Between the two wards, Ward A made the respondents feel welcome better than Ward B.

The majority of respondents in both wards (96.1% and 85.7% in Ward A and Ward B respectively) felt it was important for nurses to make them feel important in the care of their child. Combining the two items on importance, 80% of the respondents in Ward A and 74.2% in Ward B responded that this was done consistently.

The above table 4.2 indicates that the majority (94.1%) of the respondents in Ward A felt it was important for nurses to treat them as valued team members when planning their child’s nursing care, whereas in Ward B, 78.1% had the same sentiment. Seventy-four-point one (74.1) percent of the respondents in Ward A and sixty-six point one (66.1) percent in Ward B felt nurses treated them as valued team members when planning their child’s nursing care for family-centred care was consistent.

Respondents from both wards agreed it is important that nurses explain the care they gave to their children (71.9% of the respondents in Ward B and 92.2% respondents in Ward A). Respondents rated the consistency in explaining the care given to their children average in Ward B (57.8%) and just above average in Ward A (66.7%).

A higher proportion of Ward A respondents (96.1%) indicated the importance of nurses explaining the expected changes in their child's condition compared to Ward B (64.1%). Three quarters (74.5%) of the respondents in Ward A and 51.6% in Ward B felt that nurses explaining about the expected changes in their child's condition for family-centred care was generally consistent.

Again, respondents from both wards indicated the importance of nurses making their children feel well cared for was profound (Ward A=96.1% and Ward B=82.9%). The majority of respondents from both wards rated the consistency in which nurses make their children feel well cared for, 71.9% in Ward B and 82.2% in Ward A.

Respondents from both wards not only rated nurses making them feel well cared for as important, Ward A 90.2% and Ward B 70.3%, but also that they did so consistently (Ward A 72.5% and Ward B 59.4%).

It can be deduced from the above findings that there is general satisfaction from the parents' views on FCC from the findings above as there are high frequency ratings from the FCCS questionnaire.

Table 4.3 Comparison of parental views on the importance of nurses' actions on family centred care between two hospital wards

	WARD A			WARD B			
Statements about nurses	**Not at all N (%)**	**Neutral N (%)**	**Very important N (%)**	**Not at all N (%)**	**Neutral N (%)**	**Very important N (%)**	**p-value**
Nurses help me feel welcomed	1 (1.96)	3 (5.88)	47 (92.16)	5 (7.94)	3 (4.76)	55 (87.30)	0.358
Nurses help me feel important in my child's care	1 (1.96)	1 (1.96)	49 (96.08)	4 (6.35)	5 (7.94)	54 (85.71)	0.175
Nurses treat me as a valued team member when planning my child's nursing care	*3 (5.88)*	*0 (0.00)*	*48 (94.12)*	*6 (9.38)*	*8 (12.50)*	*50 (78.13)*	*0.002**
Nurses give explanations about the nursing care that they provide	*2 (3.92)*	*2 (3.92)*	*47 (92.16)*	*9 (14.06)*	*9 (14.06)*	*46 (71.88)*	*0.023**
Nurses explain about the changes I could expect in my child's condition	*2 (3.92)*	*0 (0.00)*	*49 (96.08)*	*15 (23.44)*	*8 (12.50)*	*41 (64.06)*	*0.000**

Nurses help my child to feel well-cared-for	1 (1.96)	1 (1.96)	49 (96.08)	7 (10.94)	4 (6.25)	53 (82.81)	0.080
Nurses help me to feel well-cared-for	*4 (7.84)*	*4 (7.84)*	*46 (90.20)*	*11 (17.19)*	*8 (12.50)*	*45 (70.31)*	*0.016**

Table 4.4 Comparison of parental views on the consistency of nurses' actions on family centred care between two hospital wards

	WARD A			**WARD B**			
Statements about nurses	**Not at all N (%)**	**Neutral N (%)**	**Very important N (%)**	**Not at all N (%)**	**Neutral N (%)**	**Very important N (%)**	**p-value**
Nurses help me feel welcomed	5 (9.80)	11 (21.57)	35 (68.63)	11 (17.19)	13 (20.31)	40 (62.50)	0.532
Nurses help me feel important in my child's care	5 (10.00)	5 (10.00)	40 (80.00)	10 (16.13)	6 (9.68)	46 (74.19)	0.637
Nurses treat me as a valued team member when planning my child's nursing care	7 (13.73)	10 (19.61)	34 (66.66)	6 (9.38)	15 (23.44)	43 (67.19)	0.706

Nurses give explanations about the nursing care that they provide	8 (15.69)	9 (17.65)	34 (66.67)	15 (23.44)	12 (18.75)	37 (57.81)	0.540
Nurses explain about the changes I could expect in my child's condition	*9 (17.65)*	*4 (7.84)*	*38 (74.51)*	*16 (25.00)*	*15 (23.44)*	*33 (51.56)*	*0.026**
Nurses help my child to feel well-cared-for	4 (7.84)	2 (3.92)	45 (88.24)	8 (12.50)	10 (15.63)	46 (71.87)	0.072
Nurses help me to feel well-cared-for	7 (13.73)	7 (13.73)	37 (72.54)	16 (25.00)	10 (15.63)	38 (59.37)	0.269

4.2.2.1 Chi-square testing

To address the 2nd objective of the study, a chi-square test was used in order to compare the parental views in the two medical paediatric wards. A statistically significant value will be seen by a p value <0.05 (5%).

In the importance subscale, Table 4.3, the items from the FCCS scale which gave a statistically significance results in the order of smallest p values were “nurses explain about the changes I could expect” (p=0.000), “nurses treat me as a valued team member when planning my child’s nursing care” (p=0.002), “nurses help me to feel well-cared-for” (p=0.016) and lastly “nurses give explanations about the nursing care that they provide” (p=0.023).

When looking at the consistency subscale, Table 4.4, the only item from the FCCS scale which gave a statistically significant result was “nurses explain about the changes I could expect in my child’s condition” (p=0.026).

4.2.3 FCCS score matches

According to Curley et al. (2009), the FCCS score is said to match if the importance and the consistency ratings in one score is the same or when the importance score is plus one compared to the consistency score (Importance=Consistency or Importance>Consistency=1). The importance rating will go according to the *parents’ expectations* were as the consistency is how the parents interpret the *nursing care* that is being rendered.

However, if the difference is more than one of the consistency compared to the importance score or if there creates an association between the importance and consistency (Importance–Consistency > 1), then there is no match. The percentage of the scores is calculated by the sum of all the matches divided by sum of the possible matches times one hundred.

Table 4.5 FCCS score matches

Statements about nurses	**% Matches**
Nurses help me feel welcomed (n=115)	*55.65 %*
Nurses help me feel important in my child's care (n=112)	72.17 %
Nurses treat me as a valued team member when planning my child's nursing care (n=115)	63.48 %
Nurses give explanations about the nursing care that they provide (n=115)	62.61 %
Nurses explain about the changes I could expect in my child's condition (n=115)	64.35%
Nurses help my child to feel well-cared-for (n=115)	*74.78%*
Nurses help me to feel well-cared-for (n=115)	70.43%

A percentage is generated for the total number of matches among all participants based on the total number of possible matches indicated in brackets next to the nurses' actions

The matches of the importance and consistency rating were calculated based on the number of matches from each item of the scale, e.g. for the 1st item on the questionnaire, "nurses help me feel welcomed", if the participant chose 5 for both the importance and consistency columns, it was considered a match. However, if another participant chose 3 for the importance part and 1 for the consistency part, it was considered not matching.

Judging from the data expressed in Table 4.5 above, there was more than a 50% match in all the findings from the respondents in Wards A and B. The lowest match was the item “Nurses help me feel welcomed” which yielded 55.65% and the highest match was found from the item “Nurses help my child to feel well-cared-for” which yielded 74.78%.

Table 4.6 Comparison of matching of ratings between importance and consistency of care in nurses’ actions between two wards

Statements about nurses	**WARD A** **N (%)**	**WARD B** **N (%)**	**p-value**
Total possible matches	51	64	
Nurses help me feel welcomed	31 (60.78)	33 (51.56)	0.323
Nurses help me feel important in my child’s care	41 (80.39)	42 (65.63)	0.079
Nurses treat me as a valued team member when planning my child’s nursing care	33 (64.71)	40 (62.50)	0.809
Nurses give explanations about the nursing care that they provide	32 (62.75)	40 (62.50)	0.978
Nurses explain about the changes I could expect in my child’s condition	35 (68.63)	39 (60.94)	0.392
Nurses help my child to feel well-cared-for	39 (76.46)	47 (73.44)	0.710
Nurses help me to feel well-cared-for	37 (72.55)	44 (68.75)	0.657

A chi-squared test was used to compare the proportions of matches between the two wards, with p values <0.05 showing statistically significance. It can be noted from the table above that there was no statistically significance comparison between the two wards as all the items gave p>0.05.

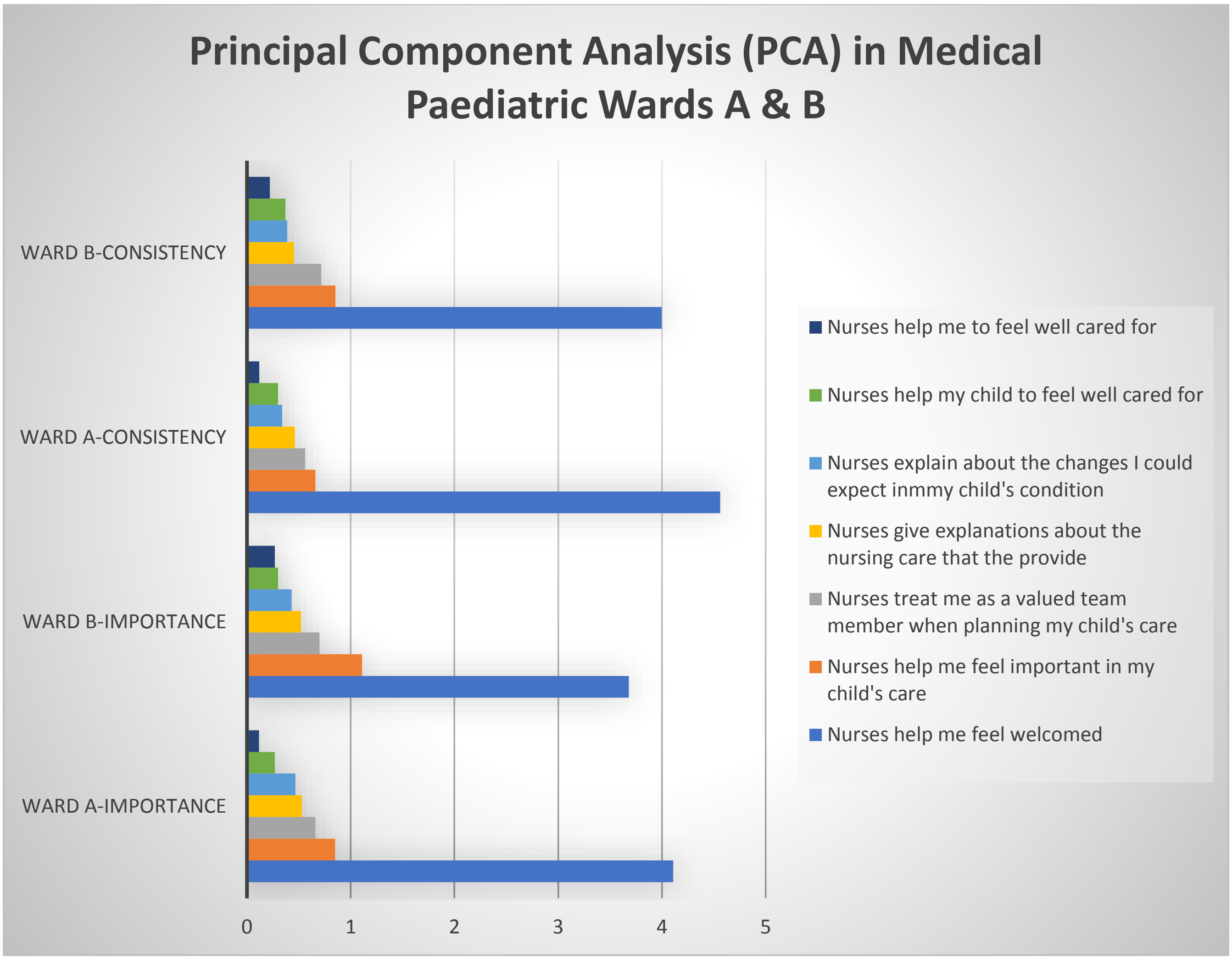
4.3 Principal component analysis

Principal Component Analysis (PCA) is a statistical technique used to reduce the data (STATA, 2014). The objective of PCA is to find unit-length linear combinations of the variables with the greatest variance.

4.3.1 Assumptions of PCA

PCA thus conceived is just a linear transformation of the data. It does not assume that the data satisfies a specific statistical model, though it does require that the data be interval-level data, otherwise taking linear combinations is meaningless (STATA, 2014). The other assumption is that both the principal components and the principal scores are uncorrelated (orthogonal) amongst each other. To run a PCA, there should be inter item correlations 0.3 (moderate) and above for most of the factors.

Prior to conducting factor analysis, the Keiser-Meyer-Olkin measure of sampling adequacy (KMO-MAS) analysis will be undertaken to determine the suitability of the size of sampling for factor analysis (Beavers et al., 2013).



Ward A-Importance: Kaiser-Meyer-Olkin measure of sampling adequacy=0.8203, Ward B-Importance: Kaiser=Meyer-Olkin measure of sampling adequacy=0.8203, Ward A-Consistency: Kaiser-Meyer-Olkin measure of sampling adequacy=0.795, Ward B-Consistency: Kaiser-Meyer-Olkin measure of sampling adequacy=0.842.

Figure 4.1 Principal Component Analysis in Medical Paediatric Wards A & B

From Figure 4.1 above, the principal components/correlation in the importance subscale in Ward A, the eigenvector with the highest eigenvalue is the principal component of the data set (eigenvalue=4.1) and accounts for 58.7% of the total variation. It is the most significant relationship between the data dimensions, which explains the importance of what nurses do in family-centred care in this academic hospital. One factor, “nurses helped the parents to feel welcomed”, had 4.1 times as much influence as the others in Ward A (factor loadings=0.754). The Keiser-Meyer-

Olkin measure of sampling adequacy is 0.8 (closer to 1), an indication that the model is fit and explains the variations correctly.

In the subscale of consistency in Ward A, the eigenvector with the highest eigenvalue is the principle component of the data set (eigenvalue=4.56) and accounts for 65% of the total variation. It is the most significant relationship between the seven data dimensions. One factor, “nurses helped the parents to feel welcomed”, had 4.6 times as much influence compared to the other six in Ward A, with very high factor loadings=0.8. The Keiser-Meyer-Olkin measure of sampling adequacy is closer to 1, an indication that the model is fit and explains the variations correctly.

In the importance subscale for Ward B, Figure 4.1 above illustrates two critical factors, which all account for 68% of the total variance in Ward B. The eigenvector with the highest eigenvalue is the principal component of the data set (eigenvalue=3.68) and accounts for 52.5% of the total variation. It is the most significant relationship between the data dimensions. The second most important aspect has an eigenvalue of 1.11 and accounts for 15.8% of the total variation. The factor “nurses helped the parents’ children to feel well-cared-for” factor had 3 times as much influence in Ward B (factor loadings=0.765). The second most influential factor was that “nurses explained about the changes they could expect in their child’s condition” (factor loadings=0.68). The Keiser-Meyer-Olkin measure of sampling adequacy is 0.795 (closer to 1), an indication that the model is fit and explains the variations correctly.

Lastly, for the principal components/correlations testing under the subscale consistency in Ward B, it shows that the eigenvector with the highest eigenvalue is the principle component of the data set (eigenvalue=3.68) and accounts for 57.5% of the total variation. It is the most significant relationship between the seven data dimensions. The factor, “nurses treated parents as valued team members when planning their children’s nursing care”, had 3.9 times as much influence as the other six in Ward B (factor loadings=0.667). The Keiser-Meyer-Olkin measure of sampling adequacy is 0.842 (closer to 1), an indication that the model is fit and explains the variations correctly.

4.4 Reliability

The principles of Cronbach’s alpha were utilised to assess the degree to which the chosen set of items measures a single one-dimensional latent construct, internal consistency or scale reliability of the research instrument’s items (Cronbach, 1951).

Table 4.7 Reliability of Family-Centered Care Scale (FCCS) items

FAMILY-CENTERED CARE SCALE ITEMS		Ward A	Ward B
1. “Nurses help me feel welcomed”	Importance	0.8724	0.84
	Consistency	0.9097	0.8485
2. “Nurses help me feel important in my child’s care”	Importance	0.8295	0.8341
	Consistency	0.8987	0.8461
3. “Nurses treat me as a valued team member when planning my child’s nursing care”	Importance	0.8622	0.8162
	Consistency	0.9009	0.848
4. “Nurses give explanations about the nursing care that they provide”	Importance	0.8544	0.8207
	Consistency	0.8897	0.8367
5. “Nurses explain about the changes I could expect in my child’s condition”	Importance	0.8434	0.828
	Consistency	0.8903	0.8604
6. “Nurses help my child to feel well cared for”	Importance	0.8629	0.8085
	Consistency	0.8976	0.8483
7. “Nurses help me to feel well cared for”	Importance	0.8616	0.8232
	Consistency	0.8964	0.8344
	Importance	0.8736	0.8459
mean (unstandardized items)	Consistency	0.9111	0.8653

Table 4.7 indicates all the items were reliable; response consistency was high as indicated by the Cronbach's alpha coefficient, which was above 0.8. In Ward A, the element "nurses help me feel important in my child's care" had the least reliable score, although reliable. In Ward B, consistency on the aspect of "nurses help children to feel well cared for" was the least (0.80). The fact that all questions produced results that were reliable means the questions asked what they were supposed to, hence valid.

4.5 Summary

This chapter presented and discussed the results obtained from the statistical analysis undertaken on respondents' views on family-centred care in an academic hospital using the FCCS questionnaire. The results were part of a design to describe parents' views regarding family-centred care with the use of the Family-Centred Care Scale and to compare parents' views in the two paediatric medical wards. Descriptive statistics were used to analyse the demographic data of the respondents, and Chi-square tests aided in comparing the parents' views of FCC in the two paediatric medical wards. FSSC score matches were described and compared as well. The PCA tests were also utilized for data reduction. Lastly, reliability tests were used to determine internal consistency of the responses.

In the next and final chapter, discussion of the main findings, limitations and recommendations will be outlined.

CHAPTER FIVE

SUMMARY, MAIN FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.0 Introduction

This final chapter will conclude the study by outlining the main findings, conclusions, contributions, limitations and suggestions for further research. The main findings will be outlined in relation to the study objectives.

5.1 Summary of the study

The purpose objectives the study was to describe and compare parents' views on family-centred care in two general paediatric medical wards of an academic hospital. Parents are the primary care givers of care in their children's lives and hospitalization of their children can impact them heavily and nurses can help alleviate this stress through principles of FCC. Identification and description of parents' expectations and how they view nurses' actions will help contribute to the literature.

5.2 Summary of main findings

The main objectives of this study were to describe and compare parents' views regarding family-centred care in two paediatric wards with the use of the Family-Centred Care Scale. Descriptive and Chi-square statistical tests were used to achieve the study objectives.

5.2.1 Section A: Demographic characteristics

In a study by Tedford and Price (2011), it was found most of the parents were mothers, as they were in this study. The results show that the highest percentage of the respondents were female in both Wards was 86.3% in Ward A and 87.5% in Ward B respectively. Many of the respondents were unemployed i.e. 37.3% and 56.3% in Ward A and Ward B, respectively The demographics of this study are not the same as similar studies to this one as most of those were conducted in developed countries such as Australia, America and Ireland (Shields, Hunter, & Hall, 2004; Shields & Nixon, 2004; Hughes, 2007) where the unemployment rates are different. It should also be born in mind that this study was done in a public-sector hospital where patients without medical insurance commonly come for treatment and care.

5.2.2 Section B: Family-Centred Care

Objective 1: Description of parents' views on FCC in the two medical wards

It can be seen from Table 4.4 and Table 4.5, that the respondents in Ward A feel that the item "nurses explain about the changes I could expect in my child's condition" is important as they gave it the highest rating of 96.1%. The consistency rating is 74.5% for this item. According to Curley (2013), the importance subscale is how the respondents (parents) view their expectations from the nurses, while the consistency is a reflection of how the parents view the nurses' actions. The second highest rated item on the FCCS is "nurses help my child to feel well cared for" as they rated it with 88.2%, with a consistency reading of 88.2%. In ward B, the highest rated item from the importance subscale with 88.9% is "nurses help me feel welcomed", with a consistency rating of 62.5%. This is followed by 85.7% of the respondents in Ward B saying that “nurses help me feel important in their child’s care one of their expectations”, and the consistency reading of 74.2%.

These findings show the researcher that the respondents from both medical wards view that the elements of FCC are being practiced, the parents’ expectations and the nurses’ actions are both giving high scores. The findings further confirm that as much as FCC has not formally received acknowledgment in the research setting, however, the basic principles are being practiced.

The matching of ratings in Table 4.6 show that generally there were good matches between the importance and consistency subscales as there is more than 50% of matching for all the items on the FCCS questionnaire. The most matched item is “nurses help my child to feel well cared for”, meaning the parents expectation and the nurses’ actions are almost 75% congruent. The second most matched item from the FCCS questionnaire is “nurses help me feel important in my child’s care”, which gave a match score of 72.17%. In a similar study by Shields & Kristensson-Hallstrom (2004) were they investigated the parents’ needs statements in order of importance, it was discovered that out of the nine statements, five highlighted communication, two highlighted trust, and the last two highlighted the importance of the parents’ ability to be involved in the care of their child. This shows that parents need an explanation about their children’s health while in hospital and feel involved during their hospital stay.

The lowest matched item from the FCCS questionnaire results was the item “nurses help me feel welcomed”, with the score 55.65%. This may be related to the restrictive visiting hours in the hospital. According to Hughes (2007), an open visiting policy for parents can help promote FCC as parents will feel welcome and come and go at their own free will. In a South African study by Irlam & Bruce (2002), it was found that there were few hospitals who acknowledged the policies of FCC, but were restrictive as they lacked rooming-in facilities for mothers of the hospitalized children. To date, rooming-in facilities are still a challenge in the hospital research setting.

Objective 2: Comparison of parents' views in the two paediatric medical wards

The results from Table 4.7 showed that there was no statistically significant difference between the findings in Ward A and Ward B. A conclusion can be made that there is no difference between the two wards in terms of how the respondents perceived FCC in the two paediatric wards.

5.3 Limitations

The questionnaire was written only in English, translation costs were not in the budget, this means non-English speaking parents were excluded.

One cannot generalise the study findings, as convenience sampling was used with a response rate of 71.4% and the study was conducted in one hospital due to lack of time and budget for the study, as required for Masters in Nursing (a research report).

5.4 Recommendations for nursing education

Education programmes can be put in place for parents by nurses regarding coping with their hospitalized child to try and alleviate the stress of having to think of the child's hospitalization.

The nurses' views on FCC should be investigated to also know how they view FCC being practiced in their wards, and in-service programmes can be in place.

5.5 Recommendations for nursing research

Although most participants were English-speaking, it would be interesting to have included non-English speaking parents as well as South Africa, especially Johannesburg accommodates people from all our nine provinces and beyond, whom some only understand their own native languages.

The study showed that parents generally feel family-centred care is being practiced, but it would be interesting to conduct research on the nurses, doctors and other allied health workers' views or perceptions on family-centred care. The researcher explained, very briefly, what family-centred care was; perhaps a brochure could have given before asking them to complete FCCS questionnaire to enhance their knowledge on family-centred care, although the questionnaire did have the nurses' actions that encompass family-centred care.

It would also be interesting to know whether the respondents' children were admitted for the first time or whether there were previous hospital admissions, as this could also have an impact on the views the respondents have with subsequent admissions, as well as the condition of the children during hospitalisation.

For children who were able to comprehend well, their views on family-centred care would be interesting to discover whether they preferred their parents to be actively involved in their care, or just be involved passively.

5.6 Recommendations for nursing practice

Upholding Baby- and Child- Friendly initiatives, which are already written by the hospital management, need to be practiced in the hospital forming part of the principles of family-centred care.

Nurses should advocate for the parents regarding the change of limited visiting hours in paediatric wards. The findings suggested that just above 40% of the parents did not feel welcomed when matching the importance and consistency score from the FCCS results. The current policy states that only breastfeeding mothers and parents of very critical children are allowed unrestricted presence. This is not fair practice as other children may feel they also want their parents present with them. The visitation hours need to be open and consistent to all the parents of the children.

5.7 Reflections of the researcher

The researcher has learned much about the process of conducting research. Challenges arose from the participants, as one had to approach parents with ailing children in order to complete the research. Some of the parents were emotionally unstable and were not included in the study for this reason. Overall, the researcher had a fruitful experience.

5.8 Conclusion

In conclusion, the findings suggest there is general satisfaction of family-centred care in the two paediatric wards from the respondents. The respondents from both wards in the study did not differ significantly in terms of family-centred care views, as portrayed by the Family-Centred Care Scale. This means that there is congruency in what the parents expect and what the nurses' actions portray. Overall, it also interesting to see that there is no difference on the matchings in both wards as in both the wards the respondents viewed that the basic elements of FCC are being practiced.

On reflection of the results of this study, the researcher was pleasantly surprised at the positive results of the study. The researcher considers that the setting in which the study was done may have impacted on the parents' responses in that they wanted to complete the questionnaire as quickly as possible and were anxious about their ailing children. The researcher believes that this study should be replicated, but on parents whose children have been discharged already. Should those findings also reflect positive results, it could then be assumed that Family Centred Care is being adequately practised in the research setting.

REFERENCE LIST

Acock, A.C., 2014. *A gentle introduction to Stata*. Stata Press, Texas.

American Academy of Pediatrics, 2012, Patient- and family-centered care and the pediatrician's role, Available: http://www.pediatrics.org/cgi/doi/10.1542/peds.2011.3084 [Accessed: 10 February 2017].

American Academy of Pediatrics, Committee on Hospital Care and Institute for Patient- and Family Centered Care, 2012. Patient- and Family Centered Care and the Pediatrician's Role. *Pediatrics*. 129 (2), 394-404.

American National Center for Family/Professional Partnerships, 2009. *Family-centered care: from theory to practice.* Available: <http://www.fv-ncfpp.org/files/1514/2420/5452/FCCforFamilies_09-19-2014-r.pdf> Accessed: 10 February 2017].

Assembly, U.G., 1999. Convention on the Rights of the Child, 20 November 1989, United Nations, *Treaty Series*, vol. 1577.

Aubuchon, M., 1958. To stay or not to stay; parents are the question. *Hospital progress,* 39(5), pp.170.

Beavers, A.S., Lounsbury, J.W., Richards, J.K., Huck, S.W., Stolits, G.J. and Esquivel, S.L., 2013. Practical considerations for using exploratory factor analysis in educational research. *Practical assessment, research & evaluation*, 18(6). Available online: <http://parentonline.net/getvn.usp?18&n=6>

Botma,Y., Greeff, M., Mulaudzi, F.M. and Wright, S.C.D., 2015, *Research in health sciences*, Pearson, Cape Town.

Bowlby, J., 1960. Separation anxiety: A critical review of the literature. *Journal of Child Psychology and Psychiatry,* 1(4), pp.251-269.

Brink, H., van der Walt, C., and van Rensburg, G., 2012, *Fundamentals of research methodology for healthcare professionals*, 4th edition, Juta, Cape Town.

Bruce, B. and Ritchie, J., 1997. Nurses' practices and perceptions of family-centered care. *Journal of pediatric nursing*, 12(4), pp.214-222.

Central Health Services Council (Great Britain). Committee on the Welfare of Children in Hospital and Platt, S.H., 1959. *The welfare of children in hospital: report of the committee*. HM Stationery Office.

Central Health Services Council (Great Britain), Committee on the Welfare of Children in Hospital and Platt, S.H., 1959. *The welfare of children in hospital: report of the committee*. HM Stationery Office.

Coetzee, M., Britton, M. and Clow, S.E., 2005. Finding the voice of clinical experience: participatory action research with registered nurses in developing a child critical care nursing curriculum. *Intensive and Critical Care Nursing*, 21(2), pp.110-118.

Commodari, E., 2010. Children staying in hospital: a research on psychological stress of caregivers. *Italian journal of pediatrics*, 36(1), p.40.

Corlett, J. and Twycross, A., 2006. Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing*, 15(10), pp.1308-1316.

Coyne, I., 2008. Disruption of parent participation: Nurses’ strategies to manage parents on children's wards. *Journal of Clinical Nursing*, 17(23), pp.3150-3158.

Coyne, I., 2015. Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations*, 18(5), pp.796-808.

Cronbach, L.J., 1951. Coefficient alpha and the internal structure of tests. *Psychometrika*, *16*(3), pp.297-334.

Cullen, K., 2006. *Health services in South Africa: A basic introduction*, Available: https://www.health-e.org.za/wp-content/uploads/2013/04/Health_services_briefing_doc.pdf [Accessed 11 April 2016].

Curley, M.A., Hunsberger, M. and Harris, S.K., 2013. Psychometric evaluation of the family-centered care scale for pediatric acute care nursing. *Nursing research*, 62(3), pp.160-168.

Darbyshire, P., 1994. *Living with a sick child in hospital: the experiences of parents and nurses*. Chapman & Hall.

Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J.R. and Hays, R., 2012. Palliative care in the pediatric ICU: challenges and opportunities for family-centered practice. *Journal of social work in end-of-life & palliative care*, 8(4), pp.297-315.

Fonagy, P. and Target, M., 2005. Bridging the transmission gap: An end to an important mystery of attachment research? *Attachment and Human Development*. 7, 3, 333-343.

Franck, L.S. and Callery, P., 2004. Re-thinking family-centred care across the continuum of children's healthcare. *Child: care, health and development*, 30(3), pp.265-277.

Gauteng Department of Health, 2016, *Annual Performance Plan, 2016/17 – 2018/19,* Gauteng Department of Health, South Africa

Gelman, A., 2013. Commentary: P values and statistical practice. *Epidemiology*, *24*(1), pp.69-72.

Gould, W., 1992. Skewness and Kurtosis Tests of Normality. *Stata Technical Bulletin*, *1*(1).

Graham, R.J., Pemstein, D.M. and Curley, M.A., 2009. Experiencing the pediatric intensive care unit: perspective from parents of children with severe antecedent disabilities. *Critical care medicine*, 37(6), pp.2064-2070.

Grove, S.K., Burns, N., and Gray, J.R., 2013, *The practice of nursing research: Appraisal, synthesis, and generation of evidence*, 7th edition, Elsevier, China.

Hamilton, L.C., 2013. Multilevel and mixed-effects modelling. *Statistics with STATA: Updated for version*, *10*, pp.387-421.

Helen, B. and Gavey, J., 2002. Responding to babies' needs through holistic care. *Nursing standard*, 16(21), pp.33-37.

Hoekstra-Weebers, J.E., Jaspers, J.P., Kamps, W.A. and Klip, E.C., 2001. Psychological adaptation and social support of parents of pediatric cancer patients: A prospective longitudinal study. *Journal of pediatric psychology*, 26(4), pp.225-235.

Hogg, C., 1996. *Health services for children and young people: A guide for commissioners and providers*. Action for Sick Children, London.

Hopia, H., Tomlinson, P.S., Paavilainen, E. and Åstedt-Kurki, P., 2005. Child in hospital: family experiences and expectations of how nurses can promote family health. *Journal of clinical nursing*, 14(2), pp.212-222.

Hughes, M., 2007. Parents' and nurses' attitudes to family-centred care: an Irish perspective. *Journal of clinical nursing*, 16(12), pp.2341-2348.

Hunsberger, M., 2000. *The effect of introducing parents of hospitalized children to the nursing mutual participation model of care, a randomized controlled trial.* Unpublished Ph.D., University of Waterloo, Ontario.

Irlam, L.K. and Bruce, J.C., 2002. Family-centred care in paediatric and neonatal nursing-a literature review. *Curationis,* 25(3), pp.28-34.

Jolley, J. and Shields, L., 2009. The evolution of family-centered care. *Journal of Pediatric Nursing*, 24(2), pp.164-170.

Kawik, L., 1996. Nurses' and parents' perceptions of participation and partnership in caring for a hospitalized child. *British Journal of Nursing*, 5(7), pp.430-434.

Kristjánsdóttir, G., 1995. Perceived Importance of Needs Expressed by Parents of Hospitalized Two-to Six-Year-Olds. *Scandinavian journal of caring sciences*, 9(2), pp.95-103.

Kristjánsdóttir, G., 1995. Perceived Importance of Needs Expressed by Parents of Hospitalized Two-to Six-Year-Olds. *Scandinavian journal of caring sciences*, *9*(2), pp.95-103.

Kuokkanen, L. and Leino-Kilpi, H., 2000. Power and empowerment in nursing: three theoretical approaches. *Journal of advanced nursing*, 31(1), pp.235-241.

Lomax, E.M., 1996. Small and special: the development of hospitals for children in Victorian Britain. *Medical history supplement*, (16), p.1.

MacKean, G.L., Thurston, W.E. and Scott, C.M., 2005. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations*, 8(1), pp.74-85.

Merrian-Webster Dictionary, 2016. Merrian-Webster Web, Available: <https://www.merriam-webster.com/dictionary/views> [Accessed: 11 April 2016].

Merrian-Webster Dictionary, 2016. Merrian-Webster Web, Available: <https://www.merriam-webster.com/dictionary/parent> [Accessed: 11 April 2016].

Ministry of Health (1959) *The welfare of children in hospital, Platt report.* London: Her Majesty's Stationary Office.

Morrison, A.L., 2004. Stress in parents of children in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, 5(6), pp.585-586.

Mortensen, J., Simonsen, B.O., Eriksen, S.B., Skovby, P., Dall, R. and Elklit, A., 2015. Family-centred care and traumatic symptoms in parents of children admitted to PICU. *Scandinavian journal of caring sciences*, 29(3), pp.495-500.

Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B. and Kersten, R., 2007. Family centered care within an infant-toddler unit. *Pediatric nursing*, 33(6), p.481.

Polit, D.F., and Beck, C.T., 2004, *Nursing research: Principles and methods*, Lippincott Williams & Wilkins, Philadelphia.

Rees, G., Gledhill, J., Garralda, M.E. and Nadel, S., 2004. Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive care medicine*, 30(8), pp.1607-1614.

Rencher, A.C. and Christensen, W.F., 2012. Wiley Series in Probability and Statistics. *Methods of Multivariate Analysis, Third Edition*, pp.759-768.

Rodwell, C.M., 1996. An analysis of the concept of empowerment. *Journal of advanced nursing*, 23(2), pp.305-313.

Roets, L., Rowe-Rowe, N., and Nel, R., 2012. Family-centred care in the paediatric intensive care unit. *Journal of nursing management*, 20(5), pp.624-630.

Shelton, T., Jepson, E. and Johnson, B.H., 1987. *Family-centered care for children with special health care needs* (Association for the Care of Children's Health, Washington, DC).

Shields, L. and Kristensson-Hallstrom, I., 2004. We have needs too: parental needs during a child's hospitalization. *Online Braz JN urs*. 2004; 3: e.

Shields, L. and Nixon, J., 1998. " I want my mummy". Changes in the care of children in hospital. *Collegian (Royal College of Nursing, Australia*), 5(2), pp.16-23.

Shields, L., 2001. A review of the literature from developed and developing countries relating to the effects of hospitalization on children and parents. *International nursing review*, 48(1), pp.29-37.

Shields, L., Pratt, J. and Hunter, J., 2006. Family centred care: a review of qualitative studies. *Journal of clinical nursing*, 15(10), pp.1317-1323.

Shields, L., Pratt, J., Davis, L. and Hunter, J., 2007. Family-centred care for children in hospital. *The Cochrane Library.*

Slade, A., 2005. Parental reflective functioning: An introduction. *Attachment & human development,* 7(3), pp.269-281.

South African Government, 2005*. Children's Act, No. 38 of 2005*. Available: <http://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf> [Accessed: 16 April 2016].

South African Nursing Council, 2005. *Nursing Act, Act No. 33 of 2005*, Available: <http://www.sanc.co.za/pdf/Nursing%20Act%202005.PDF.> [Accessed: 11 April 2016].

STATA, 2014*, STATA user's guide release 14*. Stata Press, Texas.

Stuart, M. and Melling, S., 2014. Understanding nurses' and parents' perceptions of family-centred care. *Nursing children and young people*, 26(7), pp.16-21.

Tedford, J. and Price, J., 2011. Role of the nurse in family-centred care: A diagnosis of cancer in a child affects the whole family, creating great uncertainty in daily life. *Cancer Nursing Practice*, 10(2), pp.14-18.

United Nations, 1989, Convention on the Rights of the Child, Available: <http://www2.ohchr.org/english/law/crc.htm> [Accessed: 4 May 2016]

World Health Organization, 1986. *The Ottawa charter for health promotion: first international conference on health promotion*, Ottawa, 21 November 1986. Geneva: WHO.

APPENDIX A

INFORMATION SHEET FOR PARENTS

Research Study: Parents' views of family centred care in a South African academic hospital in Gauteng

Good day,

My name is Sinnah and I am a Child Nursing Master's student at the University of the Witwatersrand. I am undertaking a research project to investigate parents' views of family centered care in an academic hospital in Gauteng, South Africa. In other words, the purpose of this research is a way that I can find out your views on how you are included in your child's care during hospitalization.

I kindly invite you to participate in the research project by completing the following short questionnaire regarding your views of family centered care in the unit that your child is admitted. The questionnaire involves you answering the questions listed by choosing a response that is valid to you. It should take approximately 15 minutes of your time.

There are no direct or indirect risks to you or your child in this research project, and there are no direct benefits to you. However, based on the results, we might be able to see the parents' views on Family Centred Care, and help the relevant units to develop a remedial programme.

Participation in the survey is voluntary and anonymous and hence I ask that you do not write your name or contact details on the questionnaire. Should you wish to withdraw from the study during or after the completion of the survey, you are completely allowed to do so, with no prejudice or negative consequences to you or your child's care.

The returned questionnaires will be captured in codes (numbers) when you return them hence your identity will not be known. The results will be written in a form of a report whereby the University and the Hospital will have the results known to them.

If you feel like you need to speak to a social worker regarding issues beyond this study, kindly speak to the unit manager, who will then arrange for counselling to take place.

If at any stage you have queries or concerns regarding research project, please feel free to contact me directly at 083 799 2797 or sinnahlazarus@yahoo.com or any ethical concerns to the university's Human Research Ethics Committee Board please contact: peter.cleaton-jones1@wits.ac.za; or Administrative Officers: Ms Zanele Ndlovu, 011 717 1252/2700/2656/1252 zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; and Lebo.moeng@wits.ac.za.

Kind Regards,

Sinnah Lazarus

APPENDIX B

CONSENT FORM FOR PARTICIPANTS

Research Study: Parents' views of Family Centred Care in a South African Academic Hospital in Gauteng

I (parent) give consent to participate in the above-mentioned study as I:

- have been informed of and understand the purposes of the study
- have been given an opportunity to ask questions
- understand I can withdraw at any time without prejudice to me or my child
- agree to participate in the study as outlined to me

- Any information which might potentially identify me will not be used in published material

Name of parent: ………………………………………………………………………

Signature: ………………………………………

Date: ……………………………………………

Gmail

Sinnah Lazarus <sinnahlazarus@gmail.com>

Permission to use Questionnaire

2 messages

Sinnah Lazarus <sinnahlazarus@gmail.com> 15 May 2016 at 11:07
To: curley@nursing.upenn.edu

Good Day Ms Curley,

My name is Sinnah Lazarus, and I am from South Africa, Johannesburg. I'm a student studying M.Sc in Child Nursing, doing my second year of study at the University of the Witwatersrand in Johannesburg.

The reason I'm writing this email is to ask for your assistance in getting permission to use the Family Centered Care Care for Pediatric Acute Care Setting? Could you also kindly attach the questionnaire?
In my research study, I would like to investigate the parents' views regarding Family Centered Care in the South African context, as we have started involving the parents of our hospitalized children in the comprehensive hospital care of their children.
The study will be done in an academic hospital, Johannesburg.

I hope my request will be fulfilled.

Kind Regards,
Sinnah M. Lazarus

Curley, Martha <curley@nursing.upenn.edu> 15 May 2016 at 19:29
To: Sinnah Lazarus <sinnahlazarus@gmail.com>

Hi — please see my website …. Highlighted below. You should find everything there. Good luck with your work ;)

Martha

Martha A.Q. Curley, RN, PhD, FAAN
Ellen and Robert Kapito Professor in Nursing Science
School of Nursing
Anesthesia and Critical Care Medicine
University of Pennsylvania
Claire M. Fagin Hall
418 Curie Boulevard - #425
Philadelphia, PA 19104-4217 USA

Office Phone: 215.573.9449
Office Fax: 215.746.2737
Curley@nursing.upenn.edu
www.MarthaAQCurley.com
www.AfterPICU.com

From: Sinnah Lazarus <sinnahlazarus@gmail.com>
Date: Sunday, May 15, 2016 at 5:07 AM
To: "Martha A.Q. Curley" <curley@nursing.upenn.edu>
Subject: Permission to use Questionnaire
[Quoted text hidden]

FCCS Scale

Please choose one of the following by ticking the response that you see best:

Statements about nurses	Section A: How important is it for nurses to do this? Not at all important				Very important	Section B: How consistently do nurses do this? Not at all consistent				Very consistent
1. Nurses help me feel welcomed……………………………………	1	2	3	4	5	1	2	3	4	5
2. Nurses help me feel important in my child's care……………………	1	2	3	4	5	1	2	3	4	5
3. Nurses treat me as a valued team member when planning my child's nursing care…………………………………………………………	1	2	3	4	5	1	2	3	4	5
4. Nurses give explanations about the nursing care they provide.	1	2	3	4	5	1	2	3	4	5
5. Nurses explain about changes I could expect in my child's condition………………………………………………………………………	1	2	3	4	5	1	2	3	4	5
6. Nurses help my child to feel well-cared-for…………………………	1	2	3	4	5	1	2	3	4	5
7. Nurses help me to feel well-cared-for…………………………………	1	2	3	4	5	1	2	3	4	5

FCCS scoring links the importance and consistency ratings in a single score based on the degree of "match" between parents' importance and consistency ratings of each aspect of nursing care.

- A "match" between parent expectations and nursing care occurs if the consistency rating for an item is the same as the importance rating for that item (e.g., scored 1 on importance & 1 on consistency etc.) or is +1 the importance score (e.g., scored 1 on importance & 2 on consistency etc.).
- There was no match if any other combination of scores are present; for example, when the consistency rating is more than +1 the importance rating (e.g., 1

importance & 3 consistency etc.) or if the consistency score was lower than the importance score (e.g., 2 importance & 1 consistency, etc.).

- The number of “matches” are summed and divided by the total number of possible matches, then multiplied by 100, to compute a percent match score.

FAMILY CENTERED CARE SCALE **FCCS Code: ………**

Section A

Demographic Information

Please indicate with [X]

1. Gender

Female	
Male	

2. Age

18-24 years old	
25-34 years old	
35-44 years old	
45-54 years old	
55+ years old	

3. Ethnicity

Black	
White	
Coloured	
Indian	
Other (please specify):	

4. Marital Status

Single (never married)	
Co-habitation (staying together out of marriage)	
Married	
Divorced	
Separated	
Widowed	

5. Highest Education Level

No schooling	
Primary School (Grade 1-7)	
High School (Grade 8-11)	
Matric (Grade 12)	
Diploma Certificate	
Bachelor's Degree	
Master's Degree	
Doctorate Degree	
Other (please specify):	

6. Employment Status

Unemployed	
Student	
Self-employed	
Employed	
Retired	
Other (please specify):	

APPENDIX E

FAMILY CENTERED CARE SCALE **FCCS Code: ………**

Section B

Please indicate with [X]

	Part 1 **How important is it for nurses to do this?** **Not at all important** **Very important**					**Part 2** **How consistently do nurses?** **Not at all consistent** **Very consistently**				
Statements about nurses										
1. Nurses help me feel welcomed	1	2	3	4	5	1	2	3	4	5
2. Nurses help me feel important in my child's care	1	2	3	4	5	1	2	3	4	5
3. Nurses treat me as a valued team member when planning my child's nursing care	1	2	3	4	5	1	2	3	4	5
4. Nurses give explanations about the nursing care that they provide	1	2	3	4	5	1	2	3	4	5
5. Nurses explain about the changes I could expect in my child's condition	1	2	3	4	5	1	2	3	4	5
6. Nurses help my child to feel well-cared-for	1	2	3	4	5	1	2	3	4	5
7. Nurses help me to feel well-cared-for	1	2	3	4	5	1	2	3	4	5

Additional comments

……

……

……

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

25 November 2016
Person No: 324514
PAG

Miss MS Lazarus
P O Box 291237
Melville
2109
South Africa

Dear Miss Lazarus

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Parents' views on family centred care in a South African Academic 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

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Human Research Ethics Committee (Medical)

Research Office Secretariat: Senate House Room SH 10004, 10th floor.
Medical School Secretariat: Phillip Tobias Building, 2nd Floor
Private Bag 3, Wits 2050, www.wits.ac.za

Tel +27 (0)11-717-1252
Tel +27 (0)11-717-2700
Fax +27 (0)11-717-1265

11 July 2016

To Whom It May Concern

SUBJECT: CONFIRMATION OF STUDY APPROVAL

Protocol Ref No: M160680

Protocol Title: Parent's Views of Family Centred Care in a South African Academic Hospital in Gauteng

Principal Investigator: Miss Sinnah Mathoto Lazarus

Department: Nursing Education

This letter serves to confirm that the Human Research Ethics Committee (Medical) has approved the above mentioned study. In order for a clearance certificate to be issued, the researcher is required to submit written approval to conduct the study in your district/institution.

The researcher has been informed that this letter is not a clearance certificate and that the study cannot commence without your approval and receipt of a clearance certificate from the HREC (Medical).

Should you have any queries, you may contact me at tel: 011 717 1252/1234/2700 or by email zanele.ndlovu@wits.ac.za

Yours Faithfully,

....

Ms Zanele Ndlovu
Administrative Officer
Human Research Ethics Committee (Medical)

UNIVERSITY OF THE WITWATERSRAND
OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH
11 JUN 2016
RESEARCH OFFICE HREC (Medical)
JOHANNESBURG

R14/49 Miss Sinnah Mathoto Lazarus

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160680

NAME: (Principal Investigator) Miss Sinnah Mathoto Lazarus

DEPARTMENT: Nursing Education
Charlotte Maxeke Johannesburg Academic Hospital

PROJECT TITLE: Parent's Views of Family Centred Care in a South African Academic Hospital in Gauteng

DATE CONSIDERED: 24/06/2016

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof Christa van der Walt

APPROVED BY: ______________________
Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 02/09/2016

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in June and will therefore be due in the month of June each year.

______________________ ______________________
Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
23 August 2016

Mrs. Sinnah Lazarus
Department of Nursing Education
Faculty of Health Sciences
University of Witwatersrand

Dear. Sinnah Lazarus

RE: "Parents' views on Family Centred Care in a South African Academic Hospital in Gauteng"

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

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

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

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

Supported / ~~not supported~~

Ms. M.M Pule
Nursing Director
Date: 2016/08/23

Approved / ~~not approved~~

Ms. G. Bogoshi
Chief Executive Officer
Date: 2016/08/23

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Ms S. Lazarus
Address	NURSING EDUCATION DEPT., UNIVERSITY OF WITWATERSRAND, 7 YORK ROAD, PARKTOWN.
Date	30/03/2017
Subject	Parents' Views on Family-Centred Care in a South African Academic Hospital in Gauteng
Ref	SL/GS/01

I, Gill Smithies, certify that I have proofed the following,

Thesis: Parents' Views on Family-Centred Care in a South African Academic Hospital in Gauteng,

to the standard as required by the University of Witwatersrand.

Gill Smithies

30/03/2017

Print | Close this window

Charlotte Maxeke Johannesburg Academic Hospital

Address	Jubilee Road, Forest Town, , Johannesburg, Gauteng
Telephone	0114884911
Fax	0116431210
Website	www.wits.ac.za

FACULTY OF HEALTH SCIENCES

Formerly known as Johannesburg General Hospital, the Charlotte Maxeke Johannesburg Hospital is an accredited central hospital with 1088 beds serving patients from across the Gauteng province and neighboring provinces. It offers inpatient and specialist outpatient's services mainly level 3 and level 2.

The hospital offers a full range of tertiary, secondary and highly specialized services.

The hospital is also the main teaching hospital for The University of the Witwatersrand.

Our visiting hours are Monday to Sunday 15h00 to 17h00

Print | Close this window