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PAEDIATRIC NURSES' PERCEPTIONS OF OBSTACLES AND SUPPORTIVE BEHAVIOURS IN END OF LIFE CARE IN PAEDIATRIC INTENSIVE CARE UNITS

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A research report submitted to the

Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

In partial fulfilment of the requirements for the degree

of

Master of Science in Nursing

Johannesburg, 2016

DECLARATION

I, Natwin Louw, declare that this research report is my own work. It is being submitted for the degree of Master of Science (in Nursing) in 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 …… 2016

Protocol Number M130638

DEDICATION

This work is dedicated to God my father, For from Him and through Him and to Him are all things To Him be the glory forever. Amen. (Romans 11:36)

I also dedicate this work to my mother who has been a true inspiration to me an angel who has gone beyond her calling for the love of her profession. Also dedicated to my son, husband, sister, aunt and brothers for their love, understanding, support and encouragement through this journey.

ACKNOWLEDGEMENTS

I thank God for his never ending love, guidance and protection during this study period.
I am also indebted to the following people, my sincere gratitude for their contributions in various ways:

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- My patients that I had the privilege of nursing who has assisted me in becoming the nurse that I am today.
- All the paediatric nurses and my colleagues who participated in the study and helped me in my professional growth.

ABSTRACT

The untimely death of a child in a highly technological intensive care unit evokes exaggerated feelings of devastation, stress, anger, helplessness and hopelessness in the child's family. The reasons are that death occurs suddenly and at times following a decision to withhold or withdraw life sustaining treatment. As a result; end-of-life care which incorporates principles of family-centred care is an important aspect of paediatric nursing. Empowering family members to participate in care plans in providing the child with a dignified death is a crucially important service that paediatric intensive care nurses can render. Though nurses yearn to nurture and provide the best care possible in end-of-life there are challenges that hinder this desire.

The purpose of the study was to identify and describe nurses' perceptions of behaviours which are obstacles to or support the provision of effective end-of-life care in paediatric intensive care units (PICU) at two public urban academic hospitals in Johannesburg. The study utilised a quantitative approach with a descriptive survey design to collect data means of the self-administered Paediatric Nurses Perceptions of End-of-Life Care (PEDS) questionnaire developed by Beckstrand et al. (2010). The total population of eighty seven (87) paediatric nurses working in paediatric and neonatal intensive care units who met the inclusion criteria were recruited to respond to the PEDS questionnaire. Sixty two (62) questionnaires were returned, a seventy two percent (72%) response rate. Descriptive statistics using SPSS' version 22 was used to analyse, describe, and summarise data in consultation with a statistician.

All the nurses (62; 100%) reported delivering direct end-of-life care to paediatric and neonatal patients during their short (less than 5 years; n=31) to long (6 to more than 30 years; n=31) PICU work experience. Most (48; 77 %) of the nurses were qualified with a

Diploma in Nursing, twelve (21%) were Bachelor's degree graduates and one (2%) Doctoral degree prepared nurse, had not participated in a specialised end-of-life care program (53; 85.5%). Nurses identified and ranked; *"poor design of units which do not allow for either privacy of dying patients and their family members", "the nurses workload being too heavy to adequately care for the dying child and grieving family" and "dealing with anxious families"* items, as the major and most frequently occurring obstacles to delivering optimal end-of-life care. Amongst supportive behaviours items the cohort ranked "*allowing family members adequate time to be alone with the child after he/she dies", "providing a peaceful, dignified bedside scene for family members once the child has died"* the highest. The most frequently occurring supportive behaviours identified were all attributes of a good death. Open ended questionnaire responses identified more helpful behaviours to end-of-life care relating to physician-nurse interactions.

Though nurses in this study were faced with obstacles perceived to hinder their ability to provide optimal care to the dying child and family members they reported care demonstrating behaviours which support the provision of optimal end-of-life care and most valued by family members. Whilst increasing awareness of end-of-life-care in PICU the findings of the study have contribute positively in decreasing the dearth of South African literature on the topic.

TABLE OF CONTENTS

		Page
DECLARATION		ii
DEDICATION		iii
ACKNOWLEDGEMENTS		iv
ABSTRACT		v
TABLE OF CONTENTS		vi
LIST OF TABLES		xi
CHAPTER ONE: OVERVIEW OF THE STUDY		
1.0	INTRODUCTION	1
1.1	BACKGROUND OF THE STUDY	1
1.2	PROBLEM STATEMENT	3
1.3	RESEARCH QUESTION	4
1.4	PURPOSE OF THE STUDY	4
1.5	OBJECTIVES	4
1.6	SIGNIFICANCE OF THE STUDY	4
1.7	DEFINITIONS OF STUDY TERMINOLOGY	5
1.7.1	Paediatric Nurse	5
1.7.2	Perceptions	5
1.7.3	Obstacles	5
1.7.4	Support	5
1.7.5	Behaviours	6
1.7.6	Family	6
1.7.7	Paediatric Palliative Care	6
1.7.8	End-of-life Care	6

1.7.9	Paediatric Intensive Care Unit	7
1.7.10	Clinical nurse specialist	7
1.8	OVERVIEW OF RESEARCH METHODOLOGY	7
1.9	ETHICAL CONSIDERATIONS	7
1.10	SUMMARY	8

CHAPTER TWO: LITERATURE REVIEW

2.0	INTRODUCTION	9
2.1	THE PAEDIATRIC INTENSIVE CARE UNIT	9
2.1.1	Family-Centred Care	10
2.2	CHALLENGES FOR THE PAEDIATRIC NURSE	11
2.3	END OF LIFE CARE	13
2.4	COMMUNICATION	14
2.5	FAMILY PERCEPTIONS	15
2.6	RELIGION ENABLING AND DISABLING FACTOR	15
2.7	NURSING PERCEPTIONS	16
2.8	SUMMARY	17

CHAPTER THREE: RESEARCH METHODOLOGY

3.0	INTRODUCTION	19
3.1	RESEARCH DESIGN	19
3.2	RESEARCH SETTING	20
3.3	POPULATION	20
3.4	SAMPLE AND SAMPLING METHODS	21
3.5	DATA COLLECTION	21
3.5.1	Instrument	22
3.5.2	Validity and Reliability of the Instrument	24

3.5.3	Pilot test	25
3.5.4	Data Collection Process	26
3.6	VALIDITY AND RELIABILITY OF THE STUDY	26
3.7	ETHICAL CONSIDERATIONS	27
3.8	SUMMARY	29

CHAPTER FOUR: DATA ANALYSIS AND RESULTS

4.0	INTRODUCTION	30
4.1	APPROACH TO DATA ANALYSIS	30
4.2	RESULTS AND FINDINGS	31
4.2.1	Questionnaire Section 1: Demographic Data	31
4.2.2	Questionnaire Section 2: Obstacles Perceived to End-of-Life Care	34
4.2.2.1	Obstacle size (intensity)	34
4.2.2.2	Obstacles perceived frequency	36
4.2.2.3	Obstacles perceived severity score	38
4.2.3	Questionnaire Section 3: Supportive Behaviours for End-of-Life Care	42
4.2.3.1	Supportive behaviours size (intensity)	42
4.2.3.2	Supportive behaviours frequency	44
4.2.3.3	Supportive behaviour intensity score	46
4.2.4	Responses to Open-Ended questions	48
4.3	DISCUSSION OF FINDINGS	51
4.3.1	Demographic Data	51
4.3.2	Obstacles Perceived to End-of-Life Care	53
4.3.3	Supportive Behaviours for End-of-Life Care	57
4.4	SUMMARY	58

CHAPTER 5: SUMMARY, DISCUSSION OF RESULTS, LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

5.0	INTRODUCTION	60
5.1	SUMMARY OF THE STUDY	60
5.2	SUMMARY OF MAIN FINDINGS	60
5.2.1	Socio-demographic Findings	61
5.2.2	Nurses' Perceptions of Obstacles To End-Of-Life Care	62
5.2.3	Nurses Perceptions of Supportive Behaviours In End-Of-Life Care	65
5.3	LIMITATIONS OF THE STUDY	66
5.4	RECOMMENDATIONS OF THE STUDY	67
5.4.1	Recommendations For Clinical Practice	68
5.4.2	Recommendations for Nursing Education	68
5.4.3	Recommendations for Further Research	69
5.5	CONCLUSIONS	69

LIST OF REFERENCES 71

APPENDICES

APPENDIX A	Information letter for participants	80
APPENDIX B	Data Collection Instrument	81
APPENDIX C	Permission from Prof Beckstrand	87
APPENDIX D	Approval from Gauteng Department of Health CMJAH	88
APPENDIX E	Approval letter from Nursing Director CMJAH	89
APPENDIX F	Approval from Gauteng Department of Health CBJAH	91
APPENDIX G	Approval from Human Research Ethics Committee	94
APPENDIX H	Approval from Postgraduate Committee	95
APPENDIX I	Language editing and proofing	96

LIST OF TABLES

Table		Page
4.1	Demographic data for nurse respondents for the total sample	32
4.2	Averages for obstacle size reported by paediatric nurses with regard to end-of-life care	34
4.3	Averages for obstacles frequency reported by paediatric nurses with regard to end-of-life care	36
4.4	Perceived severity scores for obstacle size and frequency in end-of-life care by paediatric nurses	38
4.5	Averages for supportive behaviours size reported by paediatric nurses with regard to end-of-life care	42
4.6	Averages for supportive behaviours frequency reported by paediatric nurses with regard to end-of-life care	44
4.7	Perceived intensity scores for supportive behaviours size and frequency in end-of-life care by paediatric nurses	46

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

An outline of the study is presented in this chapter. This introductory chapter provides a brief background to the study, problem statement, purpose of the study, and objectives, significance of the study and definitions of study terminology of terms. A framework of research methodology used, validity and reliability of the study as well as ethical considerations are also presented.

1.1 BACKGROUND OF THE STUDY

Death is the last thought on anybody's mind. The emotions produced by death are multiple and comprise fear, helplessness, despair, sorrow, resentment, anger pity, and fear. (Hickey and Quin, 2012).These feelings, experienced by family members, are exaggerated when a life is lost in an intensive care setting, for the reasons that death occurs suddenly and at times, following a decision to withdraw or withhold life sustaining treatment.

Advances in healthcare have seen an increase in life saving medical and surgical procedures for life threatening paediatric conditions, with the end result being an increase in paediatric admissions to intensive care units (ICU). The unexpected hospitalisation of a child with an illness that is life-threatening may be overwhelming and extremely stressful for the family unit. A critical illness unquestionably creates a professed crisis for the child, but the true holistic approach to healthcare should embrace incorporation of the family

members into caring for this child (Sturdivant and Warren, 2009). Furthermore, the probability of death occurring as an outcome to admission into intensive care is high.

The annual (January – December 2012) death statistics in a paediatric intensive care unit (PICU) of an academic hospital in Johannesburg reported 144 deaths from the 655 children admitted into the unit. Therefore, it can be seen that end-of-life care is an essential aspect of paediatric intensive care practice. Longden (2011) concurs that since "paediatric intensive care settings have become a nationwide priority there is a growing emphasis on improving end-of-life care" in these paediatric nursing care situations.

"A child's death is the ultimate and devastating loss expressed by parents as unique, complicated, stressful, dramatic, and disruptive" (Longden, 2011). Moreover, it is a societal belief that children should outlive their parents. In most cultures it is a terrible misfortune to bury one's child, which makes the death of a child an emotional and challenging issue. Cultural and religious beliefs have a direct influence on decisions, perceptions and needs of patients and family members on end-of-life care. Therefore, as healthcare practitioners it is very important to incorporate spiritual and cultural beliefs that meets the needs of the dying child and their family in the provision of optimal end-of-life care. End-of-life care is an essential feature of nursing. Nurses by the nature of their scope of practice and proximity to the patient develop close relationships with the family members and dying patient, which allows the nurse the privilege of understanding a family's dynamics, including cultural and spiritual beliefs concerning death. The nurse can use this invaluable insight to render quality end-of-life care, known as an "ideal death," which is dignified, peaceful and comfortable (Mc Callum and Mc Conigley, 2013). However when a death occurs abruptly, creating such an environment for the patient and family members is not always achievable.

The findings of the same study by Mc Callum and Mc Conigley (2013) suggest that current end-of-life care, whether sudden or expected is inadequate and does not meet the needs of the family members and dying child. Pain and other distressing symptoms associated with death; discordance and poor communication among families, patients, and healthcare workers' about care plans and goals were factors found to be lacking in care (Nelson, Agnus, Weissfeld, Puntillo, Danis, David, Mitchell, and Cook, 2006). A study by Beckstrand, Rawle, Callister, and Mandleco (2010) found that one of the reasons for this inadequate end-of-life care was as a result of the nurses' perception that their opinions and insight into the family was undervalued.

1.2 PROBLEM STATEMENT

In the South African setting, research on end-of-life care is in its infancy and focused on adult ICU (Langley and Schmollgruber, 2006; Schmollgruber, 2007; Bodole, 2009; Gundo, 2010). Nursing care of a child differs from that of an adult (Langner, Beecham, Candy, Langner, and Jones, 2008; Lacy, Smith, and Cox, 2008; WHO, 2008b). Consequently, the dynamics concerning death of an adult versus that of a child are different. Furthermore, The need to improve paediatric palliative care has become a global as well as a national priority (WHO, 2008a; Campbell, 2011; Longden, 2011; Meiring and Johnson, 2012) In an editorial published by a South African Journal, Campbell (2011) found that there is a pressing need to develop palliative care for children in South Africa, this article also brought to light the scarcity of South African published literature on paediatric palliative care. Little is known about nurses` perceptions concerning end-of-life care in South African PICUs. Therefore there is a need to investigate nurses` perceptions of obstacles and supportive behaviours in end-of-life care in PICU.

1.3 RESEARCH QUESTION

What are paediatric nurses perceptions of obstacles and supportive behaviours in end-of-life care in paediatric intensive care units?

1.4 PURPOSE OF THE STUDY

The purpose of this study is to identify and describe nurses' perceptions of behaviours which are obstacles to or support the provision of effective end-of-life care in neonatal and paediatric intensive care settings at two public urban academic hospitals.

1.5 OBJECTIVES

- To identify and describe nurses` perceptions of behaviours which are obstacles to optimal end-of-life care.
- To identify and describe nurses` perceptions of supportive behaviours which facilitate optimal end-of-life care.

1.6 SIGNIFICANCE OF THE STUDY

It is believed the results of the study may help identify nurses` perceptions of behaviours which are obstacles to or support the provision of effective end-of-life care. Literature reviewed by the researcher suggests that current end-of-life care is inadequate and does not meet the needs of the dying child and family members (Mc Callum and Mc Conigley, 2013). It is hoped that the outcome of this study, when published, will contribute positively to clinical, educational and evidenced based care guidelines in nursing care of the dying child and family members in intensive care settings.

1.7 DEFINITIONS OF STUDY TERMINOLOGY

1.7.1 Paediatric Nurse

In the study a paediatric nurse, intensivist nurse or nurse is a professional nurse registered with the South African Nursing Counsel under regulation R2598 and has undergone basic nursing education and training (SANC, 1984).

1.7.2 Perceptions

In the study nurses perceptions were obtained by them completing the Paediatric Nurses Perceptions of End-of-Life Care (PEDS) questionnaire. Perceptions is defined as an idea, belief or an image that someone holds according to his/ her understanding (Bodole, 2009).

1.7.3 Obstacles

In the study obstacles refers to challenges, barriers or impediments that interferes with or prevent the provision of effective, optimal or evidenced based end-of-life care. An obstacle is defined as something that interferes with or prevent action or progress (Oxford dictionary, 2005).

1.7.4 Support

In the study supportive behaviours are those actions that are helpful, encourage, assist and facilitate the provision of effective, optimal or evidenced based end-of-life care. Support is defined as to help or encourage somebody or something by saying or showing that you agree with them or it (Oxford dictionary, 2005).

1.7.5 Behaviours

Behaviours as described in the study are actions or factors relating to nursing practice, family members, physicians and the institution which includes the environment and

policies, which poses an effect on or reaction to end-of-life care. Behaviour is defined as the manner in which a person, object or phenomenon conducts, works or reacts to a particular situation or stimulus (Oxford dictionary, 2005).

1.7.6 Family

For the purpose of the study family refers to the people, biological or non biological, who are closely related to the patient and includes parents, grandparents, brothers, sisters, uncles, aunts and significant others. The term family consists of all those that make up the structure of the patients social support which he or she maintains central and essential relations (Tsaloukidis, 2010).

1.7.7 Paediatric Palliative Care

As defined by World Health Organisation (WHO) “palliative care for children is the active and total care of the child’s body, mind and spirit and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health care providers must evaluate and alleviate a child’s physical, psychological and social distress” (WHO, 1998).

1.7.8 End-of-Life Care

Refers to “The care and supportive services that a patient with an advanced disease or trauma and family receives after the decision has been made to limit life-sustaining therapy” (Latour, Fulbrook and Albarran, 2009)

1.7.9 Paediatric Intensive Care Unit (PICU)

The study was conducted in neonatal and paediatric intensive care settings at two public urban academic hospitals in Johannesburg. PICU is a designated hospital unit in which health professionals provide continuous care to critically ill patients, aged 0 to 18 years

presenting with actual and potential life threatening conditions, by using special equipment (Gundo, 2010).

1.7.10 Clinical nurse specialist

In the study a clinical nurse specialist in this study is a professional registered nurse who holds a specialist qualification in either paediatric or intensive care nursing sciences under the provisions of the Nursing Act (SANC, 2005)

1.8 OVERVIEW OF RESEARCH METHODOLOGY

The research design is the set of logical approaches taken by the researcher to answer the research question. The research design forms the blueprint of the study and determines the methodology used by the researcher to obtain sources of information, such as subjects, elements and units of analysis, to collect and analyse data and to interpret results (Brink, Van de Walt and Van Rensburg, 2007). This study was conducted using a quantitative approach with a descriptive survey design. The total population of eighty seven (n=87) nurses, working in the neonatal intensive care unit (NICU) and PICU of two urban public academic hospitals, who met the sample criteria were invited to complete the Paediatric Nurses Perceptions of End-of-Life Care (PEDS) questionnaire.

1.9 ETHICAL CONSIDERATIONS

As pointed out by Polit and Beck (2010) when research involves human beings it is intended that the researcher must deal with ethical issues. Thus, the following ethical issues were considered:

The research proposal was presented to the Department of Nursing Education for peer review and validation of the questionnaire. To ensure scientific integrity, credibility,

relevance and permission to conduct this study, the proposal was submitted to the University's Therapeutic Sciences Postgraduate Committee; permission was granted **(Appendix H).** Ethical clearance to collect data from nurses was obtained from the Wits University Human Research Ethics Committee. The research was approved and ethical clearance certificate number **M130638** was issued **(Appendix G).** Application letters (**Appendix A)** requesting permission to collect data from nursing staff were submitted the Gauteng Department of Health Research Committee, the hospital superintendents, nursing services managers and operational managers and permission was granted by the above mentioned authorities to conduct the research study. The ethical principles which were adhered to throughout the research study were: veracity, respect for persons, beneficence and non-maleficence, confidentiality and anonymity.

1.10 SUMMARY

This chapter of the research report provides an outline of the study. In this chapter an introduction and background of the study were introduced. The problem statement, research question, purpose of the study and objectives were outlined. In addition, significance of the study, relevant definitions, an overview of the research methodology and ethical considerations were described.

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

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

The literature reviewed relates to a variety of factors that has a positive or negative influence on the nurse's ability to provide quality end-of-life care. This review of literature on end-of-life care has been categorised in distinct but related areas namely; PICU which is a highly technological environment, family-centred care which integrates family in caring for the child, paediatric nursing and the challenges they face in providing end-of-life care, communication as fundamental nursing skill, parental perceptions on how they experienced the loss of their child, religion as an obstacle or helpful behaviour in end-of-life care as well as nurses perceptions on end-of-life care.

2.1 THE PAEDIATRIC INTENSIVE CARE UNIT (PICU)

The PICU is described as a hospital unit in which specially trained professionals provide care to critically ill patients between the ages of 0 to 18 years old by using special equipment. It is a designated unit where patients are admitted for continuous monitoring by healthcare professionals with potential and actual life-threatening conditions (Gundo, 2010). Paediatric intensive care settings are characterised by their intensive, highly technical emphasis on life-saving practices such as, intensive intravenous administration of medications, artificial hydration, nutrition supplementation and the use of mechanical ventilation (Doorenbos, Lindhorst, Starks, Aisenberg, Curtis and Hays, 2012). Furthermore, the probability of death occurring as an outcome to admission into intensive care is high (Singhal, Kumar, Puliyel, Singh and Srinivas, 2001; Hoyert, Mathews and Menacker, 2004; Solomon, Morrow and Argent, 2014).

2.1.1 Family-Centred Care

The nursing care in PICU identifies the family as a constant in the child's life and is based on the philosophy of family-centred care. This requires a commitment from the healthcare system and nursing staff to develop a mutual partnership with the parents by supporting, respecting, encouraging and enhancing the strength and competence of the family (Wong, 1997). "Families are supported in their natural caregiving and decision making roles by building on the unique strengths and acknowledging their expertise in caring for their child" (Hockenberry and Wilson, 2007). It is not just the needs of the child that is considered, but the family as a whole. The philosophy also identifies diversity among family backgrounds and structures, family actions and aspirations as well as support, services and information needs.

Enabling and empowerment are two basic and important concepts in family-centred care. However, there has been considerable research published on family-centred care and although healthcare personnel enthusiastically accept the concept they have been slow to implement the practice (Doorenbos, Lindhorst, Starks, Aisenberg, Curtis and Hays, 2012). The philosophy necessitates stretching beyond clinical practices which have become accustomed to the institution and personnel. Family-centred care requires viewing the family as the centre of care, with family input serving as a major determining factor of interventions provided, (Hockenberry and Wilson, 2007). Although paediatric policies in South Africa have improved by incorporating family-centred care principles, due to responses of concerns from parents to have continuous access to their child, several units has refrained from only allowing brief visitations and has improved paediatric care by making provisions for parents to room with their children. Doorenbos, et al. (2012) states that "positive attachment and emotional security for the child is achieved through supporting rooming-in arrangements of parents with the ill child". The stress of travelling for the parent and the stress of the hospital stay for the child and parent can be

significantly reduced with rooming-in arrangements. Research also recommends that such arrangements in paediatric care units can reduce anxiety experienced parents triggered by changes in the parent role which may take place during paediatric hospitalisations (Roets, Rowe-Rowe and Nel, 2012).

However it is important to note that the researcher has observed limited application of this policy in NICU and PICU. The visiting protocol only allows parents to visit their child during the day shift (07H00 to 19H00). Most of these parents have limited resources and cannot afford to travel to and from the hospital on a daily basis. On occasion, as per parental request and special agreement with the healthcare team, visitation hours are extended for a family with a dying or deceased child.

The above scenario supports the findings of a South African study by Roets, Rowe-Rowe and Nel (2012) which observed the gap which exists between valuing family-centred care and implementing it within clinical practice. The authors also found that paediatric nurses were challenged by the role of interacting with and providing psychological support to families of children in the PICU because of the high stress levels of the family who found themselves with insufficient coping strategies.

2.2 CHALLENGES FOR THE PAEDIATRIC NURSE

The motivation behind the choice of paediatrics as a discipline for most nurses is the wish to save the lives of and reduce suffering in children (Moloney-Harmon and Curley, 2001). As a result being faced with a child who is in the process of dying or has died can be particularly distressing for the nurse. A self-report from paediatric nurses who participated in a study investigating child deaths in the PICUs in Cape Town by Vivian (2012) acknowledges that distress was exacerbated by the fact that whilst the nurses were mourning the death of a patient they were preparing to render comprehensive care to

another patient therefore suppressing grieving for the dead patient. This is a daily harsh reality faced by the nurses working in PICU in South Africa, where bed occupancy and demand is high. The resultant outcome of this is a higher incidence of patient deaths and overburdened nurses. Even though the primary responsibility of the paediatric nurse is to provide optimal end-of-life care for the child and family, nurses acknowledge there exists both external and internal constraints which hinder their ability to do so. The nursing care of a dying patient and family is multidimensional and includes: close observation, management and documentation of the physiological, psychological and social aspects (Bloomer and O' Connor, 2013). In addition to this is pressure to avail a bed and prepare for the admission of the next critically ill patient.

Amongst the many challenges for the paediatric intensive nurse in the delivery of effective end-of-life care, is the provision of privacy for counselling, saying last goodbyes and cultural rituals that are often performed. The primary reason for this is the open plan structure of most intensive care units in South Africa (Schmollgruber, 2007). Fridh, Forsberg and Bergbom (2007) emphasise that the hospital setting influences the family members, patient and staff and the unit lay out may have a positive or a negative effect on the care. A study exploring the experiences of family members who lost a loved one in an ICU reported that there is insufficiency of privacy and the need for improved physical space (Abbott, Sago, Breen, Abernethy and Tulsky, 2001). It is often challenging for the nurse to create a therapeutic private environment for effective end-of-life in communal rooms where only a thin curtain divides the beds.

Stressors that the paediatric nurse is confronted with in the in ICU, especially the novice nurse, is the knowledge of what to do when and how to care for the dying child and family. The provision of optimal care for a child at the time of death is the most honourable of all nursing skills, yet nurses are often deficient in knowledge and uncomfortable with it (Jones, Sampson, Greathouse, Legett, Higgerson and Christie, 2007). In a research study

conducted by Beckstrand, Callister and Kirchhoff (2006) nurses stated that their nursing education had not sufficiently equipped them to deliver optimum end-of-life care and that they often learned “the hard way.” Nurses who work in intensive care settings have received little training and education in care of dying patients and family members. Hansen, Goodell, DeHaven and Smith (2009) propose that education is not the only the necessity of intensive care nurses. Supplementary elements which may be as important for providing end-of-life care include a work environment with good communication and collaboration between nurses and doctors the use of palliative care services and adequate support of patients, family members and staff. Caring for the dying child in the paediatric intensive care environment is very stressful and necessitates the nurse to have an efficient set of skills and knowledge to support family.

End-of-life care is an essential feature of nursing and it has been found that professional nurses often do not participate or in are not involved or in the process of decision making, on initiating life sustaining treatment or the withdrawal thereof (Carnevale, Benedetti, Bonaldi, Bravi, Trabucco and Biban, 2011). Exclusion of the nurses in healthcare decisions may be particularly stressful when futile aggressive medical treatment is continued, as one of the basic nursing roles is to serve as an advocate for the patient and family. Nurses working in the PICU experience several stressors related with their work, together with the provision of effective end-of-life care for dying children and their families. These stressors are at times shared with external constraints on the nurse’s actions which may affect the way the nurse provides care or articulates emotions, which may lead to moral distress (Lee and Dupree, 2008).

2.3 END-OF-LIFE CARE

WHO (1998) defines palliative care for children as “the active and total care of the child’s body, mind and spirit and also involves giving support to the family. It begins when illness

is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited". Palliative care is an essential component of paediatric intensive care. Healthcare providers in these settings should always bear in mind that death is part of life and not an enemy that needs be defeated (Langley and Schmollgruber, 2006). However, it must be understood that palliative care interventions do not serve as a means to hasten death, but rather support optimum functioning and quality of life for the time the child has left. Attention is given to matters faced by the child and parents, with respect to the process of death, death and providing the best pain and symptom management (Hockenberry and Wilson, 2007).

2.4 COMMUNICATION

Communication has been gaining a huge amount of attention in paediatric critical care literature. Communication between healthcare workers and parents was recognised as a major concern (Carnevale, et al., 2011). Beckstrand, Callister and Kirchhoff (2006) agree that a vital component of end-of-life care to family members is clear and honest information. Most family members whose children were admitted to PICU were more satisfied with the honesty and the manner in which nurses communicated (Longden, 2011). It is also understood that skilful communication may empower a family to adjust better to challenging circumstances such as losing a child. Effective communication is a very important nursing skill and the foundation of the therapeutic relationship. Poor communication, on the other hand, can produce lifelong anger and increased levels of anxiety amongst family members (Onyeka, 2010).

2.5 FAMILY PERCEPTIONS

Improving the quality of end-of-life care in PICU is a priority and can be achieved by incorporating parental perceptions on how they experienced the loss of their child, together with nurse's perceptions. Both healthcare professionals and family members agree that improvements in end-of-life care is needed. Losing a child is the most devastating loss expressed by parents as dramatic, complicated, unique, stressful and disruptive (Longden, 2011). Moreover, it is a societal belief that children should grow up and outlive their parents. In most cultures it is a terrible misfortune to bury one's child and makes the death of a child an emotional and challenging issue. A qualitative study done by Robinson, Thiel, Backus and Meyer (2006) found that the majority of the parents, whose children had passed on, were influenced by their spirituality to guide them on decision-making in end-of-life, to give meaning to the loss and to sustain them emotionally.

2.6 RELIGION ENABLING AND DISABLING FACTORS

The cultural and religious beliefs held by the family of a dying child are an important element of end-of-life care. These beliefs become the mechanism through which the family makes sense of and copes with the tragedy and taboo of the loss of young life. Thus healthcare providers who care for the critically ill children should uphold a great degree of sensitivity and understanding toward the dying child and family member's spiritual background. Robinson et al. (2006) reported that in one study, it was found that sixty to eighty percent of parents whose children were hospitalised had spiritual needs that were unmet.

Even though religious beliefs support the dying child and family members, at times family member's strong religious faith may hinder the initiation of end-of-life care. Brierley,

Linthicum and Petros (2012), state they are concerned that children are being imperilled to futile care in expectation of miraculous intervention due to deeply held beliefs in religion. In justification of this statement, Brierley, Linthicum and Petros (2012) reviewed the end-of-life care of 203 cases in which children had a very poor prognosis over a three year period. During the study, it was found that in 96% of the cases studied the family agreed to withdraw or limit treatment. However in 65% of the remaining cases, the family did not agree to the withdrawal or limitation of intensive care. For the reason that these family members held strong religious beliefs that intensive care should not be withheld or withdrawn due to anticipation of divine intervention and complete cure and that the healthcare provider's predictions were pessimistic and wrong. It is important for intensive care nurses to support families in difficult times, even though such cases may pose difficulties in providing optimal end- life-care.

2.7 NURSING PERCEPTIONS

Providing optimal end-of-life care to the dying child and family members requires the nurse be equipped with knowledge. Rapid changing healthcare needs, together with technological advancements, compels the intensive care nurse to have sound skills and knowledge. Parents, siblings and the child who is dying have the right to be cared for by a knowledgeable nurse, one who is competent and educationally prepared to perform adequate nursing care. Additionally, literature brings into being that a nurse who is educationally prepared and skilled in delivering evidenced based palliative care has a positive attitude towards caring for patients who are dying (Brent et al., 1991; Brockopp, King and Hamilton, 2007; Engler, Cusson, Bronkett, Cannon-heinrich, Goldburg, West and Petwon, 2009; Chiplaskey, 2011). Nurses working in PICU and NICU who do not have sufficient education in end-of-life care, find caring for dying patients and the patients' families overwhelming (Hansen, Goodell, DeHaven and Smith, 2009). However a survey conducted by Beckstrand, Callister and Kirchhoff (2006) the respondents, members of the

American Association of Critical Care Nurses, did not find insufficient education on end-of-life care as a major obstacle to delivering optimal end-of-life care. Importantly, nurses are the backbone of the health system and their opinions on healthcare matters are essential to improving the wellbeing of the nation at large. Surveys conducted in Egypt and the USA on paediatric critical care nurse's perceptions, recognised that working in a highly technological environment, the switch form curative care to palliative care, staff shortage, troubled family members, deficiency of nursing involvement in end-of-life decision making and poor communication as major obstacles to providing end-of-life care (Heaston, Beckstrand, Bond and Palmer, 2006; Beckstrand, et al., 2010; Moawad, 2013).

Despite being faced with all these obstacles, nurses remain the most valued healthcare practitioner's in terms of developing therapeutic relations, support, advocating and simply just caring for the dying child and relatives as perceived by family members (Longden, 2011). Paediatric nursing is a special calling and supporting families at their most vulnerable time, such as losing child, is an honourable privilege. Nurses who participated in the studies perceived; family presence, involvement in death and dying, a peaceful and dignified bedside side scene and honest and clear physician communication of the child's prognosis, as helpful behaviours in providing optimal end-of-life care (Beckstrand, Bond, and Palmer,2006; Heaston, Beckstrand, Smith, Heaston, and Bond,2008; Beckstrand et al.,2010; Moawad,2013).

2.8 SUMMARY

Provision of end-of-life care for a child in a highly technological environment that emphasises curative measures may be challenging for health care providers and particularly distressing for family members. Therefore it is not just the needs of the dying child that is considered but the family as a whole. Family presence and a dignified beside scene were perceived as a very helpful behaviours by paediatric intensives nurses in a

study conducted in the USA (Beckstrand, et al., 2010). The literature reviewed brings to light various challenges that hinder nurses from providing optimal end-of-life care. Improving end-of-life care in paediatric settings has become global and national priority (WHO, 2008a; Campbell, 2011; Longden, 2011; Meiring and Johnson, 2012). Literature was reviewed to make connections from on global trends as well as bring meaning to study findings and draw conclusions a South African perspective. Thus an enquiry on, what are paediatric nurses perceptions of obstacles and supportive behaviours in end-of-life care in paediatric intensive units was made.

CHAPTER THREE

RESEARCH DESIGN AND RESEARCH METHODS

3.0 INTRODUCTION

Research methodology refers to the research plan that describes how, when and where data will be collected and analysed (Parahoo, 2006). In this chapter the research methodology will be described. This includes the research setting, study population, sample and sampling, data collection, the instrument including its validity and reliability, pilot testing of the instrument, validity and reliability of the entire study. As well as ethical issues which were taken into account.

3.1 RESEARCH DESIGN

The research design ”forms the blueprint of the study and determines the methodology used by the researcher to obtain sources of information, such as subjects, elements and units of analysis, to collect and analysis data and to interpret results” (Brink, Van de Walt and Van Rensburg, 2007).

A quantitative approach with a descriptive survey design was adopted for this study. The quantitative approach comes from the idea that human phenomena along with variables in human behaviour can be studied objectively (Uys and Basson, 2000). In view of the fact there is little known about nurses’ perceptions of enabling and disabling factors to the provision of optimal end-of-life care in PICUs in South Africa, a descriptive design fulfilled the need and means to gather more information needed on this sensitive topic.

3.2 RESEARCH SETTING

This study was conducted in the PICUs at two urban public tertiary academic hospitals in Johannesburg. Paediatric and neonatal intensive care settings at level three tertiary public hospitals were ideal settings because they were supported by specialists' consultations in all disciplines, including complex laboratory and hi-tech investigations and imaging services (Bersten and Soni, 2003). Tertiary academic hospitals offer a full range of specialised services and have large patient bed capacity. Patients admitted to these units are between the ages 0 and 18 years, critically ill, often intubated, requiring ventilation support and haemodynamic monitoring for survival or for pre- and post-major operation observations. It is a designated unit where patients with actual and potential life threatening conditions are admitted for continuous monitoring by healthcare professionals, (Gundo, 2010). Furthermore, the probability of death occurring as an outcome to admission was high as per the statistics obtained from the death records of the hospitals.

3.3 POPULATION

Brink, Van de Walt and Van Rensburg (2007) define population as a "complete set of persons that possess some common characteristics that is of interest to the researcher." A preliminary audit conducted in January 2013 indicated there were a total of eighty seven (n=87) registered nurses were employed in NICU and PICU at both hospitals where the study was conducted.

The majority of nursing staff employed in these units are professional nurses who have completed a comprehensive nursing degree or diploma and is registered with South African Nursing Council under R2598 (SANC, 1984). In addition, some of them hold a post basic qualification in child health nursing science, or intensive nursing care science and/or neonatal intensive nursing science.

3.4 SAMPLE AND SAMPLING METHOD

According to Uys and Basson (2000), sampling is a “process for obtaining a representative sample of the entire study population.” A convenience sampling method was utilised for selection of the study settings. Total sampling were used to obtain study respondents. Brink, Van de Walt and Van Rensburg (2007), define convenience sampling as a non-probability method which involves recruitment of readily available subjects who are involved with the phenomenon until the desired number is obtained. In this case the total population (n=87) of nurses working in neonatal and paediatric intensive care settings were invited to participate in the study. Of the eighty seven (n=87) questionnaires handed out sixty two (n=62) were returned. This is an acceptable response rate of 72%.

The inclusion criteria for the sample were:

- Professional nurse registered with SANC
- The nurse should be employed on a full-time basis
- The nurse should have nursed a child who was in the process of dying or has died within the last twelve months
- Ability to read English
- The nurses` willingness to participate in the research study

3.5 DATA COLLECTION

Data collection is the systemic gathering of information relevant to the research purpose, objectives or questions of a study (Burns and Grove, 2007). A survey utilising a self-administered questionnaire was used for the study.

3.5.1 Instrument

A survey utilising self-administered questionnaire was used for the study. According to Brink, Van de Walt and Van Rensburg (2007) this technique may be used when the researches objective is to gather factual information about the respondents; the purpose of questions is to determine what are their thoughts, perceptions, attitudes, beliefs, feelings, motives, plans, experiences, knowledge levels and memories. Subjects must answer the questions about the study variable directly and for that reason, a questionnaire was used to determine what paediatric nurses perceptions were regarding end-of-life care in PICU. Nurses in this study were invited to complete the Paediatric Nurses Perceptions of End-of-Life Care (PEDS) questionnaire **(Appendix B**) which was developed by Beckstrand et al. (2010). The PEDS questionnaire is written in English and takes approximately 25 minutes to complete. The (PEDS) questionnaire consists of three sections:

Section 1: Comprised items which elicit respondents' demographic information such as years of experience, gender, academic qualifications, the amount of dying patients they have nursed unit type, the position held at healthcare facility and if they have participated in any end-of-life care educational programs.

Section 2: had 31 items in which respondents were asked to rate obstacles to end-of-life care according to size and frequency. The size of the obstacle was rated on a 5 point Likert scale in which 0 indicated not an obstacle to 5 which indicated a severely large obstacle. The frequency of the obstacle was also rated on a 5 point Likert scale in which 0 indicated never occurs to 5 which indicated always occurs. Respondents were also asked

to add and rate another obstacle to end-of-life care which they thought was not included in the questionnaire.

Section 3: Consisted of 19 selected supportive behaviours in which respondents were asked to rate the size and frequency of supportive behaviours. The size of supportive behaviours were rated on a 5 point Likert scale where 0 indicated not a help to 5 which indicated severely large help. The frequency of supportive behaviours was also rated on a 5 point Likert scale where 0 indicated never occurs to 5 which indicated always occurs. Respondents were also asked to add and rate another supportive behaviour that facilitates with optimal end-of-life care which they thought was not included in the questionnaire. Respondents were also asked in an opened question if they had the ability to change just one aspect of end-of-life care, what it would be. The (PEDS) questionnaire was used for the study because validity and reliability were carefully reviewed in other studies (Heaston, et al., 2006; Beckstrand, Smith, Heaston, and Bond, 2008; Beckstrand, Moore, Callister, and Bond, 2009; Beckstrand et al., 2010; Attia, et al., 2012).

Some **modifications to the original questionnaire** were made, approved by the developer (Appendix C), to adapt the questionnaire to the South African context. The changes made based on the layout and numbering of questions were as follows:

- Section 1 (obstacle items) was moved to section 2 (obstacle items) in this study, numbered 9 to 39 and 40 as an open ended question
- Section 2 (supportive items) was moved to section 3 (supportive items) in this study, numbered 41 to 59 and 60 and 61 as open ended questions
- Section 3 (demographic data) was moved to section 1(demographic data) in this study, numbered 1 to 8.

The following questions were removed:

- How many beds are in your unit?
- How many hours per week do you usually work?

- Have you ever been certified as a CCRN?
- Are you currently certified as a CCRN?

3.5.2 Validity and Reliability of Instrument

The PEDS questionnaire originated from a pioneer study by Kirchhoff and Beckstrand (2000) investigating common barriers and supportive behaviours perceived by paediatric nurses in end-of-life care to address a dearth in literature on the subject of concern. To meet study objective of describing the importance of several obstacles and supportive behaviours in providing end-of-life care as perceived by critical care nurses who cared for dying patients; the authors developed a questionnaire entitled National Survey of Critical Care Nurses Regarding End-of-Life Care from information received from focus groups and an extensive literature review. The initial questionnaire was pre-tested and administered to 45 critical care nurses. Calculation of the Cronbach alpha yielded a score of 0.86 for the 25 obstacle items and 0.82 for the 23 helpful behaviours. The outcome of the survey was the PEDS questionnaire with some items removed or rephrased for clarification from the National Survey of Critical Care Nurses Regarding End-of-Life Care questionnaire (Beckstrand, Rawle, Callister and Mandleco, 2010)

Beckstrand et al., 2010 conducted a pilot study to further develop and test adequacy of the PEDS questionnaire. The responses received from the open ended questions in the questionnaire from the pilot study and updated published literature reviews on end-of-life care; resulted in the modification of the PEDS questionnaire to include both the size and frequency of perceived obstacles and supportive behaviour in providing end-of-life care to dying patients. The revised instrument was pre-tested on 21 intensive care nurses and several minor grammatical alterations made. The PEDS questionnaire has been adapted for use in surveys investigating nurse perception of end-of-life care in oncology, adult critical care and emergency specialities. Content validity in each of the studies was

strengthened with recommendations made by nurse experts and pre-testing the instrument during pilot studies (Beckstrand et al., 2010).

Reliability refers to the degree to which an instrument can be depended on to produce consistent results (Brink, Van de Walt and Van Rensburg, 2007). Beckstrand et al. (2010) tested the internal consistency of the PEDS questionnaire and obtained Cronbach alpha coefficients of 0.93 and 0.88 on the items measuring obstacles to end-of-life care items and 0.85 and 0.79 on the supportive behaviours. According to Polit and Beck (2010) these values indicate acceptable reliability as they are above 0.7

3.5.3 Pilot Test

A pilot test was conducted in one of the two research settings, a cardio thoracic ICU, where both adult and paediatric patients are nursed intensively. The results from the pilot test were not included in the main study. The purpose of the pilot was to establish: the feasibility of the study in terms of time taken to complete the questionnaire as well as content and face validity. Pretesting of a measuring instrument consists of trying it out on a small number of persons having characteristics similar to those of the target group of respondents (De Vos, Strydom, Fouche and Delport, 2005). Five (n=5) nurses possessing similar characteristics to those used in the main study and whom had met the inclusion criteria participated in the pilot test. All five (n=5) respondents stated that the questionnaire was easy to answer but was time consuming because it took approximately twenty five minutes to answer. However, the respondents suggested that although there were too many questions to answer none of the questions should be removed. They recommended that when conducting the main study, respondents should be given sufficient time to complete the questionnaire since the questions asked would assist in collecting vital information. The recommendation was taken into consideration and the study respondents were given sufficient time to complete the questionnaire and were instructed to drop it in a box which was left in the unit and emptied every 24 hours.

3.5.4 Data Collection Process

Permission to conduct the research study was obtained from ethical, professional and organisational bodies including management of the two academic hospitals. Data collection took place from the 21st January to May 6th 2014. An information letter (Appendix A) inviting nurses to participate in the study explaining the nature and purpose of the study was distributed by hand during the first week of data collection period. During the second week period, the researcher distributed the questionnaire to the study sample by hand. The instructions on the questionnaire included the following: conditions of consent giving, how to complete the questionnaire and the return of all (complete or incomplete) questionnaires to a sealed drop box which was left in the units throughout the data collection period. The sealed drop box was emptied every 24 hours. Data collection was discontinued on the 6th of May 2014, as no more questionnaires were obtainable from the sites. The collected questionnaires was coded and kept in a safe place.

3.6 VALIDITY AND RELIABILITY OF THE STUDY

Validity and reliability were ensured by using the PEDS questionnaire instrument, which was validated and used in other studies (Beckstrand, Callister and Kirchhoff, 2006; Heaston et al., 2006; Beckstrand, Smith, Heaston, and Bond, 2008; Beckstrand, Moore, Callister, and Bond, 2009; Beckstrand et al., 2010; Attia, et al., 2012).The researcher did not deviate from the procedures stipulated in the protocol. Data collection was carried out by the researcher only. A statistician was consulted for data analysis and interpretation of the findings to ensure accurate statistical conclusions were made.

The questionnaire was reviewed by the researcher's supervisor, colleagues, course lectures and the Department of Therapeutic Sciences for content and face validity.

Structural changes, formatting and the order of items were made on the questionnaire based on feedback from the above mentioned authorities.

3.7 ETHICAL CONSIDERATIONS

Conducting research does not only require diligence and expertise but also scientific honesty and scientific integrity. In order to produce sound knowledge for practice is essential to conduct research ethically (Burns and Grove, 2007). As pointed out by Polit and Beck (2010) when research involves human beings it is envisioned that the researcher must deal with the ethical issues. The following ethical issues were considered:

The research proposal was presented to the Department of Nursing Education for peer review and validation of the questionnaire. To ensure scientific integrity, credibility, relevance and permission to conduct this study, the proposal was submitted to the University's Therapeutic Sciences Postgraduate Committee; permission was granted **(Appendix H)**. Ethical clearance to collect data from nurses was obtained from the Wits University Human Research Ethics Committee. The research was approved and ethical clearance certificate number **M130638** was issued **(Appendix G)**. Application letters requesting permission to collect data from nursing staff were submitted to and approved by the Gauteng Department of Health Research Committee, the hospital superintendents, nursing services managers and operational managers. The ethical principles which were adhered to throughout the research study were: Autonomy, beneficence and non-maleficence, confidentiality and anonymity.

Autonomy

Participation in the study was voluntary and respondents were not remunerated.

Respondents were invited to participate in the study by means of an information letter **(Appendix A)**. By completing the questionnaire respondents gave consent to participate in the study.

Beneficence and non-maleficence.

Non participation in the study did not carry a penalty. Respondents were informed prior to answering the questionnaire that their participation in the study may evoke feelings of emotional distress and arrangements for a counsellor were made if they experienced emotional distress. The researchers contact details were made available to arrange counselling if needed (Appendix A). The hospitals where the study was conducted were safeguarded as the researcher adhered to data collection methods as stipulated in the permission letter to conduct research. The findings of the study will be made available to the research settings and recommendations for end-of-life care disseminated in a publication of the study or part thereof.

Confidentiality and anonymity

Anonymity of the respondent was assured as no names were required on the questionnaire. The collected questionnaires were coded and kept in a safe. The data captured on the computers and saved on memory sticks were encrypted. The data collected will be kept for a period of five years as specified by the University of the Witwatersrand.

3.8 SUMMARY

This chapter presented the research methodology and included the research design, setting, population, sample and sampling, instrument used for data collection including its validity and reliability, data collection procedure, ethical issues and validity and reliability of the study. The next chapter will present data analysis and discussion of results.

CHAPTER FOUR

RESULTS AND DISCUSSION OF FINDINGS

4.0 INTRODUCTION

This chapter describes the analysis of data using descriptive statistical tests and interpretation of the findings. Computer statistical package 'SPSS' version 22 was utilised and data files were set within. Data entered once and then verified during the second direct entry. In order to achieve the study objectives descriptive statistics were used. The descriptive tests (frequencies, measures of central tendency and dispersion and reliability) were used to synthesize the respondent's socio-demographic data and questionnaire schedule.

4.1 APPROACH TO DATA ANALYSIS

In order to interpret demographic data descriptive statistics were used. For ease of interpretation percentages for these results were taken to the first decimal point.

For all obstacles and supportive behaviours items, frequencies, measures of central tendency and dispersion, and were calculated. To determine which items were perceived to be the largest obstacles or supportive behaviours and which items were perceived to occur most frequently items were ranked on the basis of their mean scores. Individually, obstacle item's size mean was then multiplied by the item's frequency mean to obtain a severity score (Beckstrand et al., 2010). Each supportive behaviour item's size mean was also multiplied by the item's frequency mean to obtain a perceived intensity score. Both perceived severity scores for obstacle items and supportive behaviour items were then ranked from highest to lowest. Responses for open-ended questions were typed into a

word file. The replies from the open-ended questions were analysed, common themes were identified, and the like responses were organised into different categories. The number of categories and the frequency of responses in each category were then determined and ranked from the highest number of responses to lowest number of responses. The above mentioned process was checked by the researcher's supervisors for scientific integrity and credibility.

Demographic information retrieved were then analysed to determine how best to divide the respondents into two groups based upon the amount of PICU work experience reported. An average length of PICU work experience was used. Nurses who had the same amount of less than an average length of PICU work experience (in years) were placed in one group, whereas nurses with more than average PICU work experience were placed into a second group. For all obstacle and supportive behaviour sizes and frequency data in groups, frequencies and measures of central tendency and dispersion were calculated. To test for significant differences among the items rated by the two group's independent samples t-tests were computed.

4.2 RESULTS AND FINDINGS

4.2.1 Questionnaire Section 1: Demographic Data

This section related to respondents demographic data which comprised of eight (8) items. Items included *"years of experience as a registered nurse"*, "*years of experience as a paediatric/neonatal nurse"*, *"gender*", *"level of education"*, *"end-of-life care experience"*, *"area of practice"*, "*current position"*, and *"participation in end-of-life educational program"*. Results of the process are summarised in **table 4.1** for the total sample (n=62). Items were combined to form coherent groups to facilitate discussion of the data

Table 4.1 Demographic data for the paediatric nurses for the total sample (n=62)

Item	Statement	Number	Percentage
1	"How many years' experience do you have as an EN/RN"		
	< 5 years	23	37.1%
	6 to 10 years	18	29.0%
	11 to 20 years	11	17.7%
	21 to 30 years	7	11.3%
	>30 years	3	4.8%
2	"How many years of Paediatric/NICU experience do you have?"		
	< 5 years	31	50.0%
	6 to 10 years	18	29.0%
	11 to 20 years	6	9.7%
	21 to 30 years	5	8.1%
	>30 years	2	3.2%
3	"What is your gender?"		
	Male	2	3.2%
	Female	60	96.8%
4	"What is your highest level of education?"		
	Diploma	48	77.4%
	Bachelor's degree	13	21.0/%
	Master's degree	-	-
	Doctoral degree	1	1.6%
5	"Over your paediatric career how many patients have you given immediate end-of-life care to?"		
	< 5	14	22.6%
	6 to 10	13	20.9%
	11 to 20	8	12.9%
	21 to 30	6	9.7%
	>30	21	33.9%
6	"In which type of unit are you employed?"		
	NICU	35	56.5%
	PICU	11	17.7%
	NICU and PICU	16	25.8%
7	"The position you hold at the facility is?"		
	Direct bedside nurse	52	83.9%
	Clinical nurse specialist	8	12.9%
	Other	2	3.2%
10	"Have you ever participated in an end-of life program?"		
	Yes	9	14.5%
	No	53	85.5%

Table 4.1 presented the socio-demographic data of the respondents. Of the total sample (n=62), most respondents 37.1% (n=23) had less than 5 years' experience as a nurse, 29.0% (n=18) had between 6 and 10 years' experience, 11.3% (n=7) had between 21 and 30 years' experience and a minority of 4.8% (n=3) had more than 30 years of experience.

In the study, nurses who had less than 5 years of working experience as paediatric or neonatal intensive nurse accounted for 50.0% (n=31) of the respondents, 29.0% (n=18) had between 6 and 10 years' experience, 8.1% (n=5) had between 21 and 30 years of experience and only 3.2% (n=2) had more than 30 years' working experience as paediatric or neonatal intensive nurse.

Females accounted for 96.8% (n=60) and males 3.2% (n=2) of the total sample (n=62). The majority 77.4% (n=48) of the respondents indicated their level of education in the category of diploma in nursing, followed by (n=13) 21.2% respondents has a bachelor's degree and one (n=1) 1.6% respondent in the doctoral degree category.

Findings revealed most of the respondents (n=21; 33.9%) had given end-of-life care to more than 30 patients, followed by fourteen (n=14; 22.6%) and thirteen (n=13; 20.9%) respondents in the less than 5 and 5 to 10 categories, respectively and 12.9% (n=8) and 9.7% (n=6) of respondents indicated their responses in the categories from 11 to 20 and 21 to 30, respectively.

In the study, a majority 56.5% (n=35) of respondents worked primarily in the (NICU), sixteen (n=16; 25.8%) of the respondents worked in (ICU) which admitted both neonatal and paediatric patients, whilst eleven (n=11; 17.7%) worked in paediatric ICU (PICU). All the respondents were in full time employment at the institutions, whereby they are required to work 42 hours per week.

A majority 83.9% (n=52) of respondents indicated they functioned as bedside registered nurses (RNs), followed by eight (n=8; 12.9%) respondents who indicated they were clinical nurse specialists. However, for the purpose of the study clinical nurse specialists referred to registered professional nurses who hold a specialist qualification in either paediatric or intensive care nursing sciences either at diploma or bachelor's degree level (SANC, 2005). Whilst two (3.2%) indicated their responses in the category of 'other.'

Most of the respondents 85.5% (n=53) indicated they had not participated in an end-of-life care educational programme, compared to nine (n=9; 14.5%) who had.

4.2.2 Questionnaire Section 2: Obstacles Perceived to End-of-Life Care

4.2.2.1 Obstacle Size (Intensity)

Table 4.2 Averages for obstacle size reported by paediatric nurses with regard to end-of-life care

Item	Obstacle	Size (Intensity)		
		Mean	SD	N
15	"Poor design of units which do not allow for either privacy or dying patients or grieving family members".	4.16	1.38	62
30	"The nurse's workload being too heavy to adequately care for the dying child and grieving family".	4.09	1.33	62
20	"Dealing with anxious family members".	3.94	0.97	62
10	"Families not ready to acknowledge their child has an incurable disease".	3.88	1.10	62
11	"The nurse having to deal with distressed family members".	3.80	0.99	62
23	"The nurse having to deal with angry family members".	3.79	1.25	62
24	"Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information".	3.77	1.18	62
35	"Language barriers".	3.50	1.47	62
28	"Instigating or continuing painful treatments or procedures when there is no hope of recovery".	3.50	1.67	62
13	"The nurse not knowing about the child's poor prognosis before the family knows the prognosis".	3.49	1.78	62
32	"Family members not understanding what "life	3.46	1.41	62

	saving measures" really mean (i.e. multiple needle sticks cause pain and bruising; ET tube won't allow child to talk; or ribs may be broken during chest compressions)".			
39	"Parental discomfort in withholding and/or withdrawing ventilation".	3.41	1.33	62
16	"The unavailability of standards of care for dying children".	3.29	1.63	62
37	"Lack of trust from parents in the medical system that has failed to cure their child".	3.24	1.46	62
25	"Lack of nursing education regarding quality end-of-life care".	3.20	1.80	62
18	"Dealing with cultural differences that families employ in grieving for their dying child".	3.17	1.39	62
14	"One parent is ready to "let go" before the other parent is ready".	3.16	1.20	62
29	"Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by family".	3.06	1.58	62
19	"No available religious support person for the family such as social worker or religious leader".	2.98	1.78	62
34	"Fear that the grieving process for the nurse will be greater if allowing themselves to become "attached" to child and family".	2.93	1.56	62
26	"Physicians not initiating a discussion with family on forgoing life sustaining treatments".	2.85	1.48	62
31	"The nurse not knowing what to say to grieving family".	2.85	1.59	62
12	"Intra-family fighting about whether to continue or stop aggressive treatment".	2.76	1.46	62
27	"Nurses believing that life-saving measures or treatments are stopped too soon".	2.76	1.59	62
17	"The child having pain that is difficult to control".	2.67	1.74	62
9	"Physicians who are overly optimistic to the family about the child surviving".	2.59	1.64	61
22	"Insufficient education of physicians about pain management in palliative care".	2.56	1.61	62
33	"Limited access to hospice services due to physician not making referrals because the physicians are not ready to accept that the child is dying".	2.53	1.66	62
21	"Nurses getting vague orders such as "titrate to effect" for pain medication".	2.37	1.62	62
38	"The discontinuity of care of the dying child from lack of communication between interdisciplinary team members".	2.32	1,85	62
36	"Unit visiting hours are too liberal".	2.23	1.64	62

On a scale of 0 (not an obstacle) to 5 (extremely large obstacle) mean intensity scores for items in the obstacle section of the questionnaire ranged from 2.33 to 4.16 (see **table 4.2**).

In the study, the items perceived as most intense obstacles to providing end-of-life care were: (1) **item 15** *"poor design of units which do not allow for either privacy of dying patients and their family members",* (mean=4.16); (2) **item 30** *"the nurses workload being too heavy to adequately care for the dying child and grieving family"*, (mean=4.08) and (3) **item 20** *"dealing with anxious families",* (mean=3.94).

On the other top 10 obstacles items, four involved issues related to family members: (1) **item 10** *"families not ready to acknowledge their child had an incurable disease",* (mean=3.88); (2) **item 23** *"nurse having to deal with angry family members",* (mean=3.79); (3) **item 24** *"family and friends who continuously call the nurse wanting an update on the patient's condition rather than calling the designated family member"*, (mean=3.77); and (4) **item 35** *"language barriers",* (mean=3.50).

The lowest scoring obstacle items were **item 36** *"unit visiting hours that are too liberal"*, (mean=2.23). **Item 21** *"nurses getting vague orders such as titrate to effect for pain medication",* (mean=2.37) was the second lowest rated item.

4.2.2.2 Obstacle perceived frequency

Table 4.3 Averages for obstacle frequency reported by paediatric nurses with regard to end-of-life care

Item	Obstacle	Frequency		
		Mean	SD	n
15	"Poor design of units which do not allow for either privacy of dying patients or grieving	4.11	1.44	62

	family members."			
30	"The nurse's workload being too heavy to adequately care for the dying child and grieving family."	4.09	1.15	62
20	"Dealing with anxious family members."	4.00	1.07	62
11	"The nurse having to deal with distressed family members."	3.81	1.19	62
13	"The nurse not knowing about the child's poor prognosis before the family knows the prognosis."	3.81	1.34	62
32	"Family members not understanding what "life saving measures" really mean (i.e. multiple needle sticks cause pain and bruising during chest compressions)"	3.59	1.34	62
10	"Families not yet ready to acknowledge their child has an incurable disease."	3.58	1.10	62
26	"Families who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information."	3.43	1.16	62
39	"Parental discomfort in withholding and/or withdrawing ventilation."	3.39	1.25	61
16	"The unavailability of standards of care for dying children."	3.38	1.64	62
23	"The nurse having to deal with angry family members."	3.35	1.28	62
18	"Dealing with cultural differences that families employ in grieving for their dying child."	3.29	1.41	62
25	"Lack of nursing education regarding quality of end-of-life care."	3.09	1.68	62
37	"Lack of trust from parents in the medical system that has failed to cure their child."	3.03	2.31	62
35	"Language barriers."	3.00	1.34	62
14	"One parent is ready to "let go" before the other parent is ready."	2.98	1.36	62
28	"Instigating or continuing painful treatments or procedures when there is no hope of recovery."	2.91	1.46	62
31	"The nurse not knowing what to say to the grieving families."	2.88	1.55	62
29	"Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family."	2.73	1.75	62
34	"Fear that the grieving process for the nurse will be greater if allowing families themselves to become 'attached' to child and family."	2.71	1.36	62
17	"The child having pain that is difficult to control."	2.68	1.74	62
19	"No available support person for the family such as social worker or religious leader."	2.67	1.14	61
12	"Intra-family fighting about whether to continue or stop aggressive treatment."	2.58	1.33	62
27	"Nurses believing that life-sustaining measures or treatments are stopped too soon."	2.54	1.43	62

26	"Physicians not initiating a discussion with family on forgoing life sustaining treatments."	2.48	1.21	62
33	"Limited access to hospice services due to physician not making referrals because the physicians are not ready to accept that the child is dying."	2.40	1.54	62
9	"Physicians who are overly optimistic to the family about the child surviving."	2.29	1.37	62
38	"The discontinuity of care of the dying child from lack of communication between interdisciplinary team members."	2.13	1.57	62
36	"Unit visiting hours that are too liberal."	2.11	1.66	62
22	"Insufficient education of physicians about poor pain management in palliative care."	2.02	1.19	62
21	"Nurses getting vague orders to "titrate to effect" for pain medication."	1.97	1.55	62

On a scale of 0 (never occurs) to 5 (always occurs), mean frequency scores for the items in the obstacle section of the questionnaire ranged from 1.97 to 4.11 (refer **table 4.3**).

The 3 items with the highest means were: (1) **item 15** *"poor design of units which do not allow for either privacy of dying patients or grieving family members",* (mean=4.11); (2) **item 30** *"the nurse's workload being too heavy to adequately care for the dying child and grieving family"*, (mean=4.09); and (3) **item 20** *"dealing with anxious families"*, (mean=4.00).

4.2.2.3 Obstacle perceived severity score

Table 4.4 Perceived severity scores for obstacle size and frequency in end-of-life care by paediatric nurses

Item	Obstacle statement	Intensity			Frequency			Perceived obstacle magnitude
		Mean	SD	Rank	Mean	SD	Rank	
15	"Poor design of units which do not allow for either privacy of dying patients or grieving	4.16	1.38	1	4.11	1.44	1	17.09

	family members."							
30	"The nurse's workload being too heavy to adequately care for the dying child and grieving family."	4.09	1.33	2	4.09	1.15	2	16.72
20	"Dealing with anxious family members."	3.94	0.97	3	4.00	1.07	3	15.76
11	"The nurse having to deal with distressed family members."	2.00	0.99	5	3.81	1.19	5	14.44
10	"Families not yet ready to acknowledge their child has an incurable disease."	3.88	1.10	4	3.58	1.10	7	13.89
13	"The nurse not knowing about the child's poor prognosis before the family knows the prognosis."	3.49	1.78	10	3.81	1.34	6	13.29
24	"Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information."	3.77	1.18	7	3.43	1.16	8	12.93
23	"The nurse having to deal with angry family members."	3.79	1.25	6	3.35	1.28	11	12.69
32	"Family members not understanding what "life saving measures" really mean (i.e. multiple needle sticks cause pain and bruising; ET tube won't allow child to talk; or ribs may be broken during chest compressions)."	3.46	1.41	11	3.59	1.34	6	12.42
39	"Parental discomfort in withholding and/or withdrawing ventilation."	3.41	1.33	12	2.39	1.25	9	11.55
16	"The unavailability of standards of care for dying children."	3.29	1.63	13	3.38	1.64	10	11.12
35	"Language barriers."	3.50	1.47	8	3.00	1.35	16	10.50
18	"Dealing with cultural differences that families employ in grieving for the dying child."	3.17	1.39	17	3.29	1.41	12	10.42
28	"Instigating or continual painful treatments or	3.50	1.67	9	2.91	1.46	18	10.18

	procedures when there is hope of recovery."							
25	"Lack of nursing education regarding quality end-of-life care."	3.20	1.80	16	3.09	1.68	13	9.88
37	"Lack of trust from parents in the medical system that has failed to cure their child."	3.24	1.46	14	3.03	2.31	14	9.81
14	"One parent ready to "let go" before the other parent is ready."	3.15	1.20	18	2.98	1.36	17	9.41
29	"Continuing life-saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by family."	3.06	1.58	5	2.73	1.75	20	8.35
31	"The nurse not knowing what to say to grieving family."	2.85	1.59	23	2.88	1.35	19	8.20
19	"No available support person for the family such as a social worker or religious leader."	2.98	1.78	20	2.67	1.14	23	7.95
34	"Fear that the grieving process for the nurse will be greater if allow themselves to become 'attached' to child and family."	2.93	1.58	21	2.71	1.36	21	7.94
17	"The child having pain that is difficult to control."	2.67	1.76	26	2.68	1.74	22	7.15
12	"Intra-family fighting about whether to continue or stop aggressive treatment."	2.79	1.46	24	2.58	1.33	24	7.12
26	"Physicians not initiating a discussion with family on forgoing life sustaining treatments."	2.85	1.48	23	2.48	1.21	26	7.06
27	"Nurses believing that life-sustaining measures or treatments are stopped too soon."	2.76	1.59	25	2.54	1.43	25	7.01
33	"Limited access to hospice services due to physician not making referrals because the physicians are not ready to accept that the child is dying."	2.53	1.66	29	2.40	1.54	27	6.07

9	"Physicians who are overly optimistic to the family about the child surviving."	2.59	1.64	27	2.29	1.37	28	5.93
22	"Insufficient education of physicians about pain management in palliative care."	2.56	1.61	28	2.02	1.19	31	5.17
38	"The discontinuity of care of the dying child from lack of communication between interdisciplinary team members."	2.32	1.85	31	2.13	1.57	29	4.94
36	"Unit visiting hours that are too liberal."	2.28	1.64	32	2.11	1.66	30	4.70
21	"Nurses getting vague orders such as, "titrate to effect" for pain medication."	2.37	1.62	30	1.97	1.55	32	4.66

To determine which obstacle items were perceived as both the most intense and the most frequently occurring, a perceived intensity score was calculated (mean obstacle intensity multiplied by mean obstacle frequency). Scores ranged from 4.66 to 17.09 (see table 4.5). The item receiving the highest scores was poor design of units which do not allow for either privacy of dying patients or grieving family members (mean=17.09). This item not only had the highest score but also was 0.36 higher than the next closest item. None of the other items had as large a difference between perceived intensity scores.

Of the remaining top 10 obstacles with the highest perceived intensity, (2) **item 30** *"the nurses workload being too heavy to adequately care for the dying child and grieving family"* (mean=16.72); (3) **item 20** *"dealing with anxious family members"*, (mean=15.76); and (4) **item 11** *"the nurse having to deal with distressed family members",* (mean=14.44); (5) **item 10** *"families not yet ready to acknowledge their child has an incurable disease"* (mean=13.89).

Items with the lowest perceived intensity scores included the concepts that nurses received vague orders such as “titrate to effect” for pain medication (mean=4.66) and that unit visiting hours were too liberal (mean=4.70) and the discontinuity of care of the dying child from lack of communication between multidisciplinary team members (mean=4.94).

4.2.3 Questionnaire Section 3: Supportive Behaviours for End-of-Life Care

4.2.3.1 Supportive behaviours size (Intensity)

Mean intensity scores for the items in the supportive behaviours section of the questionnaires ranged from 2.79 to 4.36 On Likert a scale of 0 (not a support) to 5 (extremely intense support), (refer table 4.5).

Table 4.5 Averages for supportive behaviours size reported by paediatric nurses with regard to end-of-life care

Item	Supportive behaviours	Size (Intensity)		
		Mean	SD	n
56	“Providing a peaceful, dignified bedside scene for family members once the child has died.”	4.36	1.09,	62
57	“Allowing family members adequate time to be alone with the child after he/she dies.”	4.36	1.09	61
48	“Physicians who are compassionate but very clear about prognosis.”	4.13	1.18	62
59	“Allowing parents to hold child while life support is discontinued.”	4.08	1.45	62
58	“Having a co-worker tell you, “You did all you could for that child” or some other words of support after the child have died.”	3.98	1.28	62
45	“Having the physicians involved in the child’s care agree about the direction care should go.”	3.88	1.25	62
49	“Physician meets in person with the family after the child’s death to offer support and validate that all possible care was given.”	3.85	1.40	62
54	“Teaching families how to act around the dying child such as, “she can still hear …it’s okay to talk to her”	3.67	1.32	62
53	“Understanding and supporting individual	3.66	1.44	62

	families' religious beliefs."			
42	"Having enough time to prepare the family for the expected death of the child."	3.58	1.25	62
50	"The nurse having had their own previous experience with the death of a family member."	3.56	1.37	62
47	"Having family members accept that the child is dying."	3.51	1.29	61
41	"Having one family member be the designated contact person for all other family members regarding patient information."	3.31	1.39	62
43	"A unit designated so that the family has a place to go to grieve in private."	3.27	1.58	62
46	"Having the unit schedule that allows for continuity of care for the dying child by the same nurses."	3.14	1.64	62
55	"Having the code status of the child status clearly described on the chart."	3.03	1.54	62
44	"Having a support person outside of work setting who will listen to you after the death of a child."	2.90	1.88	62
51	"Having the family physically help care for the child."	2.79	1.78	62
52	"Bereavement debriefing sessions to discuss how to remember/honour the child."	2.79	1.75	62

The items with the highest mean scores were: (1) **item 57** *"allowing family members adequate time to be alone with the child after he/she dies"*, (mean=4.36) (2) **item 56** *"providing a peaceful, dignified bedside scene for family members once the child has died",* (mean=4.36) both **items 56** and **57** has equal mean scores; (3) **item 48** *"physicians who are compassionate, but very clear about the prognosis",* (mean=4.13); (4) **item 59** *"allowing family to hold the child while life support is discontinued"* (mean=4.08); (5) **item 38** *"having a co-worker tell you, "you did all you could for that child" or some other words of support after the child has died"* (mean 3.98); (6) **item 45** *"having the physicians involved in the child's care agree about the direction care should be given",* (mean=3.88); (7) **item 49** *"physician meet with the family after the child's death to offer support and validate that all possible care was given"* (mean=3.85).

Of the remaining top 11 items, four dealt with supportive behaviours that occurred before a patient's death: (1) **item 54** *"teaching families how to act around the dying child such as,*

"she can still hear …it's okay to talk to her" (mean=3.67); (2) **item 53** *"understanding/supportive individual family's religious beliefs",* (mean=3.66); (3) **item 42** *"having adequate time to prepare the family for the unexpected death of the child",* (mean 3.58); and (4) **item 50** *"the nurse having had their own previous experience with the death of a family member",* (mean=3.56).

Supportive behaviours that occurred least frequently were: (1) **item 52** *"bereavement debriefing sessions to discuss how to remember the child"*, (mean=2.79); (2) **item 51** *"having family physically help care for the child"*, (mean=2.79); and (3) **item 44** *"having a support person outside of work setting who will listen to after the death of a child"*, (mean 2.90).

4.2.3.2 Supportive behaviours frequency

On a Likert scale of 0 (never occurs) to 5 (always occurs) mean scores for frequency of items in the supportive behaviours section of the questionnaire ranged from 3.93 to 1.52 (see to **table 4.6**).

Table 4.6 Averages for supportive behaviours frequency reported by paediatric nurses with regard to end-of-life care

Item	Supportive behaviours	Frequency of occurrence		
		Mean	SD	n
59	"Allowing family to hold the child while life support is discontinued."	3.93	1.29	62
57	"Allowing family members adequate time to be alone with the child after he/she dies."	3.82	1.33	61
56	"Providing a peaceful, dignified bedside scene for family members once the child has died."	3.82	1.33	62
48	"Physicians who are compassionate, but very clear about prognosis."	3.63	1.33	62
58	"Having a co-worker tell you, "You did all you could for that child" or some other words of	3.40	1.47	62

	support after the child has died."			
45	"Having the physicians involved in the child's care agree about the direction care should go."	3.40	1.45	62
46	"Having a unit schedule that allows for continuity of care for the dying child by the same nurses."	3.40	1.45	62
54	"Teaching families how to act around the dying child such as, "she can still hear …it's okay to talk to her"."	3.24	1.41	62
53	"Understanding/supporting the family's religious beliefs."	3.18	1.28	62
50	"The nurse having had their own previous experience with the death of a family member."	3.15	1.34	62
49	"Physician meets in person with the family after the child's death to offer support and validate that all possible care was given."	3.14	1.77	62
42	"Having enough time to prepare the family for the expected death of the child."	3.11	1.23	62
41	"Having one family member be the designated contact person for all other family members regarding patient information."	2.94	1.29	62
47	"Having family members accept that the child is dying."	2.79	1.19	61
55	"Having the code status of the child clearly described on the chart."	2.67	1.57	62
43	"A unit designated so that the family have a place to grieve in private."	2.47	1.83	62
44	"Having a support person outside of work setting who will listen to you after the death of a child."	2.31	1.71	62
51	"Having the family physically care for the child."	2.13	1.59	62
52	"Bereavement debriefing sessions to discuss how to remember/honour the child."	1.52	1.64	62

Item 59 *"allowing patients to hold the chid while life support is discontinued",* (mean=3.93) and **item 57** *"allowing family members adequate time to be alone with the child after he/she dies",* (mean=3.82) were the 2 most frequently occurring supportive behaviours. Other frequently occurring behaviours were: (1) **item 56** *"providing a peaceful, dignified bedside scene for the family members once the child has died",* (mean=3.82); (2) **item 48** *"physicians who are compassionate, but very clear about the prognosis",* (mean=3.63); (3) **item 58** *"having a co-worker tell you, "you did all you could for that child" or some other words of support after the child has died",* (mean 3.40); (4) **item 45** *"having the physicians involved in the child's care agree about the direction care should go",* (mean=3.40); (5)

item 46 *"Having a unit schedule that allows for continuity of care for the dying child by the same nurses."*, (mean=3.40).

Supportive behaviours that occurred least frequently were: (1) **item 52** *"bereavement debriefing sessions to discuss how to remember the child"*, (mean=1.52); (2) **item 51** *"having family physically help care for the child"* (mean=2.13); and (3) **item 44** *"having a support person outside of work setting who will listen to you after the death of a child"*, (mean=2.31).

4.2.3.3 Supportive behaviours intensity score

A perceived intensity score was calculated (mean size multiplied by mean frequency) in order to establish which items were perceived as both the most supportive and most frequent. All items scores ranged from 4.24 to 16.65 (see **table 4.7**).

Table 4.7 Perceived intensity scores for supportive behaviours size and frequency in end-of-life care by paediatric nurses

Item	Supportive behaviour	Intensity			Frequency			Perceived supportive behaviour magnitude
		Mean	SD	Rank	Mean	SD	Rank	
56	"Providing a peaceful, dignified bedside scene for family members once the child has died."	4.36	1.09	1	3.82	1.33	3	16.65
57	"Allowing family members adequate time to be alone with the child after he/she cries."	4.36	1.09	1	3.82	1.33	2	16.65
59	"Allowing parents to hold the child while life support is discontinued."	4.08	1.45	4	3.93	1.29	1	16.03
48	"Physicians who are compassionate but very clear about prognosis."	4.13	1.18	3	3.63	1.33	4	14.99

58	“Having a co-worker tell you, “You did all you could for that child” or some other words of support after the child have died.”	3.98	1.28	5	3.40	1.47	5	13.53
45	“Having the physicians involved in the child’s care agree about the direction care should go.”	3.88	1.25	6	3.40	1.45	6	13.19
49	“Physician meets in person with the family after the child’s death to offer support and validate that all possible care was given.”	3.85	1.40	7	3.14	1.77	10	12.08
54	“Teaching families how to act around the dying child such as, “she can still hear …it’s okay to talk to her”.”	3.67	1.32	8	3.24	1.41	7	11.89
53	“Understanding/supporting individual family’s religious beliefs.”	3.66	1.44	9	3.18	1.28	8	11.63
50	“The nurse having had their own previous experience with the death of a family member.”	3.56	1.37	11	3.15	1.34	9	11.21
42	“Having enough time to prepare the family for the expected death of the child.”	3.58	1.25	10	3.11	1.23	11	11.13
47	“Having family members accept that the child is dying.”	3.51	1.29	12	2.79	1.19	13	9.79
41	“Having one family member be the designated contact person for all other family members regarding patient information.”	3.31	1.39	13	2.94	1.29	12	9.73
46	“Having a unit schedule that allows for continuity of care for the dying child by the same nurses.”	3.14	1.64	15	2.66	1.67	15	8.35
55	“Having the code status of the child clearly described on the chart.”	3.03	1.56	16	2.67	1.57	14	8.09
43	“A unit designated so that the family has a place to go to grieve in private.”	3.58	1.25	10	3.11	1.23	11	8.07
44	“Having a support person outside of work setting who will listen to you after the death of a child.”	2.90	1.88	19	2.31	1.71	17	6.69
51	“Having the family	3.51	1.29	12	2.79	1.19	13	5.94

	physically care for the child."							
52	"Bereavement debriefing sessions to discuss how to remember/honour the child."	2.79	1.75	19	1.52	1.64	19	4.24

The three items perceived as most supportive and most frequently occurring were (1) **item 57** *"allowing family adequate time to be alone with the child after he/she dies"*, (mean=16.65); (2) **item 56** *"providing a peaceful, dignified bedside scene for family members once the child has died",* (mean=16.65). Item 57 and 56 has equal mean scores. (3) **Item 59** *"allowing parents to hold the child while life support was discontinued",* (mean=16.03).

Four other highly scoring items were related to interdisciplinary teamwork: (1) **item 48** *"physicians who are compassionate but very clear about the prognosis",* (mean 14.99); (2) **item 58** *"having a co-worker tell you, "you did all you could for that child" or some other words of support after the child has died",* (mean=13.53); (3) **item 45** *"having the physicians involved in the child's care agree about the direction care should go",* (mean=13.19) and (4) **item 49** *"physician meets in person with family after the child's death to offer support and validate that all possible care was given",* (mean=12.08).

Item 54 "*Teaching families how to act around the dying child such as, she can hear you …it's okay to talk to her",* (mean=11.89); **item 53** *"understanding/supporting individual's family's religious beliefs",* (mean=11.21); **item 50** *"the nurse having had their own experience with the death of a family member"*, (mean=11.21) and **item 42** *"having enough time to prepare the family for expected death of child",* (mean=11.13) were also among the top 11 most intense and frequent supportive behaviours.

Items with the lowest perceived supportive behaviours scores, included (1) **item 52** *"bereavement debriefing sessions to discuss how to remember/honour the child"*,

(mean=4.24); (2) **item 51 *"having the family physically help care for the child",*** (mean=5.94); (3) **item 44** "having a support person outside of work setting who will listen to you after the death of a child", (mean=6.69).

4.2.4 Responses to Open-Ended Questions

The (PEDS) questionnaire included three open ended questions: **item 40** related to obstacles and **items 60** and **61** related to supportive behaviours.

Question 40 asked respondents to describe any missing obstacles in the provision of end-of-life care which they thought were not included. Ten out of the 62 respondents responded to the question. The following obstacles emerged from the data taken: unprofessional behaviour of staff members, not enough time to focus on end-of-life care, parents financial constrains for burial, unrealistic expectations of doctors from nurses, conflict between junior and senior staff and calling parents at the last minute. These 6 items were perceived as additional obstacles, which were not included in the questionnaire, by the ten respondents. However, only 6 responses were considered as missing obstacles in the provision of end-of-life care that were not included in the questionnaire.

Questions 60 asked respondents **to describe any missing helpful behaviour in providing end-of-life care which they thought were** not included in the questionnaire. Additional helpful behaviours which emerged from the data were: encouraging family members to name the deceased new born baby and referring grieving family members to a support group. From the 62 respondents 12 responded to the item, however only 2 out of 12 responses were considered helpful behaviours.

Question 61 asked nurses if they had the ability to change just one aspect of the end-of-life care given to dying paediatric patients, what it would be. Fifteen out of 62 respondents made the following statements:

- To give everybody in the family a chance to mourn their loved one, not only close family.
- Privacy for parents and the dying patient and to give them more time to perform their religious, cultural rituals for closure.
- Nurses should be given formal training to do it.
- Ensure they have privacy to mourn for as long as they want to.
- Be more empathetic to parents and to use simpler medical terms so that they can understand.
- To follow up their grieving process. Example, refer to social worker.
- If multi-disciplinary team can be informed on end-of-life care, especially how to talk to the family.
- I would like to keep in touch with the family even after death and at least know if they are coping and have adjusted to life again.
- To have clear criteria for when to continue treatment and when should it be stopped.
- Full support of the parents and showing more remorse.
- Not prolonging suffering and emotional trauma to parents of the dying child not to give false hope to parents.
- I would restructure the infrastructure to allow more room and more time for the family to be with the baby at the end-of-life care and to be involved to fully understand.
- Inform and counsel parents and do not give them false hope.
- To inform the parents on time about the condition of the baby and comfort them or even refer them to counselling or make contact after the child has passed on.

- To comfort parents and do counselling until they understand the condition of the baby.
- Take staff for appropriate courses and have debriefing time.

Fifteen responses were grouped into the following categories;

- More time to mourn (3 responded).
- Improved communication and bereavement follow-up session between parents and nurses (9 responded out of 15 respondents).
- Referral for counselling or social worker (4 responded).
- Provide sufficient privacy and poor design of units (5 responded).
- End-of-life care guidelines and educational programmes (4 responded).

4.3 DISCUSSION OF MAIN FINDINGS

The main purpose of this study was to measure paediatric nurses' perceptions of the severity and frequency of listed obstacle items and the intensity and frequency of helpful behaviours to providing end-of-life care to dying patients and their families.

4.3.1 Demographic Data

The first section of the questionnaire included eight items through which the respondent's demographic profile was described. The results show that the most respondents 37.1% (n=23) had less than five years of experience as a nurse, 29.0% (n=18) had between six and 10 years' experience, whilst 11.3% (n=7) had between 21 and 30 years of experience. A minority of 4.8% (n=3) had more than 30 years of experience. Nurse's years of experience in nursing care is an essential element which contributes to quality nursing. (Dunn, Otten, and Stephens, 2005; Ablett and Jones, 2007) lay emphasis on the

positive impact of years of experience in end-of-life care on nurses approaches towards caring for patients who are dying. A larger number of nurses with more clinical experience are needed in the critical care setting, the reason being more experienced nurses make important contributions because they approach situations which require critical decision making with cautiousness.

The results revealed that 50.0% (n=31) had less than five years of working experience as a paediatric or neonatal intensive nurse, 29.0% (n=18) had between six and 10 years' experience, 8.1% (n=5) had between 21 and 30 years of experience, with a minority of 3.2% (n=2) having more than 30 years working experience. McMillen (2008) also found that senior nurses had more skills in dealing with end-of-life care decisions and were more recognised by the multidisciplinary healthcare team.

The results shows that 96.8% (n=60) of the respondents were female and 3.2% (n=2) were male. These results are consistent and reflect the trends of most studies that have been conducted on nurses globally, where female nurses dominated the sample population, (Rooda, Clements and Jordon 1999; Beckstrand et al. 2006; Gundo, 2010;Mc Callum and Mc Conigley, 2013) found that gender difference has no influence on attitudes and therefore perceptions towards death.

In South Africa nurses who graduate from colleges exit with a diploma and nurses who graduate from universities exit with a Bachelor's degree; a majority of 77.4% (n=48) respondents' highest level of education is a diploma in nursing and 21.2% (n=16) hold a Bachelor's degree in nursing. In addition, there is a lack of literature in South Africa on the content of curricula of diploma and Bachelor degree nursing science, particularly research studies focusing on educating students on end-of-life care. However, Ferrell, Virani and Grant (2005) concurs that a basic nursing qualification does not adequately prepare nurses to deliver optimal, evidenced based end-of-life care.

Based on all the respondents, 22.6% (n=14) stated they had given immediate end-of-life care to less than five patients and 33.9% (n=21) had given more than 30 patients immediate end-of-life care. Engler et al. (2009), Brockopp and King Hamilton (2007) and Brent et al. (1991) found that increased exposure to death and death related experiences were associated with a more positive approach toward the care of dying patients and understanding of end-of-life care amongst nurses. Considering the respondent's experience with palliative care, their perceptions on obstacles and supportive behaviour on end-of-life care are of value to meet the study goals.

Direct bedside nurse accounted for 83.9% (n=52) and clinical nurse specialist for 12.9% (n=8). In the settings where the research study was conducted it was observed that both the clinical nurse specialist and the bedside nurse were involved in direct patient care. Although the clinical nurse specialist's primary roles are to function as shift leader, as well as a consultant for other staff members but do often participate in direct bedside care. Direct bedside nurses are fundamental to end-of-life care and are often the most deeply involved and consistent care providers to the dying patient and family members, (Wholihan and Anderson, 2013). However, for the purpose of this study direct bedside nurses are registered professional who does not hold a specialist qualification in either paediatric or intensive care nursing sciences. Thus, their primary role is to function as a direct bedside nurse in PICU and NICU.

A minority of 14.5% (n=9) had participated in an end-of-life care educational programme, whereas 85.5% (n=53) had never participated. This item was included as participation in end-of-life care educational programmes, for the paediatric and neonatal intensives nurse, is vital to ensure that quality end-of-life care is provided to the dying child and family. Mallory (2003) concurs that nurses who have participated in palliative care educational programs are more likely to have an optimistic attitude towards caring for patients who are

dying. Chiplaskey (2011) stated that the prospective for a "good death" is by being cared for by skilled nurses who are recognised as being educationally equipped to execute adequate end-of-life nursing care. Current undergraduate nursing curriculum is not sufficient to arm nurses with the necessary skills and knowledge to provide optimal, evidenced based end-of-life nursing care for the dying patient and family.

4.3.2 Obstacles Perceived to End-of-Life Care

The second part of the questionnaire as presented in **Table 4.2** elicited respondent's perceptions on obstacles to end-of-life-care. Obstacles size with the highest mean scores reported by paediatric nurses with regard to end-of-life care were;(1) **item 15,** "*poor design of units which do not allow for either privacy of dying patients and their family members"* (Mean=4.16). **Item 15** was also ranked (1) in **Table 4.3** as the most frequently occurring obstacle with a (mean=4.11). In **Table 4.4** paediatric nurses perceived **item 15** as a huge obstacle to providing optimal end-of-life care ranked (1) as well according to perceived obstacle magnitude (POM=17.09) score. Fridh, Forsberg and Bergbom (2007) highlighted that the patient, staff and family members are influenced by the hospital environment and the ward lay out either has a negative or a positive effect on the care. Beckstrand et al. (2010) and Moawad (2013) found this obstacle intensity as a lower level obstacle. In a similar study conducted by Heaston, Beckstrand, Bond and Palm (2006) on emergency nurses perceptions on end-of-life care, reported that the same item, "*Poor design of emergency departments not allowing for privacy of the dying patient or the grieving family members*," ranked as the third highest obstacle to providing EOL care in emergency departments. Furthermore, in a sequel study which included the frequency of the items, Beckstrand, Smith, Heaston, and Bond (2008) had the same obstacle of poor unit design ranked second out of all 28 obstacles. Additionally, a study exploring the experiences of family members who had lost a loved one in an ICU reported there was a need for improved physical space and lack of privacy (Abbott, et al. 2001). It was

discovered by Kjerulf et al. (2005) that most family members appreciate having a private room in which to grieve.

Item 30, *"the nurses workload being too heavy to adequately care for the dying child and grieving family",* (mean=4.08) ranked as the second highest from 31 items in **Table 4.2**. **Item 30** was also ranked (2) in **Table 4.3** as one of the most frequently occurring obstacle with a (mean=4.09). In **Table 4.4** nurses perceived **item 30** as both one of the most intense and one of the most frequently occurring obstacles, with a POM score of 16.72 ranked as the second highest. Beckstrand et al. (2010) established that this obstacle intensity was a lower level obstacle in their study. However, in a similar study on emergency nurses conducted by Heaston et al. (2006) and Beckstrand et al. (2008) this item was ranked (1) with the greatest magnitude in both studies. In South Africa, "nurse's workload being too heavy to adequately care for the dying child and grieving family" serves as a major obstacle due to staff shortages, high bed demand and occupancy in PICU. Intensive nursing care of a dying child and family members is multidimensional and includes: close observation, management and documentation of the physiological, psychological and social aspects, (Bloomer and O' Connor, 2012). Although paediatric/neonatal intensives nurses face these major challengers when providing the best care possible at the end-of-life, WHO (1998) states that even when resources are limited effective end-of-life care for the dying child and family members can be successfully implemented.

Furthermore, paediatric nurses ranked **item 20,** "*dealing with anxious families",* (mean=3.94) as (3) as one the obstacles size with the highest mean scores in **Table 4.2**. **Item 20** was also ranked (3) in **Table 4.3** as one of the most frequently occurring obstacle with a (mean=4.00) score. In **Table 4.4** paediatric nurses perceived **item 20** as a major obstacle to providing optimal end-of-life care ranked (3) according to perceived obstacle magnitude (POM=15.76) score. Moawad (2013), who conducted her study in Egypt, had

different findings to this study. Dealing with anxious family members was ranked 8 out of 26 obstacles, mean score 3.83 and (SD 1.11). Beckstrand et al. (2010) found this obstacle intensity as a middle level obstacle ranked at 16, mean score 3.11 and POM score 11.10. The frequency of this items results were similar to this study where it was ranked 4, mean score 3.57 and POM score 11.10. It can therefore be deducted that family members will experience anxiety when faced with the death of a child is a frequently occurring obstacle in most PICU/NICU. It can therefore be assumed that in Beckstrand et al.'s (2010) and Moawad's (2013) studies, nurses were well equipped when dealing with anxious family members as they did not perceive this obstacle as a high level.

These results were supported by the findings of Hickey and Quin (2012) and Longden (2011) on parental perceptions on end-of-life care. Parents described a child's death as a devastating event which manifests in severe anxiety, inflated by the fact that it is sudden. It can therefore be ascertained that nurses perceive family as being anxious and parents admit this emotion. Family members will always have high levels of anxiety; it is a natural emotion experienced by parents when confronted with the death of a child and is a constant factor which will always occur. In a South African study by Vivian (2012) it was found that nurses were challenged by the role of interacting with and providing psychological support to families of children in the PICU because of the high stress levels of the family who found themselves with insufficient coping strategies. The high impact of this obstacle can be addressed if nurses are equipped with the skill to deal with anxious family members. The type of care the dying child receives can have a profound influence on the parent's capability to deal with the death of a child. Empowering family members to participate in care plans to provide the child with a dignified death is a crucially important service that PICU nurses can render (Longden and Mayer, 2007). Although the dying child is the primary recipient of nursing care, literature suggests that family be viewed as the core of care, with family input serving as a major determining factor of interventions provided. This philosophy is known as family centred care, which necessitates stretching

beyond clinical practices that have become the custom of the institution and personnel, (Hockenberry and Wilson, 2007).

Item 36 *"unit visiting hours that are too liberal"*, ranked 31 with an intensity mean score of 2.23, frequency mean score 2.11 and POM score 4.70 was perceived as a low level obstacle. A possible explanation would be that the visiting protocol where the research study was conducted allows parents to visit their child anytime during the day shift (07H00 to 19H00). Other low level obstacles which do not occur frequently were: **item 44** "The discontinuity of care of the dying child from lack of communication between interdisciplinary team members", ranked 29 with an intensity mean score 2.32, frequency mean score 2.13 and POM 4.94, which was a higher level obstacle in Beckstrand et al. (2010) study. **Item 21** "Nurses getting vague orders such as, titrate to effect for pain medication", intensity mean score 2.37, frequency mean score 1.97. **Item 26** was also a lower level obstacle in Beckstrand et al. (2010) study. Additionally it was noted that most of the items related to physicians were perceived as small obstacles to end-of-life care by the nurses.

4.3.3 Supportive Behaviours for End-of-Life Care

The third part of the questionnaire as presented in **Table 4.5** elicited respondent's perceptions of supportive behaviours in end-of-life care. Supportive behaviours size with the highest mean scores reported by paediatric nurses with regard to end-of-life care were**; item 57 "***allowing family members adequate time to be alone with the child after he/she dies",* (mean=4.36) in **Table 4.5** was ranked 1. **Item 57** was also amongst the top 3 rated items in **Table 4.6** as the most frequently occurring supportive behaviour with a (mean=3.82). In **Table 4.7** paediatric nurses perceived **item 57** as a huge help to providing optimal end-of-life care ranked (1) according to perceived supportive behaviours magnitude (PSBM=16.65) score.

Furthermore, **item 56** *"providing a peaceful, dignified bedside scene for family members once the child has died"*, has a (mean=4.36) score, ranked 1 in Table 4.5 was perceived by nurses in this study as a huge supportive behaviour. In **Table 4.6 item 56** was also ranked as a helpful behaviour which occurred frequently with a (mean=3.82). Study respondents ranked item 56 as 1 with a (PSBM=16.65) score. There is a high level of agreement amongst respondents that **item 57, 56** and **59** are very helpful behaviours which occur frequently in the settings where the study was conducted

The research results are similar to the study outcomes of Heaston et al. (2006); Beckstrand et al. (2008); Beckstrand et al. (2010) and Moawad (2013). The highly ranked supportive and most frequently occurring behaviours are all attributes of a good death (Steinhauser, Clipp, McNeilly, Christakis, McIntyre and Tulsky, 2000). In a qualitative study conducted by Steinhauser et al. (2000) on patients, family members and healthcare providers, all parties agreed that family presence during the transition period of the patient into death is an essential element in optimal end-of-life care. Heaston et al. (2006) concurs that the above mentioned helpful behaviours were perceived as very helpful behaviours for the reason that they are controlled by nurses and therefore has been highly ranked.

Furthermore, physician related supportive behaviours see **Table 4.7** with mean scores between 4.03 and 3.85. were also perceived as very helpful behaviours by the nurses in the provision of effective end-of-life care were: **item 48** *"Physicians who are compassionate, but very clear about prognosis"*, ranked 3 mean score, 4.03**, item 45** *"Having the physicians involved in the child's care agree about the direction care should go"*, ranked 6 mean score 3.88, **item 49** *"Physician meets in person with the family after the child's death to offer support and validate that all possible care was given"* ranked 7 mean score 3.85. **Item 48** and **45** in a study conducted by Beckstrand et al. (2010) were

also perceived as major supportive behaviours in providing end-of-life care. It can therefore be extrapolated from the findings that nurses in this study perceives the above mentioned behaviours displayed by physicians as very helpful behaviours that occur frequently in the provision of end-of-life care.

4.4 SUMMARY

This chapter sought to expound on the results gathered from the PEDS questionnaire and to determine paediatric nurses perceptions on obstacles and supportive behaviours in end-of-life care in PICU. Descriptive statistics were used to describe findings from the questionnaire. Main findings that surfaced from the study were; related to obstacles and supportive behaviours in end-of-life care in PICU as perceived by nurses. Major obstacles identified and described were; “poor design of units which do not allow for either privacy of dying patients and their family members”, “the nurses workload being too heavy to adequately care for the dying child and grieving family” and “dealing with anxious families”. Major supportive behaviours identified and described were; “allowing family members adequate time to be alone with the child after he/she dies, “providing a peaceful, dignified bedside scene for family members once the child has died” and physician related supportive behaviours.

The following final chapter will present a summary of the study, main findings, limitations, recommendations and conclusions.

CHAPTER FIVE

SUMMARY, MAIN FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.0 INTRODUCTION

The concluding chapter presents a summary of the study; main finding which emerged as well as the limitations. The main findings will be described in relation to the study objectives. Finally the recommendations for clinical nursing practice, nursing education and areas for further research are also presented as well as the conclusions.

5.1 SUMMARY OF THE STUDY

The purpose of the study was to identify and describe nurses' perceptions of behaviours which are obstacles to or support the provision of effective end-of-life care in neonatal and paediatric intensive care settings at two public urban academic hospitals. Paediatric intensive nurses are skilled health care professionals who care for dying children and their parents. Delivering end-of-life care in a highly technological unit can be challenging for the paediatric nurse. Identification and description of paediatric nurses perceptions on end-of-life care will contribute to literature.

5.2 SUMMARY OF MAIN FINDINGS

Descriptive statistics were used to achieve the study objectives. The descriptive tests (frequency, mean and standard deviation) were used mean scores and POM scores were used to determine the impact of an obstacle in providing end-of-life care. The impact of

supportive behaviours in end-of-life care was determined by mean scores and PSBM scores.

5.2.1 Socio-demographic Findings

In this study, direct bedside nurse accounted for 83.9% (n=52) and clinical nurse specialist for 12.9% (n=8). Direct bedside nurses in this study are registered professional nurses who do not hold a specialist qualification in either paediatric or intensive care nursing sciences. It can be stipulated from the data obtained that there is an increased need for specialist nurses in paediatric and neonatal intensive care settings. Ferrell, Virani and Grant (2005) concur that a basic nursing qualification does not adequately prepare nurses to provide optimum, evidenced based end-of-life care that meet the needs of the dying patient and family members.

A majority 85.5% (n=53) of the nurses had never participated in an end-of-life care educational programme and a minority of 14.5% (n=9) had participated. Participation in end-of-life care educational programmes, for the paediatric and neonatal intensives nurse, is vital to make certain that quality end-of-life care is provided to the dying child and family. Providing optimal end-of-life care to the dying child and family members requires the nurse be equipped with knowledge. Rapid changing healthcare needs, together with technological advancements, compel the intensive care nurse to have sound skills and knowledge.

Most respondents 37.1% (n=23) had less than five years of experience as a nurse, 29.0% (n=18) had between six and 10 years' experience. To translate results, a majority 66.1% (n=41) from a total sample of 62 nurses had less than 10 years' working experience. An essential element that contributes to nursing quality is the nurse's years of experience in nursing (Dunn, Otten and Stephens, 2005). Increased years of experience of a nurse in

end-of-life care is associated with positive attitude towards caring for dying patients (Ablett and Jones, 2007). A study conducted in the USA, where critical care nurses were asked to identify and quantify obstacles to end-of-life care in a critical care setting, established that highly experienced, older nurses perceived distressed family members as a one of the most frequently occurring obstacles to nursing a dying patient. Kirchhoff and Beckstrand (2000), concur that more experienced nurses may have found and mastered ways to deal with common obstacles. To make sense of the study's results and in comparison, the majority in this study sample had less than five years working experience in nursing and therefore most perceived obstacles related to family anxiety as high level or very large obstacles.

5.2.2 Nurses' Perceptions of Obstacles to End-of-Life Care

The most frequently occurring obstacles for paediatric end-of-life care in a critical care setting are, *"poor design of units which do not allow for either privacy of dying patients or grieving family members",* was perceived as a high level obstacle, ranked number 1 with a mean intensity score 4.16 and POM score 17.09 and was also ranked as the most frequently occurring obstacle in providing end-of-life care Beckstrand, et al. (2010) and Moawad (2013) found this obstacle intensity as a lower level obstacle. In a similar study conducted by Heaston et al. (2006) on emergency nurses perceptions on end-of-life care, reported that the same item, ranked as the third highest obstacle. One of the many challenges for the paediatric intensives nurse, in the delivery of effective end-of-life care, is the provision of privacy for counselling, saying last goodbyes and cultural rituals which are often performed, for the reason that most of the ICU in South Africa are managed on an open plan system (Schmollgruber, 2007).

Furthermore, perceived by paediatric intensives nurses as one the most frequently occurring major obstacles is *"the nurse's workload being too heavy to adequately care for*

the dying child and grieving family", ranked 2 with an intensity mean score 4.09 and POM score 16.72. Beckstrand et al. (2010) found this obstacle's intensity as a lower level obstacle in their study. However, in a similar study on emergency nurses conducted by Heaston et al. (2006) and Beckstrand et al. (2008) this item was ranked (1) with the greatest magnitude in both studies In South Africa, nurse's workload being too heavy to adequately care for the dying child and grieving family serves as a large obstacle due to staff shortages, high bed demand and occupancy in PICU (Vivian, 2012). Intensive nursing care of a dying child and family members is multidimensional and includes close observation, management and documentation of the physiological, psychological and social aspects (Bloomer and O' Connor, 2012). Although paediatric and neonatal intensive nurses face these major challengers in providing the best care possible at the end-of-life, WHO (1998) states that effective end-of-life care for the dying child and family members can be successfully implemented even when resources are limited.

Paediatric nursing is a very special calling, because it provides the opportunity to play a key role in a child's life when that child and family members need you most. Paediatric intensive care emphasises curative and aggressive lifesaving treatment (Moawad, 2013). Conversely, when the critically ill child's condition no longer responds to aggressive treatment and the continuation of this treatment will not benefit the patient, the transition from curative care, to end-of-life care is essential. However, as healthcare practitioners who have devoted their careers to saving lives and reducing suffering of children, being faced with a child who is in the process of dying, or has died, can be particularly distressing.

Additionally, other highly ranked most intense and frequently occurring behaviours which were perceived by nurses as obstacles to providing effective end-of-life care were mostly related to family anxieties. The third rated behaviour were; *"dealing with anxious family members"*, intensity mean score 3.94 and POM score 15.76. Followed by "the nurse

having to deal with distressed family member's", intensity mean score 3.80 and POM score 14.48.These are amongst the five highest ranked obstacles.

Moawad (2013) and Beckstrand et al. (2010) identified that these behaviours displayed by family to be amongst the most frequently occurring. The intensity with which these behaviours occurred in their studies was not as high as this study results. It can therefore be deducted that family members will experience anxiety when faced with the death of a child it's a frequently occurring obstacle in most PICU and NICU. These result supports Longden (2011) and Hickey and Quin (2012) study findings on parental perceptions on end-of-life care. Parents described that a child's death is a devastating event which manifest in sever anxiety and is inflated by the fact that it is sudden. It is therefore discovered that, nurses perceive family as being anxious and parents are admitting to this emotion. Family members will always have high levels of anxiety it is a natural emotion experienced by parents when faced with the death of a child it is a constant factor which will always occur. The high impact of this obstacle can be addressed if nurses are equipped with the skill to deal with anxious family members. Not to stray away, but the type of care that the dying child receives can have a profound influence on the parent's ability to cope with the death of a child.

Empowering family members to participate in care plans in providing the child with a dignified death is a crucially important service that paediatric intensive care nurses can render (Longden and Mayer, 2007). Although the dying child is the primary recipient of nursing care, literature suggest that family be viewed as the centre of care, with family input serving as a major determining factor of interventions provided. This philosophy is known as family-centred care which necessitates stretching beyond clinical practices that have become custom to the institution and personnel (Hockenberry and Wilson, 2007).

Unit visiting hours that are too liberal were perceived by nurses as a low level obstacle that does not occur frequently. Is most possibly not perceived as an intense obstacle because visiting protocol where the research study was conducted, allows parents to visit their child anytime during the day shift (07H00 to 19H00). Other obstacles that are low level obstacle which do not occur frequently are; the discontinuity of care of the dying child from lack of communication between interdisciplinary team members. This result was a higher level obstacle in Beckstrand et al. carried out in 2010. Nurses' getting vague orders such as, "titrate to effect" for pain medication, and this item was also a lower level obstacle in Beckstrand (2010) study.

5.2.3 Nurses Perceptions of Supportive Behaviours in End-of-Life Care

The most helpful and frequently occurring behaviours which were perceived by nurses to providing effective end-of-life care were *"allowing family members adequate time to be alone with the child after he/she dies",* mean score 4.36, PSBM score 16.65 and "*providing a peaceful, dignified bedside scene for family members once the child has died"* mean score 4.36, PSBM score 16.65 both ranked 1. Followed by *"allowing parents to hold the child while life support is discontinued"*, mean score 4.08, PSBM score 16.03. These findings are similar to studies conducted in the USA and Egypt (Heaston et al., 2006; Beckstrand et al., 2008; Beckstrand et al., 2010; Moawad, 2013). The highly ranked supportive and most frequently occurring behaviours were all attributes of a good death (Steinhauser et al., 2000). In a qualitative study conducted by Steinhauser et al. (2000) on patients, family members and health care providers, all parties agreed that family presence during the transition period of the patient into death is an essential element in optimal end-of-life care. Heaston et al. (2006) concurs that the above mentioned helpful behaviours were perceived as very helpful behaviours for the reason that they are controlled by nurses and therefore has been highly ranked.

Additionally, the following items related to physicians with mean scores between 4.03 and 3.85. were also perceived as very helpful behaviours by the nurses in the provision of effective end-of-life care were*: "physicians who are compassionate, but very clear about prognosis" mean score 4.13, PSBM score 14.99, "Having the physicians involved in the child's care agree about the direction care should go",* mean score 3.88, PSBM score 13.19*, and "Physician meets in person with the family after the child's death to offer support and validate that all possible care was given",* mean score 3.85, PSBM score 12.08*.* Beckstrand et al. (2010) had similar study results where these items were also perceived as major supportive behaviours in providing end-of-life care. Nurses in the study perceived the above mentioned behaviours displayed by physicians as very helpful behaviours that occur frequently in the provision of end-of-life care. It can therefore be extrapolated from the study results that a joint effort from both nurses and physicians is very helpful in meeting the needs of the dying child family members.

5.3 LIMITATIONS OF THE STUDY

The following limitations were faced:

- The use of convenience sampling and a relatively small sample. The sample size requirements were met but due to the small sample size, study findings cannot be generalised.
- Study findings were generalised to PICU. No distinctions were made between NICU and PICU.
- The use of a structured questionnaire to collect data on a sensitive topic such as end-of-life care was a limitation, as one-on-one interviews would generate a more in-depth understanding of obstacles and supportive behaviours in end-of-life care from a South African context.

- The description and identification of paediatric intensives nurses working in public hospitals perceptions on end-of-life care and not including nurse's perceptions from nurses working in private hospitals. Nurses working in private hospitals have different challenges compared to nurses working in state hospitals. From the researcher's experience, there are more instances of futile care in private hospitals when the prognosis for the unstable child is poor. Nurses working in private hospitals are less likely to participate in or initiate end-of-life discussions. Most private hospitals have an ethics committee to facilitate in decision making of complicated do not resuscitate cases and there are certain procedures which have to be carried out before treatment is withdrawn.

5.4 RECOMMENDATIONS OF THE STUDY

The principal purpose of paediatric intensive care is to help patients survive acute life threatening conditions. When the goal to preserve life fails then the switch from acute care to end-of-life care has to take place. This switch is one of the most difficult and important aspects of paediatric intensive care. Death even when predicted, the time surrounding the death of a child can be stressful for both the nurse and families. Paediatric nurses in this study has highlighted major obstacles to end-of-life care such as lack of privacy due to poor unit design, overload of work and anxious family members. Foremost supportive behaviours to providing end-of-life care perceived by the study respondents were; *"allowing family members adequate time to be alone with the child after he/she dies"* and "*providing a peaceful, dignified bedside scene for family members once the child has died"*.Followed by *"allowing parents to hold the child while life support is discontinued.*

5.4.1 Recommendations for Clinical Practise

Nurses in this study have highlighted a need for more private space on behalf of grieving family members. Though, remodelling PICU layouts for better privacy on behalf of the dying child and family members may be a costly and long term change. It is recommended that nurses input serves as a major factor when designing these units.

Experienced paediatric/ neonatal intensive care nurses should support and mentor junior and newly qualified nurses to enable them to care for the dying patient and highly emotional anxious family members.

End-of-life care requires resources for caregivers which address obstacles such as overworked nurses.

Evidenced based nursing protocols which guide the clinician on end-of-life care practises should be developed and implemented in paediatric intensive care settings.

Highly rated supportive behaviours may serve as guidelines in delivering end-of-life care.

5.4.2 Recommendations for Nursing Education

The goal of end-of-life care is not to cure, but to provide the dying child and family members with comfort and to maintain the highest possible quality of life for as long as life remains. The nurses' knowledge influences the quality of care provided to these patients and family members. (Leviton and Fretz, 1990). Lack of nursing education has not been perceived as a major obstacle in end-of-life care by paediatric intensives nurses' in this study. Socio-demographic findings brings to light the majority of the respondents has never participated in end-of-life care educational programs. It is also evident from literature that undergraduate nursing education does not adequately prepare paediatric intensive nurses to deliver optimal, evidenced based end-of-life care, (Ferrell, Virani and Grant, 2005).

5.4.3 Recommendations for further research

The results in this study have also highlighted supportive behaviours which are displayed by both the nurse and physicians that occurs frequently. More research is required to recognise and implement strategies which may support highly rated supportive behaviours and to reduce highly rated obstacles In South Africa, research on end-of-life care in paediatric intensive care is in its infancy. Further research on obstacles and supportive behaviours in end-of-life care using a qualitative approach will facilitate tailoring of future quantitative instruments to accommodate the South African setting. There is also a need to conduct surveys on nurse's knowledge on end-of-life care and family member's perceptions on supportive behaviours and obstacles in end-of-life care received. These recommendations for further research will enable nursing professionals to understand the true state of end-of-life care in the acute paediatric setting and thus implement policies to improve end-of-life.

5.5 CONCLUSIONS.

In conclusion this study has highlighted nurses' perceptions of behaviours which are obstacles to or support the provision of effective end-of-life care in a paediatric intensive care setting. The study also measured the intensity and frequency with which these behaviours occurred. Identifying and quantifying these obstacles to end-of-life care, disseminating the study findings then implementing strategies on ways to reduce these impediments that paediatric intensive nurses perceive as major obstacles may improve end-of-life care. Furthermore, major helpful behaviours which paediatric nurses perceive as being supportive in providing end-of-life care may serve as guidelines in caring for dying children and family members in PICU. Future research is needed on strategies to decrease the magnitude of major obstacles and increase the magnitude of major supportive behaviours in PICU. It is hoped that the outcome of this study, when published,

may contribute positively to end-of-life care as well as the dearth on literature in end-of-life care in paediatric and neonatal intensive settings.

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INFORMATION LETTER

Research study: Nurses` perceptions of obstacles and supportive behaviours in end of life care in paediatric intensive care units of academic hospitals in Gauteng?

Dear Colleague

I am Natwin Louw, currently a student at the University of the Witwatersrand undertaking a Master's Degree in Intensive Care Nursing. I hereby would like to invite u to participate in the research study.

The purpose of this study is to identify the nurses` perceptions on the intensity and frequency of obstacles and supportive behaviours regarding what constitutes effective end of life care in neonatal and paediatric intensive care settings. In this questionnaire you will be requested to rate the size and the number of times health care professionals and family display behaviours which you considered to be obstacles to you rendering good end of life care to a child under you care who is dying. There are also items in which are requested to indicate the size and number of times you perceived supportive behaviours from your colleagues and family. Data gathered from this research will be used to inform and make recommendations to facilitate optimal end of life nursing care in NICU and PICU.

The PEDS questionnaire will be distributed to you on your next shift. By completing of the questionnaire you will be giving your consent to participate in this study. The questionnaire takes approximately 23 minutes to complete. To maintain anonymity please do not write your name on the questionnaire. Participation is voluntary and carries no penalty. Please return all questionnaires to the collection in your unit, whether completed or not before the end of the week. All the questionnaires will be handled by myself and kept in a safe place, with limited accessibility.

There is a small risk that completing the PEDS questionnaire may remind you of nursing a neonate or paediatric patients and evoke feelings of emotional distress. I have arranged for a counsellor to be available for debriefing. Please contact me on the number below so I can arrange counselling.

Thank you for taking time to read this letter. Your participation in this research study will be greatly appreciated. I readily am available on the contact numbers below to address enquiries concerning this study.

Yours Sincerely

.....

Telephone number: 073 412 9654

The Paediatric Nurses Perceptions of End of Life Care (PEDS) questionnaire

Completion of this questionnaire is voluntary and indicates consent to participate in the research study.

The end of life is recognized as an important life phase. Paediatric/NICU nurses are frequently responsible for care of patients who are at the end of life and dying.

SECTION 1: DEMOGRAPHIC DATA

1. How many years' experience do you have as an RN? □□

2. How many years of PICU/NICU nursing experience do you have? □□

3. What is your gender? □ Male □Female

4. What is your highest completed level of education?
   - □Diploma in Nursing
   - □Master's degree, Nursing
   - □Bachelor's degree, Nursing
   - □Bachelor's degree, (other)
   - □Master's degree (other)
   - □Doctoral degree
   - □Other

5. Over your paediatric nursing career, how many patients have you given immediate end-of-life care to?
   - □ Less than 5
   - □ More than 30
   - □ Between 21 and 30
   - □ Between 11 and 20
   - □ Between 5 and 10
   - □ Other

6. In which type of facility are you primarily employed?
   - □ NICU
   - □PICU

7. The position you hold at the facility is?
   - □ Direct care/Bedside Nurse
   - □ Clinical Nurse Specialist
   - □ Department Manager/Educator
   - □ Other (Please specify)

8. Have you ever participated in an End-of-Life Nursing Education Program?
   □NO □ YES

SECTION 2: OBSTACLES

The following items pertain to your perceptions of possible obstacles to providing end-of-life care for dying paediatric patients and their families. Please mark the circle that most closely characterizes **how large an obstacle** you have found each item to be then mark how large an obstacle you have found each item to be then mark the box for how **frequently** you have experienced the obstacle as you have cared for dying children.

0- Not an obstacle	**0- Never occurs**
1- Very small obstacle	**1- Almost never occurs**
2- Small obstacle	**2- Sometimes occurs**
3- Medium obstacle	**3- Fairly often occurs**
4- Large obstacle	**4- Very often occurs**
5- Severely Large obstacle	**5- Always occurs**

		Indicate how large obstacle is.	Indicate how often obstacle occurs.
9	Physicians who are overly optimistic to the family about the child surviving.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
10.	Families not ready to acknowledge their child has an incurable disease.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
11.	The nurse having to deal with distressed family members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
12.	Intra-family fighting about whether to continue or stop aggressive treatment.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
13.	The nurse knowing about the child's poor prognosis before the family knows the prognosis.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
14.	One parent is ready to "let go" before the other parent is ready.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
15.	Poor design of units which do not allow for either privacy of dying patients or grieving family members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
16.	The unavailability of standards of care for dying children.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
17.	The child having pain that is difficult to control.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
18.	Dealing with the cultural differences that families employ in grieving for their dying child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
19.	No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

20.	Dealing with anxious family members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
21.	Nurses getting vague orders such as, "titrate to effect" for pain medication.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
22.	Insufficient education of physicians about pain management in palliative care.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
23.	The nurse having to deal with angry family members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
24.	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
25.	Lack of nursing education regarding quality end-of-life care.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
26.	Physicians not initiating a discussion with family on forgoing life sustaining treatments.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
27.	Nurses believing that life-saving measures or treatments are stopped too soon.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
28.	Instigating or continuing painful treatments or procedures when there is no hope of recovery.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
29.	Continuing life saving measures in a child with a poor prognosis due to real or imagined threat of future legal action by the family.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
30.	The nurse's workload being too heavy to adequately care for the dying child and grieving family.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
31.	The nurse not knowing what to say to the grieving family.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
32.	Family members not understanding what "life-saving measures" really mean (i.e., multiple needle sticks cause pain and bruising; ET tube won't allow child to talk; or ribs may be broken during chest compressions.)	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
33.	Limited access to hospice services due to physician not making referrals because the physicians are not ready to accept that the child is dying.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

		Indicate how large obstacle is.	Indicate how often obstacle occurs.
34.	Fear that the grieving process for the nurse will be greater if allowing themselves to become 'attached' to child and family.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
35.	Language barriers	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
36.	Unit visiting hours that are too liberal.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
37.	Lack of trust from parents in the medical system that has failed to cure their child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
38.	The discontinuity of care of the dying child from lack of communication between interdisciplinary team members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
39.	Parental discomfort in withholding and/or withdrawing ventilation.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

40. Please describe any missing obstacles in detail. Indicate how large each obstacle is and how frequently it occurs.

_____

_____

_____

SECTION 3: SUPPORTIVE BEHAVIOURS

The following items pertain to your perceptions of possible **Supportive behaviours** to providing end-of-life care to dying children and their families. Please mark the circle that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behaviour as you have cared for dying children.

6- Not a help
7- Very small
8- Small
9- Medium
10- Large
11- Severely Large

6- Never occurs
7- Almost never occurs
8- Sometimes occurs
9- Fairly often occurs
10- Very often occurs
11- Always occurs

		Indicate how large of help you found each item is.	Indicate how often you have experienced this.
41.	Having one family member be the designated contact person for all other family members regarding patient information.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

42.	Having enough time to prepare the family for the expected death of the child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
43.	A unit designed so that the family has a place to go to grieve in private.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
44.	Having a support person outside of work setting who will listen to you after the death of a child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
45.	Having the physicians involved in the child's care agree about the direction care should go.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
46.	Having a unit schedule that allows for continuity of care for the dying child by the same nurses.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
47.	Having family members accept that the child is dying.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
48.	Physicians who are compassionate, but very clear about prognosis.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
49.	Physician meets in person with the family after the child's death to offer support and validate that all possible care was given.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
50.	The nurse having had their own previous experience with the death of a family member.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
51.	Having the family physically help care for the child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
52.	Bereavement debriefing sessions to discuss how to remember/honour the child.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
53.	Understanding/supporting individual family's religious beliefs.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
54	Teaching families how to act around the dying child such as, "she can still hear....its okay to talk to her."	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
55.	Having the code status of the child clearly described in the chart.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
56.	Providing a peaceful, dignified beside scene for family members once the child has died.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
57.	Allowing family members adequate time to be alone with the child after he/she dies.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
58.	Having a co-worker tell you, "You did all you could for that child," or some other words of support after the child have died.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑
59.	Allowing parents to hold the child while life support is discontinued.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ❑ ❑ ❑ ❑ ❑ ❑

60. Please describe any missing helpful behaviours in detail. Indicate how large they are and how frequently they occur.

61. If you had the ability to change just one aspect of the end-of-life care given to dying paediatric patients, what would it be?

THANK YOU FOR YOUR PARTICIPATION.

Please return this the enclosed envelope and post into the collection boxes in the ward.

APPENDIX C

From: Siza Khoza
Sent: 12 March 2013 08:01 AM
To: renea@byu.edu
Cc: Shelley Schmollgruber
Subject: Request: National Survey of Paediatric Nurses' Perceptions of End-of-Life Care Questionnaire

Good morning Prof. Beckstrand

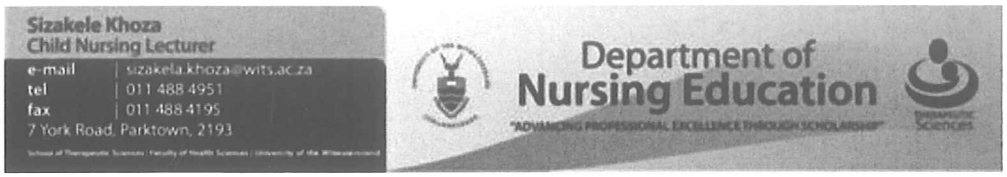
I am Sizakele Khoza a Child Nursing lecturer at the University of the Witwatersrand. I am supervising student who has selected end-of-life care in Paediatric ICU as a research focus for a MSc research report. Clinical research into end of life care issues by professional nurses in the South Africa is still in its infancy and we were excited to read your work on this topic and especially this research. As a starting point my student is keen to obtain the nurse's views on how they apply our policy on death and dying in paediatric wards and whether this enables the nurses to provide good quality nursing care to dying children and their families. Thus far the questionnaire developed for your study is the most appropriate to initiate research into end of life care in our paediatric settings.

My requests to you:

1. Please supply us with a copy of the questionnaire
2. Permission to use the questionnaire in our study

Thanking you in advance

Regards,



From: Renea Beckstrand [mailto:Renea_Beckstrand@byu.edu]
Sent: 21 March 2013 03:53 PM
To: Siza Khoza
Subject: RE: Request: National Survey of Paediatric Nurses' Perceptions of End-of-Life Care Questionnaire

I've attached the file; however, it was created in WordPerfect. If you cannot open it or if it is jumbled, let me know and I'll fax you a copy. Please notify me if you publish any article using data gathered by this tool.

Renea L. Beckstrand, PhD, RN, CCRN, CNE

Professor

Brigham Young University, College of Nursing Provo, UT 84602 renea@byu.ed

APPENDIX D

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. O. Noge
(011): 488-3793
(011) 488-3753
13 December 2013

Natwin Louw
Department of Nursing Education
Faculty of Health Science
University of the Witwatersrand

Dear Natwin

RE: "Paediatrics Nurses' Perceptions of Obstacles and Supportive Behaviours in end of life care in Paediatrics Intensive Care Units"

Permission is granted for you to conduct the above research 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.

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.

Approved/ not approved

Bogoshi

Ms. G. Bogoshi
Chief Executive Officer
19.12.2013

Nursing Education

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2193, South Africa
Tel: +27 11 488-4272 • Fax: +27 11 488-4195 • E-mail: Patricia.Apfel@wits.ac.za
Website: www.wits.ac.za

APPENDIX E

Natwin Louw
Department of Nursing Education
Faculty of Health Sciences
University of the Witwatersrand
7 York Road
Parktown 2193

The Director of Nursing Services
Charlotte Maxeke Johannesburg Academic Hospital
5 Jubilee Road
Parktown 2193

CHARLOTTE MAXEKE
NURSING OFFICE
11 -12- 2013
RECEIVED
JHB HOSPITAL - JHB HOSPITAAL

Dear Mrs Pule ,

Re: REQUEST TO CONDUCT RESEARCH AT CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL (CMJAH)

Request for permission to conduct research in the paediatric intensive care units at the Charlotte Maxeke Johannesburg Academic Hospital

I am Natwin Louw, currently a student at the University Of Witwatersrand undertaking a Master's Degree in Intensive Care Nursing. This research report will be submitted as a partial fulfilment of the course. I have chosen a study aimed at identifying nurses' perceptions on the intensity and frequency of obstacles and supportive behaviours regarding what constitutes effective end of life care in neonatal and paediatric intensive care settings. It is anticipated that the results of the study will produce information that may be helpful in improving end of life care of paediatric patients and their family members. I hereby wish to request your permission to invite nurses working in Paediatric Intensive Care Units to participate in the study.

The information needed for the study will be gathered by using a questionnaire which is attached to the letter. The questionnaire consists of scales designed to measure the frequencies and intensities of obstacles and supportive behaviours in end of life care. The collected information might also be beneficial in discovering any issues that needs to be addressed and may contribute to nurse education and practice in end of life care.

Confidentiality and anonymity will be maintained throughout the study. Each potential participant will receive an information and consent letter. A week later questionnaires will be handed out to each potential participant. Completion of the questionnaire by the participants will be taken as them giving consent to participate in the study.

The research study has been approved by the faculty of Health Sciences of the University of Witwatersrand. Ethical clearance has been granted by the Health Sciences Research Ethics Committee.

Research is supported
89 [signature] 12/12/2013

THERAPEUTIC Sciences

Thank you for taking time to read this letter. If you have any queries or would like to discuss this matter further before making a decision, please do not hesitate to contact me at 073 412 9654 or my supervisor Mrs S.Khosa email siza.khoza@wits.ac.za.

Yours sincerely
Natwin Louw
MSc Nursing Student

Leeds ethics Committee approval 14.01-21

APPENDIX E

Nursing Education

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2193, South Africa
Tel: +27 11 488-4272 • Fax: +27 11 488-4195 • E-mail: Patricia.Apfel@wits.ac.za
Website: www.wits.ac.za

Natwin Louw
Department of Nursing Education
Faculty of Health Sciences
University of the Witwatersrand
7 York Road
Parktown 2193

The Chief Executive Officer
Chris Hani Baragwanath Academic Hospital
R68 Old Potchefstroom Road
PO Bertsham
Johannesburg
2013

Dear Mr. Sandile Mfenyana

Re: REQUEST TO CONDUCT RESEARCH AT THE CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

Request for permission to conduct research in the paediatric intensive care units at the Chris Hani Baragwanath Academic Hospital

I am Natwin Louw, currently a student at the University Of Witwatersrand undertaking a Master's Degree in Intensive Care Nursing. This research report will be submitted as a partial fulfilment of the course. I have chosen a study aimed at identifying nurses' perceptions on the intensity and frequency of obstacles and supportive behaviours regarding what constitutes effective end of life care in neonatal and paediatric intensive care settings. It is anticipated that the results of the study will produce information that may be helpful in improving end of life care of paediatric patients and their family members. I hereby wish to request your permission to invite nurses working in Paediatric Intensive Care Units to participate in the study.

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Confidentiality and anonymity will be maintained throughout the study. Each potential participant will receive an information and consent letter. A week later questionnaires will be handed out to each potential participant. Completion of the questionnaire by the participants will be taken as them giving consent to participate in the study.

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THERAPEUTIC Sciences

Thank you for taking time to read this letter. If you have any queries or would like to discuss this matter further before making a decision, please do not hesitate to contact me at 073 412 9654 or my supervisor Mrs S.Khosa email siza.khoza@wits.ac.za.

Yours sincerely
Natwin Louw
MSc Nursing Student

R14/49 Ms Natwin Glacolin V Louw

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130638

NAME: (Principal Investigator)	Ms Natwin Glacolin V Louw
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital, Paediatric Intensive Care Unit
PROJECT TITLE:	Paediatric Nurses' Perceptions of Obstacles and Supportive Behaviours in end of life care in Paediatric Intensive Care Units
DATE CONSIDERED:	28/06/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms Sizakele Khoza
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/07/2013

Approved CEO 14.02.10

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 Secretary in Room 10004, 10th floor, Senate House, University.
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.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G

R14/49 Ms Natwin Glacolin V Louw

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130638

NAME: (Principal Investigator)	Ms Natwin Glacolin V Louw
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital, Paediatric Intensive Care Unit
PROJECT TITLE:	Paediatric Nurses' Perceptions of Obstacles and Supportive Behaviours in end of life care in Paediatric Intensive Care Units
DATE CONSIDERED:	28/06/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms Sizakele Khoza
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/07/2013

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Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX H

POSTGRADUATE OFFICE APPROVAL

Faculty of Health Sciences
Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172040

Reference: Ms Thokozile Nhlapo
E-mail: thokozile.nhlapo@wits.ac.za

07 January 2014
Person No: 564962
PAG

Miss NGV Louw
19 Mantle Close, Ext12
Ennerdale
1830
South Africa

Dear Miss Louw

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Paediatric nurses' perceptions of obstacles and supportive behaviours in end of life care in paediatric intensive care units* 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

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	Natwin Louw
Address	Wits Dept of Nursing Education
Date	08/04/2015
Subject	Paediatric Nursing in End of Life Care by Natwin Louw
Ref	SS/GS/08

I, Gill Smithies, certify that I have proofed and language edited:

Masters: Chapters 1 to 5 - End of Life Care in Paediatric Nursing, by Natwin Louw,

to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies

08/04/2015