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University of Cape Town

TO EVALUATE THE SUPPORT REQUIRED FOR STAFF IN THE PAEDIATRIC UNIT IN DORA NGINZA HOSPITAL, PORT ELIZABETH, IN CARING FOR CHILDREN WITH LIFE LIMITING AND LIFE THREATENING ILLNESSES

FLORENTINA URECHE

STUDENT NUMBER: URCFLO001

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SUPERVISOR: DR MICHELLE MEIRING

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DECLARATION:

DECLARATION

I, Florentina Ureche, hereby declare that this is my own work and each significant contribution and quotation in this dissertation, from the work of other people has been attributed, cited and referenced.

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Signature Signed by candidate Date: 30.01.2013

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS **1**

DECLARATION **3**

TABLE OF CONTENTS **4**

LIST OF TABLES **6**

LIST OF FIGURES **8**

LIST OF ABBREVIATIONS **9**

ABSTRACT **11**

CHAPTER 1 ..... **13**

1.1. INTRODUCTION 13

1.2 THE INTEREST IN THE STUDY 14

1.3 DEFINITION OF TERMS 17

CHAPTER 2: LITERATURE REVIEW **21**

2.1. THE IMPACT OF LIFE LIMITING AND LIFE THREATENING ILLNESSES ON CHILDREN 21

2.2 THE IMPACT OF LIFE THREATENING AND LIFE LIMITING ILLNESSES ON FAMILIES 24

2.3 EFFECTS OF CARING FOR CHILDREN WITH LL AND LTI'S ON HEALTH PROFESSIONALS 27

2.4 PAEDIATRIC PALLIATIVE CARE **30**

2.4.1 INCIDENCE OF LLIs' AND LTIs' 30

CHAPTER 3: RESEARCH METHODOLOGY **36**

3.1 AIM AND OBJECTIVES 36

3.2 STUDY DESIGN 36

3.3 STUDY SITE 36

3.4. STUDY POPULATION 37

3.5. DATA COLLECTION 38

3.6. DATA ANALYSIS 41

3.7. ETHICAL CONSIDERATIONS 43

CHAPTER 4: RESULTS **45**

4.1 INTRODUCTION 45

4.2 RESPONSE RATE 48

4.3 DESCRIPTIVE STATISTICS: CHARACTERISTICS OF PARTICIPANTS 49

4.4. DESCRIPTIVE STATISTICS FOR THE QUESTIONNAIRE ITEMS 52
4.5 RESULTS FOR SUMMATED SCORES PERTAINING TO KNOWLEDGE, EMOTION, COMMUNICATION AND SUPPORT 58
4.6 RELATIONSHIP BETWEEN FACTORS AND DEMOGRAPHIC VARIABLES 60
4.7 STAFF'S PERCEIVED EDUCATIONAL NEEDS REGARDING PAEDIATRIC PALLIATIVE CARE AND THEIR INDICATED LEARNING MODALITIES 66
4.8 QUALITATIVE DATA RESULTS 68
CHAPTER 5: DISCUSSION 77
5.1 INTRODUCTION 77
5.2 RESPONSE RATE TO THE QUESTIONNAIRE 77
5.3 CHARACTERISTICS OF THE POPULATION-DEMOGRAPHIC VARIABLES 77
5.4 RESULTS RELATED TO LEVEL OF KNOWLEDGE 79
5.5 RESULTS RELATED TO THE EMOTIONAL COMPETENCE 92
5.6 RESULTS RELATED TO COMMUNICATION COMPETENCE 97
5.7 RESULTS RELATED TO LEVEL OF SUPPORT 99
5.8 STAFF'S EDUCATIONAL NEEDS AND LEARNING MODALITIES 103
5.9 QUALITATIVE DATA RESULTS 105
5.10 LIMITATION OF THE STUDY 108
5.11 STRENGTHS OF THE STUDY 109
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS 111
6.1 INTRODUCTION 111
6.2 CONCLUSIONS 111
6.3 IMPLICATIONS 113
6.4 RECOMMENDATIONS 114
REFERENCES 118
APPENDICES 131
I: Participants' information letter and the Questionnaire 131
II: Human Research Ethics Committee- University of Cape Town 139
III: Clearance: Walter Sisulu University 140
IV: Internal memorandum- medical superintendent DNH 141
V: Permission to conduct research in Paediatric Department- HOD 142

LIST OF TABLES

Page

Table:2.1: : ACT/ RCPCH , 1997 categories 21

Table: 4.1: Characteristics of the Participants to Focus Group Discussions 45

Table: 4.2: Focus group discussion: Summarized themes and sub-themes 46

Table 4.3 : Paediatric Department statistics for the specialist clinics 2010,2011 47

Table 4.4: Gender distribution 49

Table 4.5: Descriptive statistic for Level of Knowledge items 53

Table 4.6: Job Title and formal training 54

Table 4.7: Job Title and Confidence in prescribing morphine 54

Table 4.8**:** t-Test: Confidence in prescribing morphine by Job Title 55

Table 4.9: Job title and the confidence in administering morphine 55

Table 4.10: Descriptive statistics for Emotional Competence 56

Table 4.11: Descriptive statistics for the Communication Competence 57

Table 4.12: The frequency table for the level of support 57

Table 4.13: Cronbach's alpha for summated scores 58

Table 4.14: Relationship between professional experience and emotional Competence 61

Table 4.15: Relationship between experience in paediatrics and communication Competence 62

Table 4.16: Relationship between Job Title and Emotional Competence 62

Table 4.17: Relationship between Experience in Paediatrics and Total Items 63

Table 4.18: MS's and SD's for Knowledge, Emotional, Communication and Support Items 64

Table 4.19: ANOVA Results – Relationships between demographic variables and Questionnaire Items 64

Table 4.20: Scheffé test values 66

Table 4.21: Descriptive Statistics: Participants' learning needs in palliative care 67

Table 4.22: Descriptive Statistics: Participants' preferred learning modality 67

LIST OF FIGURES

Figure		Page
Figure.4.1:	Bar chart indicating experience in medical profession	50
Figure 4.2:	Bar graph indicating experience in Paediatrics	51
Figure 4.3:	Pie Chart displaying the job categories distribution	51
Figure 4.4:	Pie Chart displaying the staff distribution in different areas	52
Figure 4.5:	Standard deviation curves for summated questionnaire items	59
Figure 4.6:	Bar graph indicating summated support factor-FS distribution	60

LIST OF ABBREVIATIONS

DNH: Dora Nginza Hospital

PE: Port Elizabeth

ECP: Eastern Cape Province

FGD: Focus group discussion

HREC: Human Research Ethics Committee

HOD: Head of Department

UCT: University of Cape Town

WSU: Walter Sisulu University

AAP: American Academy of Pediatrics

PI: Principal investigator

HIE: Hypoxic Ischaemic Encephalopathy

HCP: Health Care Professional

PQ: Pilot questionnaire

LTI: Life threatening illness

LLI: Life limiting illness

MDT: Multi-disciplinary team

IDT: Interdisciplinary team

TDT: Transdisciplinary team

PICU: Paediatric intensive care unit

PPC: Paediatric palliative care

PPT: Paediatric palliative team

NICU: Neonatal intensive care unit

WHO: World Health Organization

BBN: Breaking bad news

EOL: End- of- life

MS: Mean Score

SD: Standard Deviation

Exp Prof: Experience in profession

Exp Paeds: Experience in Paediatrics

ABSTRACT

INTRODUCTION

With increasing number of children diagnosed with LL and LT illnesses, health care providers working in acute paediatric settings are called upon to respond to the needs of these children and their families which are complex in nature. To respond to the challenges of care, professionals need to become familiar and comfortable with the provisions of PPC with its focus on the relief of pain and suffering and improvement of quality of life of paediatric patients with LL and LTIs' from the time of diagnosis, alongside potentially curative treatments. Exploring HCPs' needs in caring for these categories of patients materialized in this research, which was the first palliative care study initiated in paediatric department at DNH, and the results are valid despite the limitations.

AIM AND OBJECTIVES: This research aimed to explore the perceived needs of support required by peadiatric staff caring for children with LL and LTIs' in the Paediatric Department in DNH and set out the following objectives: **1)** To identify the need for **educational support**; **2)** To explore the **emotional impact** on HCP caring for children with LL and LTI; **3)** To identify the kind of **support required** for staff in order to offer the best possible care to these pediatric patients and their families.

RESEARCH METHODOLOGY: This was a cross-sectional study which combined both qualitative and quantitative components of research methodology. The study employed a preliminary FGD group with professionals followed by a Pilot Questionnaire and a self-administered Questionnaire.

RESULTS: The response rate was 75%, with 72 % of the study population represented by nurses and 28% by doctors. Participants 'self-reported knowledge deficits were compared with previous studies. **Confidence to prescribe morphine** in children with LL and LTIs was rated the lowest knowledge item among 85% of total participants of which 71% were doctors. Lack of knowledge of the **WHO pain ladder** was reported by 74% of staff, a finding supported by numerous studies. Knowledge of **PPC** was found to be poor among 75% of participants as shown by similar studies.

BBN to the child-patient rated inadequate among 50% of staff and **EOL decisions** (either emotional or practical) were poorly rated by 81% participants. Poor **debriefing (**73%) and **bereavement**

support structures were indicated by 71% of participants. Two significant statistical relationships were found between demographics: 1) experience in paediatrics and communication and 2) job category and support level. These findings confirm that with more experience of working with children, the better the communication skills and that nurses support each other better than doctors in the absence of formal support systems.

Among PPC **educational needs** the greatest learning was of EOL issues (43%) and a workshop was the preferred learning format (55%).

The themes emerged from qualitative questions highlighted the need for personal support in areas such as education and training in pain and symptom management, communication skills such as BBN and emotional support structures. Development of pediatric palliative care services (PPC unit and PPC Team) as well as PPC education for paediatric staff was among needs which require institutional recognition and further support.

CONCLUSIONS

1. Despite its limitations, the overall findings of this study are significant and suggest that the gaps and inadequacies in health professional's knowledge should be soon addressed through training programs, informal education and mentorship as well as continuous medical education.

2. Dora Nginza hospital's management and Paediatric department also have the duty to ensure consistent and on-going emotional support of its staff by identifying and addressing risks factors leading to stress, burnout and compassion fatigue among HCP and to develop debriefing and bereavement structures for all paediatric staff.

3. Development and integration of PPC services within the paediatric department have been suggested not only by participants but the need is dictated by the departmental statistics. Development of PPC services in DNH are in line with national and international recommendations that aim to provide the best quality of care to a vulnerable category of peadiatric patients: children with LL and LTIs.

There is no keener revelation of a society's soul than the way in which it treats its children"

Nelson Mandela

CHAPTER 1

1.1. INTRODUCTION

Caring for sick children is demanding and yet very rewarding for paediatric health care professionals. Attending to children with acute illnesses and restoring them to good health is everyone's goal and achieving cure brings satisfaction to health professionals and parents alike. On the other hand, caring for children with chronic and complex, incurable diseases such as life threatening (LTIs') and life limiting illnesses (LLIs') may be a difficult task for health professionals.

Nowadays medical advances and technological progress have improved the outcome and survival of many incurable conditions in childhood. Previously fatal diseases such as childhood cancer emerged as the success story of the late 90's, and can now be cured in over 70% of cases[1].For many children with congenital heart disease, access and advances in cardiac surgery offer real hope of a normal life[2].

Other conditions such as non-malignant LL and LTIs' and their resultant- multiple impairments continue to pose many challenges for health professionals[3].

Medical achievements have created a medically fragile population, *technology- dependent* at times and with unpredictable life expectancy[4]. Advances in the medical field have changed society's perception that regards death in childhood as avoidable and rejects the inability to cure as a medical failure, thereby increasing the number of children who live and suffer from incurable conditions[5].

Yet despite concerted medical efforts to save lives, death in childhood still happens.

1.2 THE INTEREST IN THE STUDY

In all cultures children are regarded as the future generation and are supposed to be growing, healthy and full of energy. This is not always the case because children suffer or die from a variety of illnesses not seen in adulthood. Parents and families, as well as societal expectations hope that the child with life threatening or life limiting disease will grow, live and fulfill his/her potential within the constraints of their illness[6].

In fact, death in childhood contradicts the order of the nature. Faced with serious illnesses, affected children have their future, dreams and hopes threatened, and the impact is felt by the children, their families and the health professionals' involved[7].

The journey with a child with a life threatening or life limiting illness is unique, emotionally charged and has long lasting effects. It can affect every aspect of a child and family's life and is often associated with exclusion and isolation, dependency and depression, anxiety and fears and ultimately with losses.

There are also families who acquire unique insight into life's central issues, develop new coping strategies and find tremendous meaning in their experiences which impact positively on unifying their families and contribute to positive growth[8].

Caring for children with complex, incurable disease is challenging. Addressing pain and symptoms, building close relationships with the patients and families and ultimately obtaining acknowledgement from the parents can be rewarding for health professionals[9].

Research evidence shows ambivalent experience among professionals: there are professionals for whom, the experience of caring or "*contributing to a dignified death*"[9] can "*be a source of profound satisfaction, renewal and affirmation*[10] while others experience high emotional strain and become vulnerable[11].

The partnership between health professionals and families results in better support for the patient and family helping them to grow and handle the situation, ensures treatment compliance and creates a feeling of security that is much needed during difficult times.

My interest in this research study started after I joined the Paediatric department in 2008 to attend to children with malignant conditions (haematological and solid tumours).

Previous experience of caring for adult oncology patients assisted me as a starting platform but I soon realized that paediatric oncology differs in many aspects from adult oncology and that I needed to acquire more knowledge, skills and expertise to enable me to attend to these children with unique conditions and complex needs.

This challenge offered me the opportunity to acquire additional knowledge and skills and gain better insight into these children and families' lives, experiences and complex care needs.

The perception that children are miniature adults is contradicted by the huge differences between children and adults. The immaturity of the child's organ systems, their different stages of growth and development are important differences between children and adults. For example, compared with adults, children with malignant conditions are more resilient, respond and tolerate chemotherapy better with fewer side effects and achieve clinical remission more often. Currently over 70% of paediatric patients diagnosed with malignancies can be successfully treated if diagnosed early[1].

Outside of the oncology clinic I was introduced to paediatric patients in the neurology clinic, which is one of the largest specialist- clinics in the department and due to the high number of patients is spread over three days of the week. Working with children with a variety of complex and often incurable conditions presented me with new challenges.

Caring for non-progressive neurological conditions is less rewarding for health professionals and the task becomes even more challenging in the absence of curative options, eventual deterioration and poor prognosis for some of these children.

Fortunately, the opportunity to care for both categories of LT (children with cancer) and LL illnesses (neurological) shaped my experience and helped me to achieve better insight into the lives and the journeys of these children and their families.

Paediatric LT and LLIs' occur within the context of growth and development: physical, emotional, social, psychological and spiritual. Knowledge of disease patterns and management combined with appropriate knowledge of child development and family systems are necessary for health professionals' accompanying a child with life limiting or threatening illness and the family through the trajectory of their disease.

Managing pain and symptoms and communicating sensitive issues, delivering continuous and compassionate care until the end of life and into bereavement is emotional and challenging for most health professionals.

Most children diagnosed with LL and LTIs' have complex needs which require constant adaptation and coordination of care throughout their journey.

Research showed that health professionals: doctors and nurses working in acute paediatric settings are increasingly under pressure to deliver the best medical care and to assist families[12].

Without appropriate knowledge and education on how to deal with the patients' particular needs and with minimal preparation and support in recognizing and handling the complex aspects of care, the task of caring can be difficult for health professionals.

In recognition of the complexity of care needs among children with chronic conditions, the South Africa Children's Act, 2005 recommends that for children with chronic illnesses "*due consideration be given to providing: specialized care, providing children with care that ensures dignity, promotes self-reliance and provides necessary support services*"[13].

Based on national and international recommendation: World Health Organization (WHO) [14] and American Association of Pediatrics (AAP) [15] in support of the needs of children with LL and LTIs' and my own observations and interest in this field, I embarked on this research with the aim to explore

the perceived needs (by self-evaluation) of support for nurses and doctors in caring for paediatric patients with LL and LTIs' in the Peadiatric Department of Dora Nginza Hospital.

The ultimate aim of this research, the first of this kind in the Paediatric Department of Dora Nginza Hospital, is to improve the quality of care for these patients and their families.

1.3 DEFINITION OF TERMS

The spectrum of LT and LLIs' conditions in childhood is very wide, encompassing both malignant and non-malignant disease[16].

A **chronic illness** is defined as an illness that is permanent or lasts a long time (more than one year) affecting the patient's quality of life. It may lead to a failure to achieve normal developmental phases, dependency on medication, excessive need for medical care or related services, special ongoing treatments[8].

The term **life threatening illness** describes a medical condition which develops in childhood that without intervention is likely to result in premature death. In LTIs' curative treatments maybe feasible but can fail: organ transplants, malignant disease, organ failure and congenital heart disease[3].

The literature defines **life limiting illness,** also known as life-shortening, as a condition presenting in childhood and characterised by the absence of curative treatments resulting in premature death in childhood or early adulthood. Some of these conditions are progressive resulting in severe deterioration and disabilities and increased dependency on parents and carers[3].

In practice, the distinction between the two entities might be difficult since an individual child may oscillate between the two definitions especially during acute exacerbations of the illness.

Multidisciplinary /Interdisciplinary/ Transdisciplinary team

The care needs for children with complex conditions such as life limiting and life threatening illnesses cannot be addressed by a single discipline and therefore a team of health professionals from different disciplines is required to deal with the complexities. The team represents an interacting group of professionals which performs interdependent activities. The team strategy is founded on common goals and vision and it requires information sharing, resources, planning, decision making and coordination.

Three different team approaches have been identified in dealing with the complex needs of care: multidisciplinary, interdisciplinary and transdisciplinary [17].

The Multidisciplinary team approach (**MDT**) consists of professionals from different disciplines (physician, nurse, pharmacist, dietician, physiotherapist, art and music therapist, social worker and psychologist), who work independently, each team making separate plans for their discipline resulting in fragmentation of care.

The Interdisciplinary team (**IDT**) working has the advantage of information sharing amongst team members (with diverse training) via formal channels of communication and periodic meetings resulting in better incorporated planning and interventions as discussed by Ajemian[18].

The Transdisciplinary team (**TDT**) model offers more integrated and comprehensive care by including the parents/families (as active members of the team) in developing the care plan based on their priorities and by assigning a primary service provider for the delivery of care. The information, knowledge and skills are shared through the regular meetings with the goal to deliver a unified care plan across disciplines[17].

Paediatric Palliative Care

The World Health Organization defines "*palliative care for children as the active total care of the child's body, mind and spirit and also involves giving support to the family. It begins when the disease is diagnosed and continues regardless of whether or not a child receives treatment directed at the*

*disease, regardless if the outcome is death or cure, and is consistent with the child and family values, regardless of the location of the patient (it can be provided in tertiary care facilities, health centers or in children's homes).*Effective paediatric palliative care" *requires broad multidisciplinary approach*, and inclusion of family, regarded as the unit of care and "*makes use of the available community resources, even if limited"*[14].

Pediatric palliative care can be integrated with curative or life-prolonging care. Control of pain and other symptoms, addressing psycho-social and spiritual issues are of paramount importance in achieving the best quality of life for the child and family.

End of life (EOL)

The EOL refers to the phase of the progressive illness for which curative treatment is not possible or an appropriate judgment that the death is imminent or it can be expected in days, weeks or months[19].

Terminal care refers to the management of patients during final stage of disease, when there is clear clinical evidence of advanced and progressive disease from the point at which the state of decline and death is inevitable in foreseeable future[20].The confusion between palliative care and terminal care originates from the association of palliative care with the 'hospice movement' out of which Palliative Medicine evolved as a specialty. Terminal care is an important part of palliative care: palliative care is not synonymous with terminal care, but palliative care includes terminal care[21].

Breaking bad news (**BBN**) was defined by Eggly et al, as any information which is "*unanticipated and perceived as negative*" by the recipient of the news[22].

Burnout was defined by Maslach[217] as "a psychological syndrome in response to a chronic interpersonal stressor on the job. It is usually cumulative and manifests in a state of physical, emotional and mental exhaustion with a sense of underachievement and no job satisfaction"[59].

Stress occurs when demands of work overwhelms ones coping resources[223].Stress is defined as physical (fatigue, sleep disturbances, change in appearance and appetite), psycho-emotional (anger, irritability, depression) and intellectual response (poor concentration, low productivity, pessimism, absenteeism) when a threat to ones' wellbeing requires adjustment to the environment[59,223].

Compassion fatigue has been described as an individual's capacity for empathy and ability to engage into a therapeutic relationship to a traumatized or suffering person[218]. Individuals with high levels of empathy and empathic responses are more vulnerable to experiencing compassion fatigue.

Emotional survival is the way in which HCP are trying to avoid emotional overload[177.]

Emotional competence is defined as a property of emotional survival. In practice emotional competence is expressed in the way the emotions skills are used to handle emotionally charged situation[177].

CHAPTER 2: LITERATURE REVIEW

2.1. THE IMPACT OF LIFE LIMITING AND LIFE THREATENING ILLNESSES ON CHILDREN

Children can be affected by a variety of LT and LLIs' during any stage of their development. According to the Association for Children with Life-threatening or Terminal Conditions (ACT/Together for short lives), and the Royal College of Pediatrics and Child Health (RCPCH) 1997, four categories of paediatric conditions have been identified as eligible for paediatric palliative care as illustrated in the following table[23].

Table 2.1: ACT/ RCPCH, 1997 categories

	Definition	Conditions	Characteristics
1	Life threatening conditions; curative treatment is feasible but can fail	• Oncological and hematological cancers • Operable Congenital heart disease	Possible cure
2	Conditions with long phases of intensive treatments aimed to prolong life and allow normal childhood, but premature death is possible	• Cystic fibrosis • Musculo- dystrophies • HIV/AIDS with ARV treatment	Normal phase following the diagnosis
3	Progressive conditions, with no curative treatment options, treatment exclusively palliative	• Mucopolysacharidosis • Batten disease • HIV/AIDS without ARVs' treatment, chromosomal abnormalities: 13, 21	Relentless
4	Conditions with severe neurologic disabilities, non-progressive, susceptible to complications	• Cerebral palsy	Unpredictable

Some disorders such as genetic conditions and, hypoxic-ischaemic encephalopathy (HIE) are obvious from a very young age, while others such as cancers develop during childhood and adolescence. These conditions vary in their aetiology and their course may be unpredictable compromising the children's life expectancy and challenging the emotions of families and care-providers alike.

The experience of suffering for children with LL and LTIs' conditions and their families is multidimensional. Physical pain and other symptoms may result from the progression of disease or are due to uncomfortable procedures or restriction of motor activity and muscular weakness. Psycho-emotionally these children may experience anxiety, fear and even depression, as well as low self-esteem and cognitive impairments. Lastly, their social relationships maybe impaired due to social restrictions due to, for example, fatigue as a result of disease or side effects of treatment, loneliness, and isolation.Some of these conditions lead to progressive deterioration of child's health and place even more pressure on families and professionals[24].

A child's experience of a LL and LTI is a complex and should be seen in the context of the child's growth and physical, emotional, social, psychological and spiritual development.

Based on this theory, research found that the child's ability to process information and participation in decision making is governed by the child's life's experience and developmental stage[25].

Children are a vulnerable population. When faced with severe illnesses resulting in a shortened life span and compromised quality of life, they become even more vulnerable to the experience of illness and stress. Children's vulnerability is due to due to their diminished autonomy (inability to give informed consent, incapable to protect their own interests) and dependency on their parents or carers)[26] . Also they may be disadvantaged by their limited legal or mental competence (inadequate understanding and lacking decision making capacity) [27].

The majority of paediatric patients with LL and LTIs' experience generalized pain and suffering as revealed in numerous studies[28, 29, 30].

Pain and symptom control in children with LL and LTIs' is widely recognized as a priority and is a well-documented health problem.

Researchers have shown that unrelieved pain can become a serious health problem causing unjustified suffering, disability, psychosocial problems and impaired quality of life for the patient. According to Mercadante[28] despite the numerous treatment options available, appropriate pain and symptom management in many instances is lacking or is inadequate in daily practice[30].

At the beginning of the 21st century and despite WHO stepwise approach to pain management, suboptimal pain control in children with LLIs' is still a major issue of concern[29].

Cancer pain remains the most common symptom, which is usually responsive to current treatment approaches, whilst other symptoms are often unrecognized and less amenable to effective therapeutic options (for example weakness, weight loss, fatigue) [30].

Mercadantes' study revealed that cancer pain can be successfully treated in 90% of patients, even in their homes if appropriate pharmacological therapies are employed and yet between 30-75% of patients with malignant conditions still experience pain as a result of under-treatment[31].

There is less information on how other severe symptoms such nausea, fatigue, dyspnoea and respiratory distress and constipation negatively impact on the quality of life of children with cancer[32].

Drake et al's study found that towards the EOL, 50% of children with LL and LTIs' are burdened by distressing symptoms such as: lack of energy, drowsiness, skin changes, irritability, pain and oedema. These symptoms were greater among children admitted in the general ward compared with children admitted in the intensive care unit[33].

With disease progression towards the final stages, regardless of diagnosis, paediatric patients experience more gastro-intestinal symptoms such as nausea, vomiting, constipation, anorexia, and cachexia, as documented by Santucci &Mack's study[34].

Research has found that pain and symptoms in patients with non-malignant LTIs' are not effectively managed. In children with multiple impairments such as: cognitive, communication, motor inability, hearing loss, blindness, feeding and nutritional problems, addressing pain and symptoms is even more challenging[3].

There is evidence that during the trajectory of the disease, the child's needs are continuously changing as a result of the child's physical and psycho-emotional development[5]. Further management should take into account disease's trajectory and its impact on the child's development.

LL and LTIs' often impact on child's psycho-emotional, social exchanges, communication and spiritual spheres as well[35].

The experience of suffering with a severe illness makes children more vulnerable to stress. The safe and secure family environment is replaced with the unfamiliar hospital setting. Their sense of well-being is overwhelmed by fear and anxiety, loneliness and isolation and increased dependency on parents. As the disease progresses towards the EOL, psychological distress increases and symptoms of depression and anxiety should be recognized and treated accordingly[36].

Reflecting on the experience with a life limiting illness, Eiser[8] supports the theory that, the impact of LL or LT illness in children is based on their cognitive level, social, emotional and physical development. The multiple challenges of these illnesses are perceived differently by infants and toddlers compared with school going children or adolescents. These children often fail to achieve their full potential, to gain independence and autonomy. They experience physical changes, social restrictions and changes in their emotional wellbeing.

2.2 THE IMPACT OF LIFE THREATENING AND LIFE LIMITING ILLNESSES ON FAMILIES

The family unit plays a fundamental role in caring for the sick child, making difficult decisions in the child's best interest and often making socio-economic sacrifices.

The sick child, parents and siblings perceive the effects of these illnesses with different intensity. The unpredictable pattern of a LL and LTIs, multiple and lengthy admissions and complex and intensive treatments may have negative effects which impact on every aspect of their lives.

During this time the family becomes "*vulnerable and resilient* "and learns to accept and integrate the child's illness while trying to maintain the balance of family life[37].

The child's physical and psycho-emotional suffering presents the parents with multiple burdens in the psycho-emotional, financial and spiritual domains. [38] .Employment issues and a lack of support can lead to physical and mental exhaustion and marriage break ups[39].

2.2.1 EMOTIONAL IMPACT

From the shock and disbelief of diagnosis, to the hopes of recovery and the possibility of saving the child, to a loss of control and threat of more losses, family "*navigates uncharted territories* "and experiences distress, changes and disruptions in the routine of family life[40].: This is the time to provide care and on-going support and to appreciate family's efforts, to decrease their fear, anxiety and isolation and to assist families to cope.

The emotional impact on the family unit is perceived in stages. The initial "*broken life world*", dominated by chaos and uncertainty, is followed by an immediate phase of "*striving to survive*". Using information and other supportive resources, families can regain hope and control of their lives and to focus in a positive direction, as found by Bjork et al'study[41].

Developing new coping strategies and finding meaning in their experiences with a child's LL or LTI was perceived as a unifying factor for families and contributed to positive growth, despite, multiple challenges[8].Similar results were found by Katz[42].

2.2.2 PSYCHOLOGICAL IMPACT

Parents and their ill children with LL and LTIs' suffer a constellation of symptoms such as fear and anxiety, depression and isolation equivalent to post-traumatic stress disorder (avoidance, re-experiencing and hyper vigilance) [4].

Researchers found that the psychological impact on the families correlates with the nature of the chronic illness and based on this assumption, Katz's study revealed that the perceived impact had much more negative effects on parents of children with LTIs' compared with the parents of children with non-LTIs'[42].

Parents of children with genetic[43], neurological disorders[44] or HIV[45, 46] feel responsible for causing the child's illness and experience fear and anguish, guilt and remorse, anger, anticipatory grief and loss. In contrast to the full array of stress, some families find positive meaning[47] (new values and attitudes, re-evaluation of goals, support systems and adaptation strategies to taking charge) and couples may develop stronger marital relationships in response to a chronic and complex condition[48].

2.2.3 SOCIO-FINANCIAL IMPACT

The families of children with life limiting or life threatening conditions are often subjected to financial difficulties. Parents have to take days off work or quit working in order to attend to the sick child. Lenton et al reported that 81% of families in his study experienced financial difficulties. Addressing or assisting with financial concerns should be offered to families where possible[3].

2.2.4 ANTICIPATORY GRIEF

The threat of the impending death or death in childhood combined with the inability to foresee and plan the future has severe consequences for parents and long-term implications for the family[5].

From the emotional impact (anxiety, anger, guilt) of the initial diagnosis, parental feelings evolve to include similar feelings of those who have experienced the death of a loved one (shock, anger, bargaining, depression and acceptance) known as anticipatory grief, as described by Kubler-Ross[49].

Recognizing parental sources of distress (the imminent loss of a child combined with feelings of loss of self-esteem and guilt) and supporting them to identify their fears, will help to deal with the issues confronting them. Practical advice, counselling and psychotherapy will assist the family to maintain normal dynamics in their lives[50].

2.2.5 THE HEALTHY SIBLINGS

The siblings are not spared from the experience of a LL or LTIs and "*they are almost universally distressed*"[51]. With all the attention on the sick sibling, they feel left out and may develop a series of emotional and psycho-social difficulties. Their special needs are manifest during their sibling's illness and after their siblings 'death.

Research done by Birenbaum on the siblings of a child dying from cancer concluded that the siblings display psycho-social (hostile behaviours, impaired cognitive and school performance, strained relationships and becoming withdrawn) and physiological responses (headaches, abdominal pains, dizziness, and enuresis) which are age related[52]. Adolescent siblings are more at risk of developing abnormal behaviours than younger siblings. The experience of potential loss or the threat of loss in the early years may have a profound and long- lasting psychological and social effect on the healthy siblings[37]. Studies found that there are not only negative outcomes from the experience with LL and LTIs'. There is beneficial effect and positive growth when open information is shared from the time of diagnosis throughout the illness and this will encourage healthy siblings' adaptation and involvement in caring for the sick child. Communication seems to have positive effects on healthy siblings '*long-term adjustment and the development of coping mechanisms*[51].

Several studies have found that the healthy sibling's perception of the illness is related to their developmental stage. Younger siblings showed significantly less positive growth and adjusting strategies while older siblings manifested more rapid personal growth, increased maturation, responsibility, independence and supportiveness and better insight in dealing with the illness[51, 53].

2.3 EFFECTS OF CARING FOR CHILDREN WITH LL AND LTI'S ON HEALTH PROFESSIONALS

Caring for children with acute conditions and restoring them to good health is extremely rewarding for doctors and nurses. On the other hand, caring for children, who are facing complex-chronic, incurable conditions such as LT and LL illnesses can be challenging.

The task of providing care for these children can be difficult and associated with high levels of stress for health professionals working in an acute pediatric setting due to low levels of formal training in palliative care as reported by research[54] or to the limited opportunity to get insight into the child's baseline condition[55]. Some health professionals are able to cope with these patients due to their long

experience of working with children, for others this task can be challenging professionally and emotionally.

When dealing with complex, incurable disease, the doctor-patient relationship is dominated by the severity and the trajectory of these illnesses, which can be characterized by unexpected reversals and responses to treatment, to plateaus of relative stability or to an inevitable fatal outcome[40].

Inability to predict accurately the trajectory of the disease [25], associated with poor prognosis, as well as treatment responses and the overall chance of survival can affect the health professionals' decision making capacity[56.] Difficult prognostication, technological-dependency, complex medico-legal issues and the fragmentation of care [35] represent barriers for many health professionals caring for children with complex conditions.

It is certain that medical and technological advances have contributed to a longer survival in patients with severe and potentially lethal disease, without curing them, thereby increasing the number of pediatric patients who continue to suffer from life threatening conditions[5].

However, even the best efforts combined with technological medical advances will not prevent all children from dying. The perception of our society focused mostly in achieving cure and fearing death adds even more pressure on health professionals caring for patients with incurable conditions, when they fail to reach the goal of cure.

2.3.1 EMOTIONAL IMPACT ON PROFESSIONALS

Caring for children and young people with LL and LT illnesses can be emotionally challenging area of care and can be a demanding work[57].

The "*emotional labour"* in caring for these children and their families is more intense and the desire to "*maintain a balance between physical and emotional labour"*[58] becomes a difficult task for health care professionals involved[58]. The unpredictable course of the disease and its undulating patterns may affect the medical professional's ability to provide consistent medical care, leading to emotional exhaustion and a sense of dissatisfaction. Research showed that health care professionals are aware

of the profound emotional disturbances when caring for patients with incurable conditions (witnessing the pain and suffering of their patients) and therefore they should systematically review their approaches[55]. Breaking bad news and dealing with the depressed child and parents combined with treatment failure are major causes for stress, compassion fatigue and burnout and these were identified as occupational stresses[220].

The impact of burnout can be severe on health professionals, impairing the quality of care delivered to the patient and resulting in feelings of incompetence, and reduced sense of achievement and job satisfaction[59]. Cherny's survey reported that stress and burnout were prevalent among oncologists and the major source of stress was due to increased workload and inadequate time to spend with patients and families, and high number of deaths. The study found that health professionals' positive attitude (self-awareness, recognizing own limitation) and recognizing EOL issues and EOL care and its role was associated with lower levels of burnout. Involvement in palliative care proved to help preventing burnout among health professionals.[219].

Providers' compassion fatigue or secondary traumatic stress is triggered in response to exposure to the patient's pain and suffering. Research highlighted that working and caring for patients with advanced illnesses and approaching EOL may affect health care providers on multiple levels: psycho-emotional health, social interactions and wellbeing of care providers[220].

2.3.2. HEALTH PROFFESSIONALS' NEEDS FOR SUPPORT

Little is known about how health care professionals cope with the challenges due to difficult dynamics that can rise when caring for these patients. Identifying risk factors in each work setting (increased workload, staff shortages, conflicts, inadequate work environment and support, limited promotion) will assist health care professionals to adapt and to redefine their expectations and attitudes in relation with their perceived capacity to heal, in the absence of effective treatments.

On the other hand, management and the institution should employ strategies to acknowledge the way to prevent burnout, stress and compassion fatigue among doctors and nurses.

Retaining experienced, well qualified staff and recruiting, motivating and training new staff as valuable resources will provide high quality of care for all patients.

Despite the challenges, attending to children with LL and LTIs' and their families can be rewarding for doctors and nurses with longer professional experience, as shown by Kavanaugh et al [60] and for others the experience of caring "*can be a source of job satisfaction, renewal and affirmation* "when the approach to care is integrated as in palliative care[10].

2.4 PAEDIATRIC PALLIATIVE CARE

2.4.1 INCIDENCE OF LLIs' AND LTIs'

The literature indicates an overall prevalence of incurable disease annually affecting 10/10,000 young people from 0-19 years old with a mortality rate of 1/10,000 from birth to 17 years old[61]. The incidence of these conditions and disability among children in the western world has been increasing[5].

Recent figures published by the International Children Palliative Care Network (ICPCN) showed that 160,000 children are affected by cancer worldwide and about 90.000 of them die from the disease[62] ICPCN. HIV/AIDS statistics of 2009 confirmed that 2.9 million worldwide are living with the disease and 260.000 died of AIDS. In the world, 7.9 million children are born with severe birth defects of genetic origin of which 3.3 million die under the age of five and around 3.2 million of surviving children may live with different disabilities[62].

The Institute of Medicine (IOM), in the United States reported that about 500,000 children cope with LTCs' and about 50,000 infants and children die each year, compared with 2.3 million adults. Worldwide these numbers are in the millions[63].

The Royal College of Paediatrics and Child Health in England has identified an annual mortality from incurable disease of 1/10,000 children aged from one to 17 years. Of these 40% of cases are due to cancer, the remaining 60% comprising conditions as such as: neurodegenerative, metabolic and genetic disease[35.]

In Africa, AIDS and cancer are the two most common incurable diseases, with HIV/AIDS directly responsible for up to 60% of death in childhood. According to WHO report on global health, these figures can be higher, in other developing countries many children are either not diagnosed or treatment is denied[64].

South African statistics show 70-100 new cases of paediatric cancer per million children per year and of the total number of new cases (1400) less than 50% are identified and treated annually. From the annual birth rate in SA of over one million, 61000 children are diagnosed with a severe congenital disorder and 5-7 children per 1000 are born with congenital heart disease[65].Statistics from Eastern Cape found 5.6% of children under the age of 15 years are HIV positive[65].

2.4.2 THE ROLE OF PAEDIATRIC PALLIATIVE CARE

As result of the enormous burden of LL and LTIs' including cancer, congenital heart disease, HIV and other conditions associated with physical and psycho-social suffering, a new approach emerged in order to meet the complex needs of care of the child and family. This new philosophy ultimately embodied in the concept of PPC was described as:" *the art and science of improving quality of life and attending to suffering for children with life-threatening conditions",* shifting focus from the disease to the child and the family[35].

According to WHO's definition, PPC's approach is holistic and multidisciplinary and offers total active care and support to the child and family from initial diagnoses of a LL or LT, incurable illness alongside disease modifying therapies and continues regardless of the disease's outcome, respecting the child and families' values, beliefs and choices[14].

Literature review shows that these children experience pain and distressing symptoms and they die after attempts at curative treatments, without having their palliative care needs addressed[35].

The role palliative care plays, may enhance quality of life, psycho-emotional, social and spiritual wellbeing of child, family and siblings if addressed early in the course of the disease and may avoid the child's exposure to poly-pharmacy and dependency on technology[66]. Mack & Wolfe observed

better outcomes for the child and family when PPC as the standard of care is integrated early alongside curative treatments[67].

The goal of PPC is to prevent and relieve suffering and to support the best possible quality of life for patients and their families. Regardless of disease stage or the need for other therapies, if introduced timeously PPC can be delivered concurrently with life-prolonging care or as the main focus of care.

As a philosophy of care, PPC functions as a well-structured system focused on effective management of pain and other distressing symptoms while incorporating psychosocial and spiritual care according to patient and family needs, values, beliefs, and culture[68].

PPC is gaining momentum and the American Academy of Paediatrics (AAP) in its policy statement recommended that "all general paediatricians, family physicians, paediatric surgeons and pain specialists need to become familiar and comfortable with the provisions of palliative care to children"[15].

As major breakthrough, Gwyther et al and Brennan et al reported that palliative care has been advanced as an international human right[70, 71]. International palliative care organizations such as International Children Palliative Care Network (ICPCN) and ACT (renamed Together for short lives) support this initiative. In its charter ICPCN states that "*PPC is a human right and that every child no matter their gender, age, race, religion, socio-economic background or geographic location should have the right to experience the best quality of life, free of pain and distressing symptoms and to die with dignity"*[71].

Recognizing the place and the role PPC in the medical arena, and translating its goal "*to add life to the child's years, not simply years to the child's life*" into practice, is a challenging task for every health professional caring for the children with LL and LTIs'[15, 72].

2.4.3 ROLE OF IMPROVED KNOWLEDGE FOR HEALTH PROFESSIONALS (PAIN AND SYMPTOM CONTROL)

The literature review examines different aspects of knowledge required by medical professionals caring for paediatric patients with life limiting and threatening conditions.

Research shows that paediatric health care providers, doctors and nurses working in paediatric setting are increasingly under pressure to care for paediatric patients who are undergoing complex treatments for life threatening and life limiting conditions. The foundation for coping with this special category of patients requires professional expertise training and support[73].

The presence of pain whether acute or chronic is one of the major reasons patients seek health care.

Wolfe et al found that despite the recognition of the need to provide appropriate pain and symptom management, in many instances this is lacking[74] and unrelieved pain continues to have a major impact on patients' quality of life and contributes to suffering, disability and psychosocial problems[75].

Research found that children with life threatening illnesses such as cancer "*suffer a great deal"* of pain [72, 74] and other symptoms such as nausea, dyspnoea and respiratory distress, fatigue and constipation[32] due to the progression of the disease or sequelae of treatment. On the other hand, children with non-malignant LTIs' experience pain, physical disabilities and cognitive impairments which impact negatively on their quality of life[3].

In a child with a life threatening condition, pain and symptom control should be the goal of each health care professional. The Association of Pediatric Oncology Nurses (APON) reaffirms that pain can be effectively managed only through appropriate assessment, identifying expected outcomes, and evaluating interventions [76]. To achieve optimal pain management and to influence disease outcomes requires knowledge that should encompass all aspects and dimensions of pain: physical, psycho-emotional and spiritual[77].

Other researchers found that knowledge and expertise in every aspect of care: medication, methods of communication, containment and support as well as good insight in child's development and family system is the key to provide care for patients suffering with LL and LTIs'[78].

Himelstein et al highlighted that skilled management of pain and symptoms should be a cornerstone for each health professional caring and helping children and family to live to their fullest [35].

Recognizing the child' need for palliative care, becoming familiar with selected pharmacological and non-pharmacological treatments (of pain and symptoms), providing support by educating the family (about what to expect as the child moves through the trajectory of illness) and consulting palliative care specialists was recommended for every paediatric health provider[79].

2.4.3.1 BARRIERS TO PAIN AND SYMPTOMS CONTROL

Despite the World Health Organization (WHO) guidelines, the under-treatment of pain and in particular cancer pain is widely recognized and well documented health issue. Yet unrelieved pain is becoming a serious health problem causing unjustified suffering for the patients[75] .Researchers highlighted health professionals' inadequate understanding of the nature of pain in children and lack of training in assessing and managing pain[80, 81].

Barriers such as: inappropriate communication skills and use of reliable valid assessment instruments and application of non-pharmacological interventions were documented. Myths, perpetuation of old practices and stereotypes, erroneous beliefs about analgesia were found among barriers to effective pain control[28, 75]. Other potential barriers identified in achieving optimal pain control were: availability of opioids as a result of legislative and economic restrictions, as well as doctor-patient fears about opioid use [82].

Patient and family ethnic and cultural background, spiritual, religious and social factors may also influence the individual's perception and responses to pain[83]. The above factors combined with patients and families beliefs and attitudes, misconceptions and poor communication regarding pain and pain management may hamper the doctors and nurses efforts in achieving effective pain control.

The prevention and alleviation of pain is the primary goal of care in a child with LL and LTIs. However this goal (WHO) may be achieved by: regular pain assessment, access to analgesia, appropriate interventions, interdisciplinary holistic approach, 24 hours/day access to care, and clear guidelines that are individualized per patient.

"C*hildren's pain is not acceptable"*[80] and the failure to recognize and to treat pain should be addressed through concerted educational efforts among health professionals, parents and general public as well through advocacy and research[35].

CHAPTER 3: RESEARCH METHODOLOGY

3.1 AIM AND OBJECTIVES

3.1.1 AIM

This study aims to evaluate the perceived support required by doctors and nurses caring for paediatric patients with LL and LT illnesses in the paediatric unit at Dora Ngiza hospital in Port Elizabeth based on their experiences in caring for these children and to determine their perceived learning needs in aspects of paediatric palliative care.

3.1.2 OBJECTIVES:

i. To identify the educational needs amongst medical professionals caring for children with LLI and LTIs'

ii. To explore the emotional impact and the way the staff perceives caring for patients with LL and LTIs'

iii. To identify the kind of support (personal and institutional) the staff requires in order to offer the best possible care to these pediatric patients and their families

3.2 STUDY DESIGN

This is a cross-sectional study which combines both qualitative and quantitative components of research methodology.

3.3 STUDY SITE:

The research site is the Paediatric Department in Dora Nginza Hospital, in Port Elizabeth-Eastern Cape Province, which is a major referral center for a large urban and rural area in Eastern Cape.

3.4. STUDY POPULATION

3.4.1. SELECTION: INCLUSION/EXCLUSION CRITERIA

The eligible participants were all health professionals working in the paediatric unit at the time the research was approved. This included all medical staff: doctors (interns, junior and senior doctors, registrars, paediatricians) and nursing staff (professional, enrolled nurses and nurse auxiliaries).

Inclusion criteria: all medical staff (doctors and nurses) working in the paediatric unit during the study period were invited to participate.

Exclusion criteria: Allied health practitioners (occupational, speech, physiotherapists, psychologist, and social worker) were not included in this study.

The sample size required for the study was 100 participants. This is based on an expected outcome (level of knowledge) of 50% with a precision of 10% around the 95% confidence interval.

3.4.2. SAMPLING

Recruiting and enrollment of the participants was done according to the different phases of the study as indicated below: focus group, piloting and the survey questionnaire.

3.4.2.1 Focus group

The participants were recruited by using the purposive sampling technique which was based on the participants' particular knowledge of the subject being researched, similar experiences and on a balanced representation for all medical staff.

Invitation letters and information regarding the participation in the focus group discussions (FGD) was given to eight paediatric health professionals and their participation was voluntary.

The process of selecting the sample of participants for the FGD was based on the fundamentals of research methodology for health care professionals, known as purposeful sampling which recognizes that some participants are "richer" informants than the others[104].

3.4.2.2 Pilot questionnaire

The questionnaire was piloted among doctors and nurses working in the Family Medicine Department who were assumed to be knowledgeable on the subject. The purpose of piloting was to evaluate the content and face validity of the questionnaire.

3.4.2.3 Questionnaire

The questionnaire was distributed among all health professionals on duty at the time of the research. Doctors were approached by the principal investigator during departmental meetings, informed about the research and the questionnaires were distributed.

As for the nursing staff working in different sections of the department (inpatients and outpatients clinics) or working in shifts, the researcher, helped by the research assistant organized separate meeting, in which the topic and the purpose of the research were announced and questionnaires distributed.

3.5. DATA COLLECTION

3.5.1. DATA COLLECTION TOOLS

3.5.1.1 Focus group

The design of data collection tool was informed by FGD and then used as a pilot to develop and test the questionnaire for the survey part of the research[105.]

The FGD was conducted with the assistance of an experienced external facilitator. The aim of the FGD as a qualitative method was to allow natural exploration into the participant's knowledge, perceptions and opinions by enabling a discussion of a variety of views.

During the one and half hour discussions, each participant was able to reflect on his own professional experience and to contribute with a substantial amount of information.

The agenda for the FGD was constructed on the findings of the literature review, advice from the supervisor and the principal investigator's (PI) experience.

The first section covered issues of confidentiality, an introduction of the participants and to the topic of the discussion. The second section aimed to elicit participants' experiences, perceptions and challenges in relation to caring for a child with LLI and LTIs.

Further discussions explored the emotional impact and the effects of caring for children with LL and LTIs' on health professionals as well as the current available support services for families and professionals. The discussions also aimed to identify the gaps and current unmet educational, emotional and support needs of paediatric health professionals.

3.5.1.2 Pilot questionnaire

The pilot questionnaire (PQ) was designed based on the information that emerged from the FGD, literature review, advice from the supervisor and PI's own experience and was piloted on a purposive sample of six participants (four doctors and two nurses) from the Family Medicine department and who voluntarily agreed to complete the pilot questionnaire in their own time over a period of ten days, (between 22.05.2011-03.06.2011).Five out of six questionnaires were completed and returned by the due time. Piloting gave the PI the opportunity to revise the final questionnaire in line with participants 'comments and confirmed that the questionnaire was appropriate and ready to be used in the" *main investigation*"[106].

The role of piloting the questionnaire was to ensure the face and content validity of the instrument, as well as its reliability.

3.5.1.3 Validity is expressed by the extent to which a measure reflects a specific domain of content or by the accuracy with which the researcher measures a specific concept. Validity of the research involves truthfulness and this is assessed by the degree to which the observations produced are rigorous, accurate and believable for the participants and reasonably account for their experiences[107] Mays. Research found that the content validity of a study is ensured by a specific process in developing the questions, writing the questionnaire or the scale items which are relevant to each content area and

by developing a measure of the construct that includes most representative items in each content area[108].

3.5.1.4 Reliability represents the extent to which the tool used in the research, can produce similar results if repeated. In qualitative research reliability is a consequence of validity and can be assessed only when the findings of the research are finalized as reliable, valid and conclusive[106].

According to Delport, reliability defines the accuracy or precision of the data collecting instrument in respect of "how well it is being measured and not on what is being measured"[106].

3.5.1.5 Questionnaire

The questionnaire was refined after analyzing the emergent themes from the FGD, comments to the pilot questionnaire, literature review, advice from the supervisor and the researchers' own experience.

The self-administered questionnaire consisted of 18 Likert scaled questions based on and scored 1to 5 to facilitate statistical analysis. The questionnaire included demographic questions and four modules covering aspects regarding knowledge, emotional, and communication levels and support level. Two questions in relation to the learning needs and the preferred learning modality, allowed the participants to rank their educational needs in the order of preference from the greatest to the least needed.

The last two open-ended, qualitative questions gave the respondents the opportunity to make personal comments regarding the personal and institutional support they may require in caring for children with LLI's and LTIs'. Participants' insights into the complex issues with regard to their perceived support needs were more important than the generalizability of results [104.]

3.5.2. DATA COLLECTION METHODS

Two hundred coded questionnaires accompanied by a covering letter (with the instructions on how to complete the questionnaire) were distributed among nurses and doctors in the department who consented freely to participate.

The participants were asked to complete and return the questionnaires after two weeks and the timeline was extended with another week. Written follow up reminders were sent in order to improve the response rate. The estimated time for completing the questionnaire was twenty minutes.

The self-administered questionnaire contained a total of 22 items. Questions 1 to 18 fell into four categories, namely: knowledge, communication, emotional level, and support. To these questions the respondents had to indicate their answers on a five-point Likert scale, varying from 1 = very poor to 5 = excellent. Note that the following interpretation intervals, each with a range of 0.8 units, were used for the mean scores derived from questions one to eighteen: *Very poor* = 1.0 to 1.8; *Poor* = 1.8 to 2.6; *Fair* = 2.6 to 3.4; *Good* = 3.4 to 4.2 and *Excellent* = 4.2 to 5.0.

A different response scale was used for the questions 19.1 and 19.2 .The participants were asked to rank-order their educational needs and the learning modalities in order of importance by scoring on a scale 1 to 5, with 1 indicating the greatest need and 5 the least need.

The last two questions in the questionnaire 19.3 and 19.4 were open-ended questions allowing the participants to express freely their opinions regarding the support they personally require as well as the institutional support. The questionnaire is appended as Appendix I.

3.6. DATA ANALYSIS

The quantitative coded data (numerical) and qualitative (narrative) data were double captured on excel spreadsheets in order to check the correctness of the captured data. The data verification was done by using the source document as the reference.

MS EXCEL 2010 data processing, Statistical packages SPSS V19 and Statistica V10 was used for data analysis in general.

EFA (Exploratory Factor Analysis) was done by using extraction and rotation methods.

Inferential statistics were calculated to determine the significance of the relationships between the biographical variables and the questionnaire items.

The significance level p = 0.05 was used for this study implying that a p-value less than 0.05 at 5% level indicates statistical significance.

The Chi-squared test was used when both variables were categorical and the *t-test* was used when one variable was categorical with only two levels and the other one was numerical.

ANOVA with the Scheffè's post hoc test were used when one variable was categorical with more than two levels and the other one was numerical. Significant ANOVA results were followed by Scheffè's post hoc test to determine the significance of differences between individual groups and effect size measures such as Cohen's d and Cramer's V were further employed to establish how big the difference or relationship was. Cohen's d and Cramer's V tests were calculated for the mean scores and frequencies in order to establish whether statistically significant results were also of practical importance.

For the interpretation of Cohen's d, the following guideline was used:

Small if 0.2 < d < 0.5; Medium if 0.5 < d < 0.8; Large if d > 0.8

For the interpretation of Cramér's V, the following guideline was used:

Small if 0.07 < V < 0.21; Medium if 0.21 < V < 0.35; Large if V > 0.35

For the purpose of statistical analysis, the questions regarding the levels of knowledge (questions 1to 8), communication (questions 13, 14, 15), emotional level (questions 9, 10, 12) and support level (questions 11, 16, 17, 18) were calculated as summated items for knowledge, communication, emotional and support.

The relationship between demographical variables and the four summated items were analysed and only the significant results are presented in descriptive statistics as bar, pie charts and frequency tables in the chapter 4-Results.

Qualitative data collected with the open-ended questions 19.3 and 19.4 was captured on the excel spread sheet. Each sentence was examined several times to assist the researcher to develop an insight into the participants' experiences and to grasp an understanding of their concerns and perceived needs. The relevant themes to the research question were identified and grouped into common, meaningful categories which will be discussed.

3.7. ETHICAL CONSIDERATIONS

A careful consideration of ethical issues is high on the agenda of any research involving human participation.

Prior to any communication with the participants, the research protocol was submitted for approval to the Human Research Ethics Committee of the University of Cape Town: HREC REF: 432/2010 (Appendix II).

Further approval was also sought from the following: Health Research Ethics and Bio-Ethics Committee of Walter Sisulu University of Umtata, Protocol number 015/011(Appendix III), Acting Medical Superintendent of Dora Nginza Hospital- Internal Memorandum, 2nd of March 2011 (Appendix IV) and the Head of Paediatric Department (Appendix V).

3.7.1Autonomy refers to respecting each participant's decision to take part to this research, confidentiality and informed consent. Autonomy was demonstrated by respecting the choice of some of the participants who did return the questionnaire or did not answer to all the questions.

3.7.2 Informed Consent was treated as a continual process and was in line with the provision of appropriate information to the participants, voluntariness in participation and freedom to decline or withdraw even after the study has started. The informed consent form was attached to the questionnaire in order to ensure that the participants will be well informed before completing the questionnaire.

3.7.3 Privacy and Confidentiality: maintaining the confidentiality and protecting the identity of the participants was high on the agenda of this research and was insured by using coded questionnaires and safely storing all returned questionnaires.

3.7.4 Beneficence: the intention of this study is to do good to the participants. As indicated in the Informed Consent letter, the feedback with the results of the research will be first made available to all the participants. It is hoped that after presenting the outcome of the research to the hospital administrators and the provincial Department of Health of Eastern Cape, the identified support needs of the nurses and doctors will be addressed.

3.7.5 Non-maleficence: the researcher did ensure that no direct or indirect harm befell the participants, by respecting the autonomy and confidentiality of the participants, ensuring fairness and equity in selection (for the participants to FGD and piloting the questionnaire) and through careful consideration of sensitive questions.

Risk of emotional distress resulting from the deep exploration of feelings, thoughts and experiences of professional's participating to the FGD was taken into consideration. A distress protocol and the standby assistance of a psychologist and a social worker were available prior to the initiation of FGD.

3.7.6 Justice: In the context of this research, the principle of individual justice is identified with the participant's right to be part of this research and to have their experiences documented and to receive the benefits of the research.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

This chapter gives a detailed description of the research results obtained after analysing the completed questionnaires.

The design of the questionnaire was influenced by the FGD. In fact the FGD informed not only the process of qualitative data gathering but also assisted in deciding which issues to include in the quantitative section of the questionnaire. The characteristics of the participants in the FGD as well as the themes and sub-themes identified by the PI after analysing the FGD discussions are presented in the following tables: 4.1 and 4.2.

Table: 4.1: Characteristics of the Participants to Focus Group Discussions

Participant	Job Title
Participant 1	Professional nurse (outpatient clinic)
Participant 2	Chief professional nurse (HIV clinic)
Participant 3	Principal medical officer
Participant 4	Intern second year
Participant 5	Junior medical officer
Participant 6	Professional nurse (paediatric ward)
Participant 7	Specialist paediatrician
Participant 8	Professional nurse (paediatric ward)

Table: 4.2: Focus group discussion: Summarized themes and sub-themes

Themes	Sub-themes
1. Emotional issues	• Effects of emotional involvement upon the staff • Coping mechanisms • The need for emotional support for staff
2. Knowledge	• Need for pain and symptom control protocols • Need for knowledge in palliative care • Revision of the undergraduate curriculum
3. Communication	• Disclosing the diagnosis • Breaking bad news
4.Institutional support	• Needs for training and educational support for professior • Needs for emotional support structures: psychologist, cou social worker • Inclusion of health professionals in decision making (Multidisciplinary team support) • Fair allocation of financial resources • Addressing staff shortages

The site of this research: Paediatric Department in DNH is the only paediatric unit within Port Elizabeth Hospitals Complex which serves as referral center and offers secondary and tertiary care to a large number of children living in the western parts of the Eastern Cape Province. The department offers services such as: emergency paediatric services, neonatology, and intensive care, general medical wards for acute and chronic patients and specialized clinics (cardiology, oncology, genetic, allergy, endocrine, renal, wellness).

The department is a satellite unit of the Walter Sisulu University of Umtata and it is assigned to the training of paediatric registrars. The Paediatric department has a total number of 208 beds. The hospital currently employs forty three doctors at all levels (interns, junior and senior medical officers, registrars and specialist pediatricians) and one hundred and ninety seven nurses (these were figures available at the beginning of the field research). The nursing staff is seldom relocated, whilst the registrars, junior

doctors and interns rotate between different sections of the department such as: medical wards, prem unit, nursery, neonatal, intensive care unit (NICU) and out-patient clinic.

The senior doctors and registrars rotate through the pediatric intensive care unit, wellness clinic and some of the specialist clinics (cardiac, renal, genetic and neurology). Throughout the specialist clinics, the Paediatric department attends to all children diagnosed with life limiting and life threatening illnesses.

Departmental statistics for 2010 and 2011, confirm that the number of patients attending specialist clinics has been increasing every year, specifically in the Neurology, Endocrine, Renal and Haematology-Oncology clinics as depicted in the following Table 4.3.

Table 4.3 : Paediatric Department statistics for the specialist clinics 2010 and 2011.

CLINICS	2010 Follow up	2010 New patients	2010 Total	2011 Follow up	2011 New patients	2011 Total
NEURO	3043	300	3343	3662	332	3994
CARDIAC	811	165	976	747	207	954
GENETIC	225	48	303	262	43	305
ENDOCRINE	93	4	97	115	4	119
RENAL	123	7	130	172	1	173
ONCOLOGY-	653	13	666	748	11	759
WELLNESS	2077	177	2254	2081	139	2220
TOTAL	7025	714	7739	7787	737	8524

Research data collection was done by using a self-administered questionnaire (Appendix I). The first part of the questionnaire collected participants' demographic data. The second section of the questionnaire contains nineteen questions.

The first eighteen questions requested the respondents to perform a self-evaluation of their experience in caring for children with LT and LLIs' in the following categories: knowledge, emotional, communication and support.

Questions 19.1 and 19.2 explored their perceived educational needs in various aspects of paediatric palliative care and their preferred learning modality respectively. The last two open-ended questions 19.3 and 19.4 gathered qualitative data regarding the research question: the perceived personal and institutional need for support required by paediatric staff in caring for children with LT and LLIs'.

The results are presented in this chapter as one group where there are similarities or separate where they differ among the categories of participants. Demographic information, descriptive statistics for the items of the questionnaire and the relationship between the demographics and the questionnaire items are displayed in charts and tables. The results of the open-ended questions are discussed and quoted.

4.2 RESPONSE RATE

Of two hundred and forty staff employed in the paediatric department (197 nurses and 43 doctors), only two hundred were on duty at the time of the field research (157 nurses and 43 doctors); forty potential participants were not available due to: study or sick leave, annual leave or special leave or declined to take part in the research.

Of two hundred questionnaires distributed among the doctors and nurses, one hundred and fifty questionnaires were completed and returned over a three week period, resulting in a response rate of 75%.

Of the participants (n=50/200) who did not return the questionnaire, the majority were working in PICU, NICU and in the medical wards.

4.3 DESCRIPTIVE STATISTICS: CHARACTERISTICS OF PARTICIPANTS

4.3.1 DEMOGRAPHIC INFORMATION: GENDER and ETHNICITY

4.3.1.1 GENDER

Of the total number of 150 respondents, 126 (84 %) were female and 24 (16%) male as depicted in the Table: 4.2; this result reflects the gender imbalance within health care system within the nursing profession. The gender distribution appears to be balanced among the doctors but this figure fluctuates at four monthly intervals when a new contingent of interns rotates in the department.

Table 4.4: Gender distribution

Job Title	Female	Male	Total
Nurses	105 97%	3 3%	108 100%
Doctors	21 50%	21 50%	42 100%
Total	126 84%	24 16%	150 100%

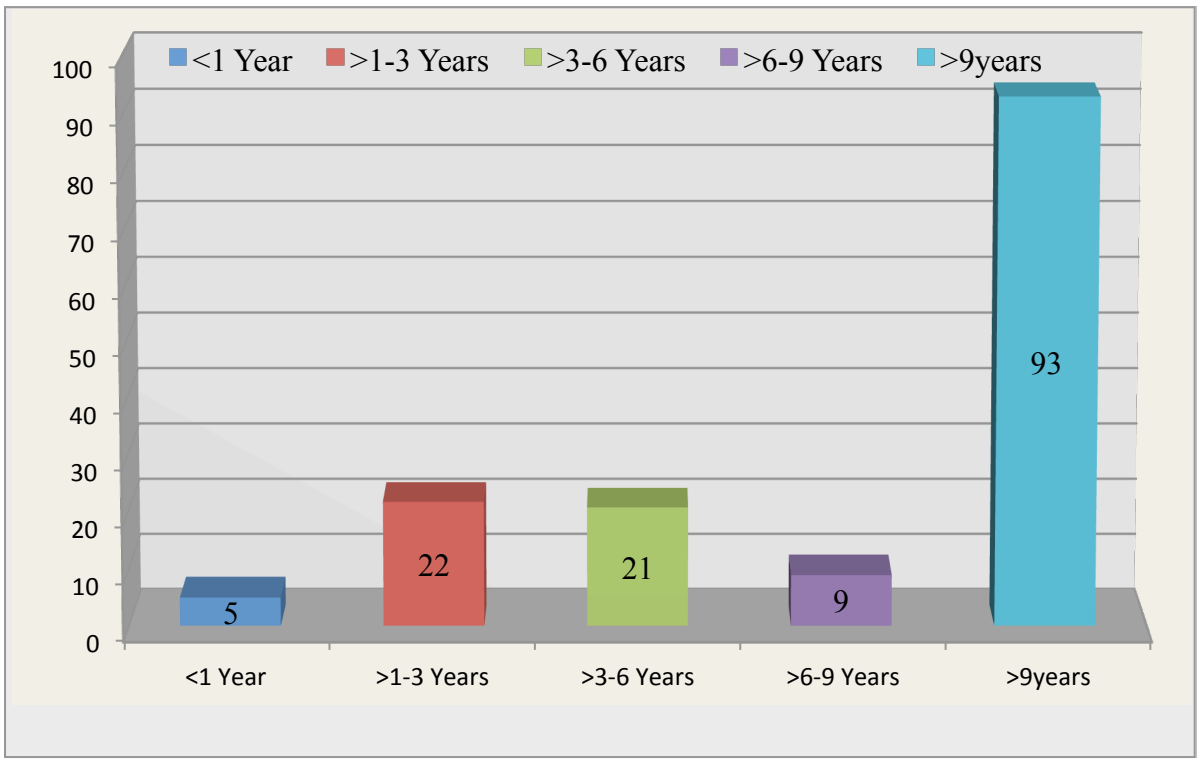
4.3.1.2 ETHNICITY

The majority of the participants were Black 88 (58 %) followed by Coloureds 39 (26%), Whites 13 (9%), Asian seven (5 %) and others, three (2%).

4.3.2 EXPERIENCE IN MEDICAL PROFESSION

As can be seen in the graph below the majority of respondents were experienced personnel with more than 9 years of medical practice.

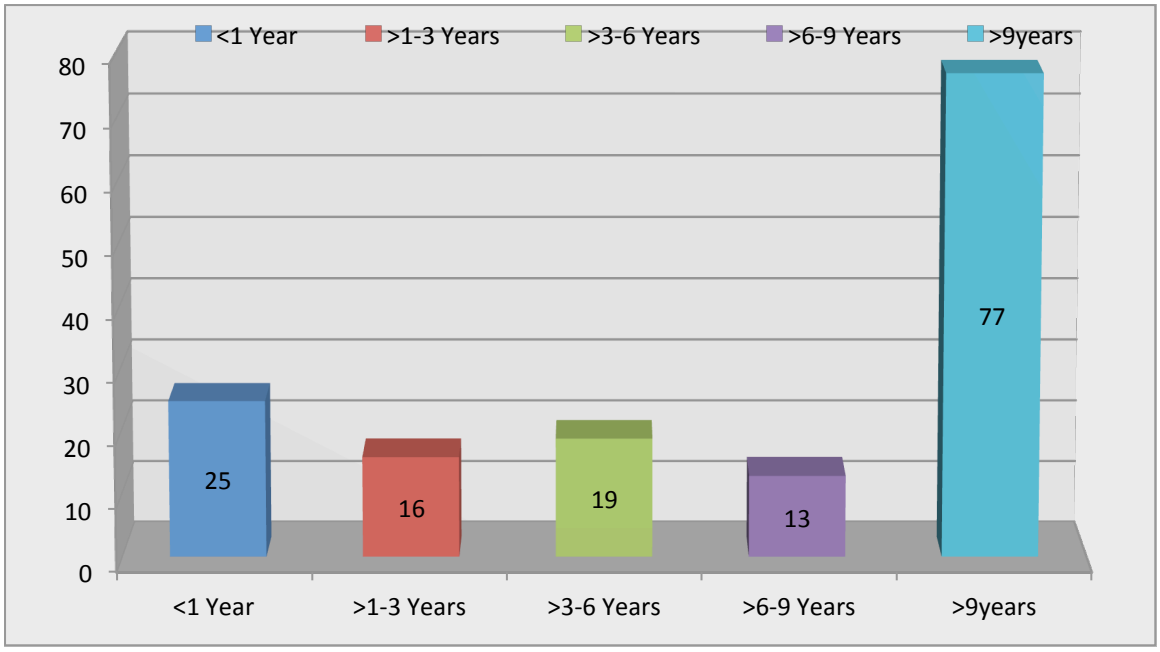
Figure.4.1: Bar chart indicating experience in medical profession



4.3.3 EXPERIENCES IN PAEDIATRICS

Of the 150 participants, half were represented by medical staff who worked in paediatrics for more than 9 years as represented in following figure:

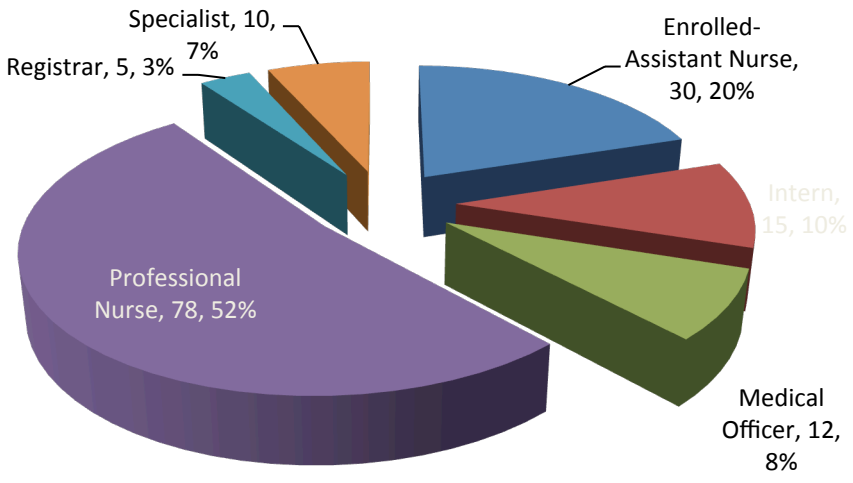
Figure 4.2: Bar graph indicating experience in Paediatrics



4.3.4 JOB CATEGORIES

Paediatric nursing staff represents more than two thirds of the participants while the doctors in all categories are just around one third. The distribution on different job categories is displayed in the following figure.

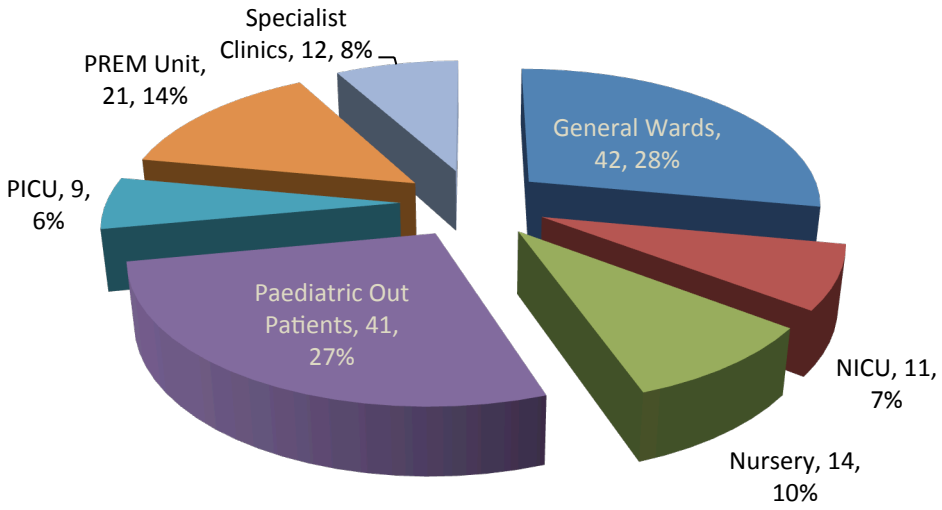
Figure 4.3: Pie Chart displaying the job categories distribution



4.3.5 AREA OF WORK

The staff (doctors and nurses) allocation at the time of the survey in the different areas within the Paediatric department can be seen in the pie chart below:

Figure 4.4: Pie Chart displaying the staff distribution in different areas



4.4. DESCRIPTIVE STATISTICS FOR THE QUESTIONNAIRE ITEMS

The first 18 questions in the questionnaire contained eighteen quantitative questions, grouped into the following categories: knowledge, emotional, communication and support.

4.4.1. ITEMS RELATED TO LEVEL OF KNOWLEDGE

The respondents were asked to rate their knowledge, by answering eight questions, in relation to the following aspects: formal training in caring for patients with complex conditions, pain management and pain assessment, symptom assessment, confidence prescribing morphine and administering morphine and knowledge about WHO pain ladder and paediatric palliative care.

Participants rated their knowledge using a five-point Likert scale format: from ***very poor-1, poor-2, fair -3, good -4*** *to* ***excellent 5.*** Table 4.5 depicts the descriptive statistics for the items related to respondents' knowledge.

Table 4.5: Descriptive statistic for Level of Knowledge items (n = 150)

Knowledge level	Mean Score	SDs'	V. Poor		Poor		Fair		Good		Excellent	
Frequencies Percentages			**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Assessing symptoms	**3.73**	0.71	0	0%	3	2%	54	36%	73	49%	20	13%
Formal training	**3.57**	0.94	3	2%	15	10%	48	32%	61	41%	23	15%
Confidence assessing pain	**3.47**	0.95	3	2%	21	14%	47	31%	60	40%	19	13%
Knowledge of pain management	**3.31**	0.92	3	2%	28	19%	48	32%	61	41%	10	7%
Confidence to admin. Morphine	**3.18**	1.20	18	12%	20	13%	51	34%	39	26%	22	15%
Knowledge of WHO pain ladder	**2.83**	1.15	21	14%	37	25%	52	35%	27	18%	13	9%
Knowledge of PPC	**2.77**	1.03	17	1 1%	44	29%	52	35%	31	21%	6	4%
Confidence prescribing Morphine	**2.31**	1.16	50	33%	32	21%	47	31%	14	9%	7	5%

Note that for mean scores (MS) derived from five-point Likert-scale items in the questionnaire, the following interpretation intervals apply: ***Very low/poor - 1.00 to 1.79; Low/poor – 1.80 to 2.59; Moderate/ Fair - 2.60 to 3.40; High/good – 3.41 to 4.20; Very high/excellent – 4.21 to 5.00.***

As depicted in the Table 4.5, only three items of the questionnaire fell into the high/good range [3.41-4.2].

The highest MS, all in the "good" interval [3.41 – 4.20] were obtained with regard to ability to assess symptoms other than pain in paediatric patients with LL and LTIs, followed formal training in caring for paediatric patients with complex illnesses and pain assessment. Table 4.6 depicts differences between job titles in relation to formal training.

Table 4.6: Job title and formal training

Job Title	Very poor	Poor	Fair	Good	Excellent	Total
Nurses	2 1.85%	8 7.41%	32 29.63%	51 47.22%	15 13.89%	108
Doctors	1 2.38%	7 16.61%	16 38.10%	10 23.81%	8 19.05%	42
Total	3	15	48	61	23	150

Chi-square 7.91 df=4 p=.09481

One of identified knowledge deficits was the confidence in prescribing morphine in paediatric population. With a MS of 2.31, 82(52%) of participants felt that their confidence in prescribing morphine was low, while only 14(9%) felt confident prescribing morphine in children**.**

Furthermore significant differences ($p<0.005$) were found in the relationship between the job title and the confidence of prescribing morphine. The results displayed in table below illustrate that 70% of doctors rated themselves as very poor to fairly confident which really does show a significant need for more training in pain control and opioid prescription.

Table 4.7: Job Title and Confidence in prescribing morphine

Job Title	Very poor	Poor	Fair	Good	Excellent	Total
Nurses	49 45%	22 20%	28 26%	7 7%	2 2%	108 100%
Doctors	1 2%	10 24%	19 45%	7 17%	5 12%	42 100%
Total	50 33%	32 21%	47 31%	14 9%	7 5%	150 100%

(Chi^2(d.f. = 4, n = 150) = 30.44; $p < .0005$; V = 0.45 Medium).

The low confidence in prescribing opioids among nurses is understandable since it is not in their current scope of nursing practice to prescribe morphine. The significance of this finding is that training nurses to prescribe opioids for children is a long way away if doctors don't even have full confidence in this matter. The MS and SD between doctors and nurses are shown in the following table.

Table 4.8: t-Test: Confidence in prescribing morphine by Job Title

Job Title	n	MS'	SD'	MS difference
Nurses	108	1.99	1.07	1.13
Doctors	42	3.12	0.99	

(t = -5.91, d.f. = 148, p = <.0005, d = 1.07, Large).

The question regarding the ability to administer the morphine was scored somewhat better in the fair interval with a MS=3.18.

Interestingly 56% of nurses versus 64% doctors rated themselves as very poor to fairly with regard to morphine administration and this is seen in the Table 4.8. This finding is contrary to the general perception that nurses would be more confident as they are more likely to administer the opioids than the doctors would. Possibly this finding is also influenced by the length of experience of the nurses.

The significance of this finding deserves further investigations and indicates the need for further education and training.

Table 4.9: Job title and the confidence in administering morphine

Job Title	Very poor	Poor	Fair	Good	Excellent	Total
Nurses	18 16%	14 13%	29 27%	28 26%	19 18%	108 100%
Doctors	0 0%	6 14%	22 52%	11 27%	3 7%	42 100%

Chi-quare 15.09 df=4 p=.00452

Knowledge of PPC and WHO pain ladder was rated as fair (MS=2.77 and MS=2.83).The fact that around 75% of respondents rated themselves in the very poor to fair interval on both knowledge items indicates the need for further education for the nurses and doctors.

4.4.2. ITEMS RELATED TO EMOTIONAL COMPETENCE

Emotional competence is a complex and critical skill. It entails resilience and the capacity and ability to manage one's emotions in challenging environments which results in individual's growth, self-efficacy and better adaptation [177,221]. Among the components or skills of emotional competence the respondents were asked to rate only three aspects: their perceived emotional status when caring for children with LL and LTIs, personal coping mechanisms and the ability to make end-of-life care decisions and the findings are depicted in the following table.

Table 4.10: Descriptive statistics for Emotional Competence (n = 150)

Emotional Competence	Mean Score	Std. Deviation	Very Poor	Poor	Fair	Good	Excellent
Frequencies Percentage			n %	n %	n %	n %	n %
Personal coping mechanisms	3.58	0.87	3 2%	10 7%	53 35%	65 43%	19 13%
Emotional status	3.43	0.84	3 2%	14 9%	60 40%	62 41%	11 7%
Ability to make EOL decisions	2.39	1.16	41 27%	44 29%	37 25%	21 14%	7 5%

A significant number of participants 81 %(122) rated their ability to make EOL decisions as very poor to fair while only 19% (28) felt well prepared to make these kind of decisions. No significant differences were found among the job categories.

This finding indicates that there is a need for more training of all health professionals in this area.

4.4.3. ITEMS RELATED TO COMMUNICATION COMPETENCE

Respondents were asked to rate the specified items pertaining to communication such as delivering bad news to the child-patient, to the parents and family, and their general communication skills in counselling the family.

Given responses were in the fair to good range for all items. However delivering bad news to the child- patient scored the lowest MS=3.15 for 40(27%) of the respondents, while BBN and communication with the parents-caregivers were in the good range with a MS of 3.43 and 3.51 respectively.

Table 4.11: Descriptive statistics for the Communication Competence (n = 150)

Communication Competence	MS	SD	V. Poor		Poor		Fair		Good		Excellent	
			n	%	n	%	n	%	n	%	n	%
Communication skills with the parents	**3.51**	0.97	6	4%	12	8%	53	5%	58	9%	21	14%
Confidence in BBN to parents	**3.43**	0.95	4	3%	20	3%	51	34%	58	9%	17	11%
Confidence in BBN to the child-patient	**3.15**	1.06	10	7%	30	20%	51	34%	45	0%	14	9%

4.4.4. ITEMS RELATED TO LEVEL OF SUPPORT

Participants were asked to rate existing emotional support structures, effectiveness of the multidisciplinary team (which should include health professionals from different disciplines, who work independently by making separate plans for each discipline in order to address the complex needs of care of children with LLI's and LTIs'), bereavement support structures and debriefing support available in their working setting. The results are depicted in Table 4.12 below.

Table 4.12: The frequency table for the level of support (n =150)

Support structures	MS	SD	V. Poor		Poor		Fair		Good		Excellent	
			n	%	n	%	n	%	n	%	n	%
MDT	**3.69**	1.12	7	5%	19	13%	24	16%	63	42%	37	25%
Emotional support structures	**2.84**	1.16	21	14%	43	29%	33	22%	45	30%	8	5%
Bereavement support	**2.61**	1.20	34	23%	40	27%	32	21%	38	25%	6	4%
Debriefing support	**2.27**	1.17	52	35%	37	25%	34	23%	23	15%	4	3%

Two items related to the support category were rated as poor: debriefing (MS=2.27) and bereavement support structures (MS= 2.61). Emotional support was rated as fair by the respondents. An overwhelming number of participants from both job categories felt that the debriefing, bereavement and emotional support structures were poor in the current setting and this finding deserves urgent attention. A significant number of participants: 100 (67%), perceived the effectiveness of MDT as good and this finding will be discussed in the next chapter.

4.5 RESULTS FOR SUMMATED SCORES PERTAINING TO KNOWLEDGE, EMOTION, COMMUNICATION AND SUPPORT

The four main items of the questionnaire pertaining to level of knowledge, emotional coping, communication competence and support were statistically calculated and analysed as summated factors (FK, FE, FC, and FS).

The internal consistency of the each summated score for each factor was verified by using Cronbach's alpha, known as a reliability index, widely used in exploratory research. Cronbach's alpha measures the extent to which the items correlate with each other and therefore measure the same construct.

Table 4.13: Cronbach's alpha for summated scores (n =150)

FK – Knowledge	0.83
FE - Emotional	0.73
FC - Communication	0.85
FS - Support	0.80
FT – Total Factors	0.83

The item analysis for the four summated scores displayed satisfactory levels of internal consistency as reflected in the Cronbach's alpha values reported in Table 4.12.

Chronbach's alpha value greater than 0.70 is sufficient evidence to support the adequate reliability of the research, according to Nunally[110].In this research the Cronbach's alpha values were all greater than the threshold value of 0.70, showing a high degree of internal consistency (reliability) of this study.

Items such as communication (0.85) and knowledge (0.83) display higher Cronbach's alpha values while emotional items show the lowest value (0.73).

4.5.1 DESCRIPTIVE STATISTICS FOR THE QUESTIONNARE ITEMS: KNOWLEDGE, EMOTIONAL, COMMUNICATION AND SUPPORT

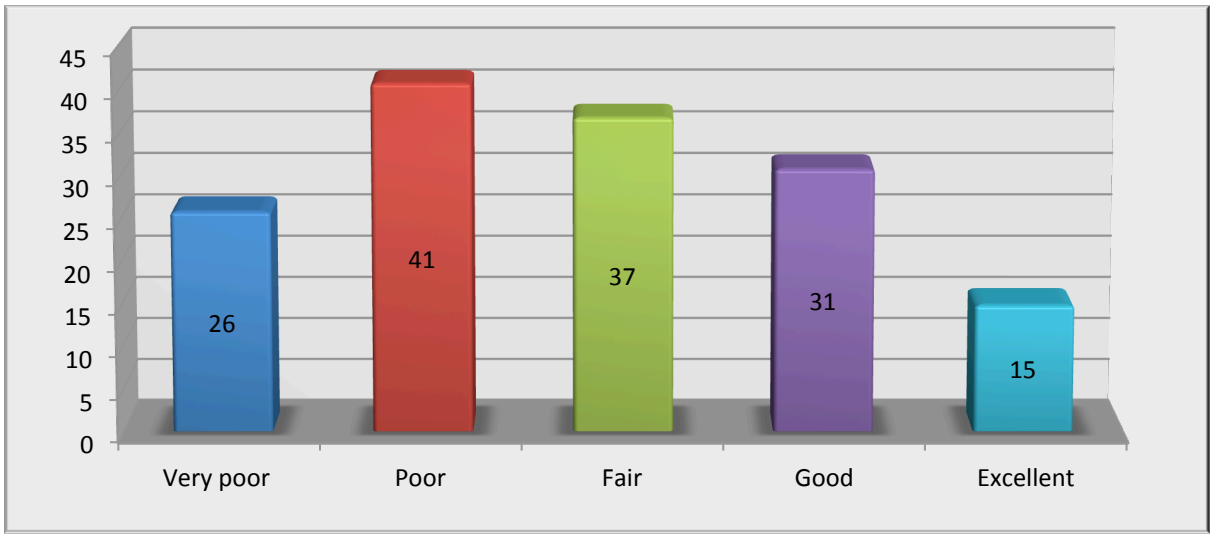
The mean score (MS) was calculated for each of the summated items: knowledge, emotional, communication, support, then the calculated scores and the frequencies were put in five categories representing an interval: very poor [1.0-1.8], poor [1.8-2.6], fair [2.6-3.4], good [3.4-4.2], excellent [4.2-5.0] as displayed in the graph below:

Figure 4.5: Standard deviation curves for summated questionnaire items: knowledge, emotional, communication and support

Among the four summated items communication rated the highest with a MS of 3.36, followed by knowledge with MS 3.15 and emotional items with MS 3.13. The summated score for support was the

lowest [MS 2.85] as illustrated in the Figure 4.5 and the distribution among respondents (Fig 4.6), supports HCP's view that support available in the paediatric setting in DNH is very low.

Figure 4.6: Bar graph indicating summated support factor-FS distribution



4.6 RELATIONSHIP BETWEEN FACTORS AND DEMOGRAPHIC VARIABLES

The relationships between demographical variables and four questionnaire items pertaining to knowledge, emotional, communication and support were statistically analysed by employing a combination of statistic tests as was described in Chapter 4 -Methodology.

To establish the relationship between categorical variables, Chi-squared demography was used and the following relationships were found to be statistically significant: Professional experience and Emotional level, Paediatric experience and Communication, Experience in Paediatrics and Total items and Job Title and Emotional level – these will be discussed further.

4.6.1 RELATIONSHIP BETWEEN PROFESSIONAL EXPERIENCE AND EMOTIONAL COMPETENCE

A significant relationship, $p<0.05$ ($p=0.039$), was found between professional experience and emotional competence (emotional status, coping mechanisms and ability to make EOL decisions). The score on the emotional competence was grouped into three categories based on the quartiles of the

score. The three categories were low (<Q1), average (Q1 to Q3) and high (>Q3) and the results are shown in the table 4.13 below:

Table 4.14: Relationship between professional experience and emotional competence

Professional Experience &Emotional competence	Low <Q1		Average Q1-Q3		High >Q3		Total	
	n	%	n	%	n	%	n	%
0-3 years	4	15%	21	78%	2	7%	27	100%
3-9 years	41	3%	21	70%	5	17%	30	100%
>9 years	24	26%	45	48%	24	26%	93	100%
Total	32	21%	87	58%	31	21%	150	100%

(Chi² (d.f. = 4, n = 150) = 10.08; p = .039; V = 0.18 Small)

All three categories of experience rated themselves in relation with their emotional competence level, mostly in the average; middle quartile (Q1 to Q3).The results are fairly similar for the categories of experience 0-3 years and 3-9 years. Interestingly, the more experienced staff rated their emotional competence lower than the less experienced practitioners and this finding will be further discussed.

4.6.2 RELATIONSHIP BETWEEN EXPERIENCE IN PAEDIATRICS AND COMMUNICATION

As displayed in the following Table 4.15 all three categories of experience fall into the average interval. However staff with longest paediatric experience (16.21%) rated communication competence better than the less experienced categories of staff: 0-3 years (3; 7%) and 3-9 years (3; 9%), in relation to communication competence.

Table 4.15: Relationship between professional experience and communication competence

Professional Experience & Communication	Low <Q1		Average Q1-Q3		High >Q3		Total	
	n	%	n	%	n	%	n	%
0-3 years	14	34%	24	59%	3	7%	41	100%
3-9 years	9	28%	20	63%	3	9%	32	100%
>9 years	12	16%	49	64%	16	21%	77	100%
Total	35	23%	93	62%	22	15%	150	100%

Chi² (d.f. = 4, n = 150) = 8.55; p = .073).

4.6.3 RELATIONSHIP BETWEEN JOB TITLE AND EMOTIONAL COMPETENCE

Although this relationship is not statistically significant at the 5% level (p=0.058), the p-value being so small still indicates that there is a fair amount of evidence that a true relationship exists in the population: doctors cope better emotionally than nurses as shown in the table below:

Table 4.16: Relationship between Job Title and Emotional Competence

Job Title &Emotional competence	Low <Q1		Average Q1-Q3		High >Q3		Total	
	n	%	n	%	n	%	n	%
Nurses	28	26%	57	53%	23	21%	108	100%
Doctors	4	10%	30	71%	8	19%	42	100%
Total	32	21%	87	58%	31	21%	150	100%

(Chi²(d.f. = 2, n = 150) = 5.70; p = .058).

4.6.4 RELATIONSHIP BETWEEN EXPERIENCE IN PAEDIATRICS AND TOTAL ITEMS

A significant relationship, $p<0.05$ ($p= 0.002$) was found between experience in paediatrics and overall survey items, including knowledge, emotional, communication and support.

Table 4.17: Relationship between Experience in Paediatrics and Total Questionnaire Items

Experience in Paediatrics & K,E,C,S items	Low <Q1		Average Q1-Q3		High >Q3		Total	
	n	%	n	%	n	%	n	%
0-3 years	10	24%	26	64%	5	12%	41	100%
3-9 years	11	34%	18	56%	3	9%	32	100%
>9years	17	22%	30	39%	30	39%	77	100%
Total	38	25%	74	50%	38	25%	150	100%

The findings show that the category with more than 9 years' experience tend to rate themselves better for all four items (knowledge, communication, emotional and support) in the 'good' and 'fair' intervals compared with less experienced categories. However the practical importance of this finding is of medium importance as confirmed by Cramer V test =0.24.

Treating each of the survey four items: knowledge, emotional, communication and support as numerical scores, ANOVA was performed to determine relationships between the survey items and the biographical variables.

The table below (Table 4.18) gives the MS' and SD' values of the factors (knowledge, emotional, communication, support) for all groupings based on the demographical variables (categories of experience and the job title), and the Table 4.19 (ANOVA results) depicts the relationships between demographic variables and Knowledge, Emotional, Communication and Support items.

Table 4.18: MS's and SD's for Knowledge, Emotional, Communication and Support Items

Questionnaire items		Professional experience			Experience in Paediatrics			Job Title	
		0-3 y	3-9 years	>9 years	0-3 years	3-9 years	>9 years	Nurses	Doctors
	n	27	30	93	41	32	77	108	42
Knowledge	**MS**	2.86	3.26	3.14	3.11	2.95	3.20	3.08	3.10
	SD	0.90	0.74	1.02	0.78	0.82	1.16	0.88	0.77
Emotional	**MS**	3.06	3.24	3.09	2.94	3.09	3.36	3.04	3.22
	SD	1.01	0.83	1.15	0.88	0.92	1.31	0.99	0.86
Communication	**MS**	3.00	3.48	3.31	3.15	3.09	3.56	3.24	3.29
	SD	1.10	0.90	1.25	0.96	1.00	1.42	1.07	0.93
Support	**MS**	2.92	2.92	2.58	2.91	2.60	2.92	3.04	2.57
	SD	1.19	0.98	1.35	1.04	1.08	1.54	1.16	1.01

Cohen's d for Job Title and FS=0.042

Table 4.19: ANOVA Results – Relationships between demographic variables and Knowledge, Emotional, Communication and Support

ANOVA		Professional Experience	Experience in Paediatrics	Job Title
	D.F.	2; 144	2; 144	1; 144
Knowledge Level	**F**	1.64	1.22	0.02
	p	.197	.300	.882
Emotional Competence	**F**	0.42	2.02	1.15
	p	.658	.136	.286
Communication Competence	**F**	1.64	3.24	0.08
	p	.197	.042	.779
Support	**F**	1.22	1.24	6.11
	p	.298	.294	.015

The table displaying the ANOVA results depicts only two significant relationships ($p<0.05$), namely: experience in paediatrics and communication ($p=0.042$) and the relationship between job title and support ($p=0.015$)

4.6.2 Relationship between experience in paediatrics and communication ($p=0.042$)

As seen in the Table 4.18 there are statistical differences between the three categories of experience in paediatrics and the communication. More experienced category of professionals in paediatric area exhibited greater confidence in communication than the less experienced professional categories: 0-3 years and 3-9 years. The significance of this finding was further analysed by using Shaffé post hoc test. The Table 4.20 (Scheffé test, above the diagonal) illustrates that the only statistical significance ($p=0.005$) was found between the categories with less experience (0-3 years) and the one with the higher experience (>9 years).This finding demonstrates that more experienced staff has greater confidence in communication.

4.6.5. Relationship between job title and support ($p=0.015$)

With regard to the relationship between job categories and support, the statistical differences are more significant. Nursing staff (MS=3.04) perceive the support higher than the doctors (MS=2.57) as seen in Table4.18.The explanation of this finding will be further discussed in the next chapter.

Furthermore Cohen's d was employed to establish the practical significance of the statistical differences between the two job categories and support. Cohen's d value of 0.32 (Table 4.20: below the diagonal) indicates that the practical significance of the finding is small and these results support the previous findings based on Chi-squared test.

Table 4.20: Scheffé test values for relationship between Communication and Experience in paediatrics(above the diagonal) and Cohen's d calculation for the relationship between Job category and Support(below the diagonal)

	0-3 years	3-9 years	>9 years
0-3 years		.777	.005
3-9 years	n.a.		.086
>9 years	0.32	n.a.	

Cohen's d

4.7 STAFF'S PERCEIVED EDUCATIONAL NEEDS REGARDING PAEDIATRIC PALLIATIVE CARE AND THEIR INDICATED LEARNING MODALITIES

Five categories of learning needs in palliative care were outlined: pain and symptom control, communication skills, ethical issues, debriefing and end-of-life issues.

The data collected during the FGD assisted the researcher to include some of participants' perceived educational needs in the questionnaire.

Most of the participants indicated that their greatest learning need was in regard to EOL issues, followed by debriefing, symptom control and ethics while communication was ranked as the least learning need. The MS', SD' and frequency distribution for each item are shown in Table 4.21.

Table 4.21: Descriptive Statistics: Participants' learning needs in palliative care (n = 150)

	Mean Score	Std Deviation	Greatest		Second		Third		Fourth		Least	
			n	%	n	%	n	%	n	%	n	%
EOL issues	**2.32**	1.42	64	43%	25	17%	29	19%	13	9%	19	13%
Debriefing	**2.37**	1.37	57	38%	30	20%	29	19%	18	12%	16	11%
Ethical Issues	**2.60**	1.31	42	27%	33	22%	35	23%	27	18%	14	9%
Pain and symptom control	**2.61**	1.46	51	34%	23	15%	31	21%	23	15%	22	15%
Communication	**3.32**	1.39	25	17%	15	10%	35	23%	37	25%	38	25%

Participants ranked their preferred palliative care learning format in accordance with their need from the greatest to the lowest.

The majority of respondents indicated as most preferred learning format the workshops while the role-play was ranked as the least learning format. The results are displayed in the Table 4.22.

Table 4.22: Descriptive Statistics: Participants' desired learning modalities (n = 150)

Learning Modalities	Mean Score	Std. Deviation	Greatest n	%	Second n	%	Third n	%	Fourth n	%	Least n	%
Workshops	**1.97**	1.30	82	55%	24	16%	21	14%	12	8%	11	7%
Lectures	**2.12**	1.38	75	50%	24	16%	25	17%	10	17%	16	11%
Bed side teaching	**2.47**	1.55	63	42%	24	16%	18	12%	19	13%	26	17%
Group discussions	**2.63**	1.41	44	29%	32	21%	31	21%	21	14%	22	15%
Role-p*l*aying	**3.17**	1.63	40	27%	16	11%	24	16%	19	13%	51	31%

4.8 QUALITATIVE DATA RESULTS

As outlined at the beginning of this chapter, a FGD helped to inform the design of the qualitative data gathering. Questions 19.3 and 19.4 were open- ended questions designed to capture participants 'concerns and perceived needs of support at personal and institutional level, in a narrative form.

4.8.1 PERSONAL NEEDS

Of 200 distributed questionnaires, 150 were returned. Only 138/150 participants responded to the question 19.3 regarding the perceived personal support required in caring for children with LL and LTIs.

Question 19.4 regarding participants' need for institutional support received comments from 140/150 participants.

The data collected from the participants narratives provided the researcher with an insight regarding the range of needs required by the doctors and nurses in caring for the children with LL and LTIs.

Analyzing qualitative data the following essential themes and sub-themes relevant to the research question emerged.

- Education and training with regard to:, knowledge about LT and LLIs and pain management
- Communication skills and BBN
- Support: emotional, psycho-social, spiritual, debriefing and bereavement support structures

4.8.1.1 EDUCATION AND TRAINING

It was clear that the participants understood that in dealing with complex conditions, specific knowledge and expertise is required to support these children and their families. This is clearly demonstrated in the discussion that follows.

4.8.1.2 KNOWLEDGE OF LIFE LIMITING AND LIFE THREATENING ILLNESSES

The need to get more education about LL and LTIs' was expressed by a large number of the participants 81(50.3%) and it can be illustrated by a few excerpts:

> **P. 049**."*…knowledge about life limiting disease. Nursing is dynamic, so we need to be updated about new developments in treatment and care of these special patients"*

The lack of suitable training and education for professionals involved in the care of children with LLCs was identified as an issue which impacts upon self-confidence as well as on care delivery.

> **P. 037**."*I think if the Department can provide me with courses that deal specifically with children; am not Paediatric trained, my experience alone does not make me perform the way I would have performed if having Paeds courses. Being trained in Peads will boost my performance and confidence"*
>
> This is really a broader statement about the need for more paediatric training in general and is not specifically about the care of chronically ill children. It does however highlight the need for more basic paediatric training even before we add additional complexities like caring for special needs children.
>
> **P.101**. "*I need formal training in caring for paediatric patient with complex illness"*
>
> **P.01**. *"Education about the child's condition, because you need to understand the condition, in order to accept how it progresses…"*
>
> **P.015**." *Orientation and consultant teaching with regard to the management &caring of these children".*
>
> **P.058**."*Having knowledgeable senior MO can educate about disease process and advice on how to deal with palliative issues.2. More exposure to palliative cases/issues (for interns) so as to increase our confidence level when dealing with palliative issue. 3. Dedicated staff members (e.g. consultant) available to discuss palliative cases and how it influences me as health professional".*

4.8.1.3 PAIN MANAGEMENT

Some participants identified specific educational needs regarding pain management and pain protocols.

P.063. *"Lectures regarding pain management and sedatives for the terminally ill".*

P148. "*Junior staff and even senior doctors need refresher courses re/pain management and teaching on how to break bad news-it helps better when one takes over the management of a patient transferred to your care".*

P.017. "*Refresher course in pain management. Review in pharmacology with specific focus of handling the side effects+ working out dosages"*

P.081."*Classification of pain and the different types of pain relief therefore i.e. pain managing."*

4.8.1.4 COMMUNICATION SKILLS, BREAKING BAD NEWS

In addition to education and training, some of the participants expressed further needs in relation to their communication skills, sharing of information and specifically in breaking bad news (this was expressed by 25(16%) of participants).

Most concerned are junior doctors as revealed by the following statements:

P.020. "*Sometimes senior doctors expect an intern to deal with talking to the family, which is difficult when you don't have the necessary experience in how to deal with questions about prognosis, etc. Sometimes you also don't have the necessary knowledge about specific condition to answer the questions appropriately.... We do not get taught at university how to break bad news, but knowing something in theory is different to actually doing it".*

P.021.*"We are taught to break bad news and deal with the illness but we don't really understand how impacts on families. Perhaps it would be useful for family members to hold discussions with doctor about what they are going through."*

P132. "*Communication towards family to support them. Giving proper education and coping skills"*

P.031."*…communication skills for communicating with parents, end-stage phase talks", understanding what the parents go through, support groups, Group discussions with colleagues…*"

4.8.1.5 SUPPORT NEEDS

Support needs appeared to differ from individual to individual. Interestingly, many respondents reported their concerns about the need for support structures able to assist not only the health professionals but the patients and their families as well. Many respondents indicated their need for dedicated emotional, psycho-social, and spiritual support structures.

The interns and nurses and senior doctors, including even the ones with longer experience in paediatrics indicated the need for emotional support, debriefing and bereavement support.

P.021." *I feel that in the medical profession it is seen as a weakness to need support (emotional, mental or even practical) when dealing with patients with life limiting illnesses. And "getting emotionally attached" is seen as wrong. Personally, an environment where emotional attachments with pts (patients) are not frowned upon would be good. Perhaps, if a patient is particularly challenging, or a long standing case, regular meetings with all health care providers+ allied health members treating the patient would be beneficial".*

P.006. "*As an intern there is a tremendous amount of stress as you feel you're pushed into these situations without enough experience" I feel a debriefing done in each ward by all staff concerned, would be helpful in coping with these life and death decisions, one must make".*

P.030.*"Having worked in Paediatrics for 30years, I feel I need tremendous support from other role players e.g. nursing staff, psychologists& social worker to assist in caring for children who suffer of LT and LL illnesses .The support one provides to the unfortunate parents will go a long way in handling with their bereavement".*

P142. "*The caring for the carers' type of support. A nurse is caring for the patient and relatives, goes through the whole process when the patient is critically until the patient dies. Throughout the process she acts as a shock absorber. At the end of the process, she needs to be taken care of herself so that she can express how she feels and gather herself for the next case".*

P141.*" I also feel that there should be psychologists available for staff working with children with LT illnesses, because sometimes you as a nurse are also affected (psychologically) e.g. by the death of the patient for example".*

P148." *Availability of the different religious "priests/pastors"/imams"/"rabbis" to assist with counselling needed with a dying child, to assist their grieving+ accommodate their religious beliefs".*

P.089." *Knowledge. Emotional care. Spiritual Care".*

P.033.*"Caring for the carer's should be a top priority*" .

P.1 *"As we deal with different cases on a daily basis, these cases do affect me emotionally. Unfortunately there is not much support you get from your colleagues due to the fact that we are short-staffed, so everyone is busy. We can only share these things during our lunch time. I am mostly depending on my family for support".*

P.3 (FGD*)"There is no support group that is offered by the department of health. The only time we were having the sessions of debriefing it was when it was provided by the NGO. Even then it was done once a year".*

P. 4 (FGD)**"***And I am sure many times you have heard "short-staffed", nurses are taking long sick leaves because they get traumatised after dealing with some issues as they are sometimes emotionally attached to some cases. So it is a vicious cycle*"

4.8.2 INSTITUTIONAL SUPPORT

One hundred and forty participants responded to the question 19.4 regarding their need for institutional support. From the analysis of captured data three main themes emerged:

- Provisions for education and training opportunities in palliative care for the health professionals
- The need for having dedicated paediatric palliative care unit within the peadiatric department
- Dedicated multidisciplinary team as fundamental part of the support structures

4.8.2.1PROVISIONS FOR EDUCATION IN PPC AND TRAINING OPPORTUNITIES

Whilst recognizing the complex and specialized field of working with children with LL and LTIs nurses and doctors identified a general lack of training, education and support.

Even when training and education needs are motivated by health professional's personal interest, it was suggested that there are institutional difficulties related to insufficient or inadequate funding and issues of staff shortages.

Some participants identified the lack of an institutional planned approach to provide them with suitable training opportunities as an issue which negatively impacts on their professional confidence and quality of service.

P127. "*All staff should have a certain level of training and competence on palliative care.*

One or two individuals should be consulted for expert advice".

P124." *The hospital management should ensure that all the personnel involved in the management of these children are adequately trained to cater for their special needs. There should be support to regular update courses organized for the personnel"*

P 5. *"What happens is that you just grab anything that comes your way in terms of training, for instance, I am a haemophilia nurse not because I wanted to do it but it was the only opportunity for me to go on training".*

P 3. "With nurses, it takes time for them to go on training. It all depends on the long list, so you have to wait for the queue. And if you decide to go for training on your own, they don't recognise that in terms of remuneration and getting higher position. If they feel you are not experienced according to them, you are less considered by the panel in an interview, no matter how many qualifications you have got".

One of the junior doctors raised the same concern:

P.028." *Putting palliative medicine teaching as part of the Family Medicine rotation. Palliative Medicine teaching in Family Medicine rotation was neglected".*

P.003. *"A pain management team which goes around or is on hand for children who are in pain.2.Specialised ward for children with LL conditions who are at the end of life.3.Play therapists to help children understand their illness 4.Meetings to discuss special case and how to go about treating a patient with input from the social workers, psychologists and auxiliary health services".*

The need of departmental formal supervision was raised by another participant; the management requires to be in touch and to have expertise in the palliative care field in order to supervise the quality of care offered to these patients.

P.019. *"Well organized training program with available resources. Examination opportunities, and to evaluate degree of improvement in knowledge and skills".*

P139. *"If I can have support systems in the institution like workshops are needed to educate the staff on communication skills e.g. counseling these patients and family and equipping them with coping mechanisms".*

4.8.2.2 PAEDIATRIC PALLIATIVE CARE UNIT

Health professionals are aware that the children with LLI and LTI have special needs and they recommended that the establishment of a dedicated PPC unit be considered.

P.020.*" there should be a separate ward for palliative care. As part of a normal ward, chronic patients are often neglected because there are children that will benefit from more time. If they had their own ward it would be better".*

P117. *"Private special unit, with available equipment and resources. Ongoing counseling for staff and family members. Enough staff to cater for patients needs and provide quality effective nursing care".*

P106. *"To have a special department for those children who need the special care. Have well trained staff, who has expertise in children with LL illnesses".*

4.8.2.3 MULTIDISCIPLINARY TEAM

Respondents expressed a need for support by a multidisciplinary team consisting of psychologists, social workers, occupational therapists, speech therapists and physiotherapists as well as representatives for different religions..

P.002. *"Multidisciplinary team of health workers (surgeons, paediatricians, physiotherapist, OT, Social worker, OT, speech therapy, dietician) all working together and update each other about needs of the patient. Proper admission space for them (open, spacious, comfortable ward). Proper protocols involved in palliative care-pain management; hygiene, oxygen, need of iv fluids".*

Further needs identified were in relation to coping with the death of a child. Due to the length of these conditions and the long-term relationship professionals have with children and their families there is a need to discuss loss and bereavement through team support, counseling and clinical supervision.

> **P139**. *"If I can have support systems in the institution like workshops are needed to educate the staff on communication skills e.g. counseling these patients and family and equipping them with coping mechanisms. We need bereavement support as well as debriefing support for the staff"*.

This research managed to identify the most stringent needs for support required by professionals in caring for children with LL and LTI at DNH. The key conclusions of the research will be discussed in more detail in the next chapter.

In summary the following items were rated by the participants as low/poor: confidence in morphine prescription, WHO analgesia ladder and PPC knowledge, ability to make EOL decisions, BBN to the child-patient, debriefing and bereavement support structures.

Two significant relationships were found: between longer experience in paediatrics and communication as well as between job categories and support: nurses rating the support better than the doctors.

The greatest learning need was in relation with EOL decisions, while the preferred learning format indicated by majority of respondents was workshops.

Participants' personal needs for support were expressed in relation to education and training about LL and LTCs, pain management, communication skills and adequate emotional, debriefing and bereavement support.

Institutional support suggested by the participants included opportunities for education and training of staff, development of a PPC unit, and adequate support structures (MDT).

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This chapter aims at discussing the essential findings of the study and the significant relationships found between demographic variables and items in the survey questionnaire.

A comparison between this study and similar studies found in the literature will also be made.

Finally, the limitations as well as the unique contribution of the findings of this research will be outlined.

5.2 RESPONSE RATE TO THE QUESTIONNAIRE

This study had a response rate of 75%. This is higher than a similar study performed by Sheetz and Sontag Bowman[110] where 54% of physicians providing components of paediatric palliative care at the Primary Children's Medical Center, Salt lake City, USA responded and lower compared with other study undertaken in Africa by Amery et al[111] where (96%) among Ugandan health professionals responded.

One cannot assume how the 25% of non-respondents would have replied to the questionnaire and how their answers would have influenced the results. The high response rate does however increase the reliability and demonstrate that the results were reflective of the views of participants and of the study site.

5.3 CHARACTERISTICS OF THE POPULATION-DEMOGRAPHIC VARIABLES

The population participating in the survey is described by gender, ethnicity, and the years of experience in medical profession, the experience in pediatrics field and job categories as well as designated areas of work.

5.3.1 GENDER AND ETHNICITY

The gender results show a big imbalance among the nurses, where 97% are female versus.3% male nurses This is understandable from a historical perspective as traditionally it was more acceptable for black women to career path for nursing profession rather than for men[112].

The gender imbalance seen within the nursing profession is not seen among the doctors, where the gender distribution is equal. The gender distribution among the doctors in our study differs from the one reflected by Sheetz and Sontag Bowmans' study on a population of physicians where 69% were male and 31% were female participants[110].

The majority of the participants were Black, followed by Coloureds, Whites, and Asian and these reflect the country's demographics[113].

5.3.2 EXPERIENCE IN PROFESSION

The participants with more than nine years of experience in the medical profession accounted for two thirds of the total population. Having such a large number of experienced, long term staff at DNH provides an opportunity to invest time in training senior staff in palliative care so they can influence the knowledge, skills, attitudes and practices of the younger, rotating staff.

5.3.3 EXPERIENCE IN PAEDIATRICS

Although half of the participants represent professionals who have worked for more than nine years in paediatrics, there is still a considerable number of staff who do not have basic paediatric training and this may make training in PPC even more difficult. The less experienced staff in paediatrics accounted for a quarter of the respondents and this would have included interns, community service doctors and junior nurses.

5.3.4 JOB CATEGORIES

Majority of participants were nurses and they represent majority of the paediatric work force and a quarter of participants were doctors. This ratio is subjected to fluctuations.

Nursing population seems to more stable compared with doctors' population which gets rotated on regular bases (interns, community service doctors, registrars) in order to get experience.

5.3.5 AREA OF WORK

The larger group of staff were allocated to the medical wards and the outpatient clinic, areas with high turnover of patients. The senior nursing staff is usually retained to work in the same area while it is common practice for the junior doctors (interns, medical officers and registrars) and newly qualified nurses to rotate in different areas of the department, in order to get exposure and to gain experience. The specialist paediatricians retain specific areas within the department based on their subspecialty, interest and experience. This staff arrangement is not different from other government hospitals. This finding poses a challenge in providing continuity of care and impacts on the quality of care for chronically ill patients with LL and LTIs'. This might be one of the reasons some participants suggested a separate PPC unit which will better quality and continuity of care.

5.4 RESULTS RELATED TO LEVEL OF KNOWLEDGE

Results of this study showed that the overall level of knowledge as assessed by the participants was adequate with deficits in certain areas which are further discussed.

5.4.1 SELF- RATED KNOWLEDGE ITEMS ASSESSED AS ADEQUATE

In this study, three of the knowledge items were rated in the good interval. These were: the ability to assess symptoms other than pain, formal training and confidence in assessing pain in children with LL and LTIs'.

5.4.1.1 ABILITY TO ASSESS SYMPTOMS OTHER THAN PAIN IN PAEDIATRIC PATIENTS WITH LIFE THREATENING OR LIFE LIMITING ILLNESSES

The highest knowledge score obtained was for the ability to assess symptoms other than pain. Nearly half of the participants self-rated this ability as good while one third indicated very poor and poor ability to assess symptoms other than pain. To compare these results which are subjective with studies using objective measurement of symptom assessment is difficult.

The results obtained at DNH are similar with those found by Sheetz and Sontag Bowman's study among a population of physicians' providing components of paediatric palliative care in USA [110].

This study found no significant differences among job categories. Looking at studies based on review of medical records it was found that nurses are more likely to report and record symptoms compared to doctors (who may not be aware or fail to document symptoms in the medical records)[114]. Carter and colleagues found that only half of the medical records contained documentation of patients' symptoms assessments done by the nurses and doctors at Vanderbilt Children's Hospital in New York[115].

Inconsistencies in symptoms assessment was not found only between nurses and doctors; Wolfe et al 'study reported inconsistencies between doctors 'who were less likely to report symptoms in children", compared with reports of their parents[74]. As the questionnaire did not include the question with regard to symptom management and one cannot assume how the participants in this study would have been rating their ability to manage symptoms.

Symptom management in children with LL and LTIs was found challenging for nearly half of doctors and half of nurses surveyed at Lucile Salter Packard Children's Hospital at Stanford, who felt inexperienced in managing patient's symptoms[57].The challenges result from the progressive pattern of the LL and LTIs and the ever changing nature of symptoms. Research proved that many symptoms remain undertreated and the area of symptom assessment and management requires additional education and training among health professionals involved in caring for these children [30].

5.4.1.2 FORMAL TRAINING IN CARING FOR PAEDIATRIC PATIENTS WITH COMPLEX ILLNESSES (LLI and LTI's

Formal training referring to training in the medical schools and the nursing colleges in the specified area under study (caring for patients with complex illnesses) recorded the second highest mean score.

The education and training recommendations for PPC encompass specific learning areas such as: understanding the multidimensional experience of suffering, skillful management of pain and other symptoms, working with the interdisciplinary team, effective communication, recognizing patients and families' cultural and spiritual diversities and responding to personal stress resulting from working with patients with LL and LTIs[117].

As an interesting finding: almost half of nurses (47.22%) and less than a quarter of doctors (23.81%) perceived their formal training in caring for patients with LL and LTIs to be good (Table 4.6, p 55).

Palliative care education for doctors and nurses in South Africa was not part of the basic undergraduate training curriculum before 2009 and therefore the accuracy of these results cannot be assessed in a self-reported study.

The findings of this study might be a valid for participants from the categories with less than nine years' experience or for some of pediatric staff who attended post-graduate courses, lectures or in-service training [117].

The doctors of all categories who reported poor formal training could have been the doctors who graduated before the inclusion of palliative care in the undergraduate curriculum for the medical students in South African universities[117] or they lacked training opportunities.

Research showed that deficiencies in palliative care practice continue despite the existence of a curriculum. In 2006, Kolarik et al revealed that the paediatric residents in Children's Hospital of Pittsburgh rated that their formal training (at the undergraduate level) before the residency program as minimal and the perceived competence did not improve with increased experience[118].This finding demonstrates that integrating PPC into the curriculum alone does not improve the quality of care for children with LL and LTIs. Staff needs ongoing mentorship and support to improve palliative care practice.

5.4.1.3 CONFIDENCE LEVEL IN ASSESSING PAIN IN CHILDREN

Pain assessment and documentation is the cornerstone of pain management. Assessing pain in children is a complex and challenging task and providing pain relief is a moral, ethical and legal obligation for all health professionals caring for children[119].

An accurate pain assessment takes into account many dimensions such as: history of pain, observation, examination and using validated tools and knowledge about pathophysiology of pain.

Confidence in assessing pain in children was rated by participants among the third highest knowledge items.

In this study**,** the confidence in assessing pain among children with LL and LTIs was the third highest item (MS=3.47).More than half of participants rated their confidence in assessing pain as good and among job categories it was found that half of the nurses and doctors perceived their confidence level as good. These results are higher than those obtained by other studies. Van Roenn et al'study that employed objective measuring instruments (cancer pain questionnaire) among a population of specialists dealing with cancer patients, found that 76% of doctors reported poor pain assessment [120].

The perception of confidence in assessing pain is not a real measure of competency and therefore the results obtained at Dora Nginza might reflect participants' overestimation of their competence with regard to pain assessment. This finding also implies that further research in this area is required.

A study which employed objective measuring instruments such as: cancer pain questionnaire et al' study among a population of specialists dealing with cancer patients, found that 76% of doctors reported poor pain assessment [120.]

Half of nurses in DNH indicated good confidence in assessing pain in children and this finding is similar to McCaffrey et al' study [121].The explanation for this finding results from nurses' unique role in assessing and managing pain. A nurse may have closer relationships with the patients and families due to their longer working shifts, and it is through nurses that most patients and families have the opportunity to report pain[121].

No significant relationship was found between the level of confidence in assessing pain and the categories of experience in DNH' study.

The literature shows that optimal pain assessment in children requires knowledge of appropriate assessment including the use of pain tools, and standard pain protocols.

Poor pain assessment and documentation as well as poor pain management among doctors and nurses was observed by Henley in a South African retrospective study (Red Cross War Memorial Children's Hospital in Cape Town in 2002) [122] .

Similar studies conducted on nurses' knowledge, attitudes and practices in relation to pain assessment in children revealed a lack of knowledge of pain tools among nurses and they were not aware of their knowledge deficit (UK study) [123] . A Canadian study concluded that pain was infrequently assessed in patients' charts [124] and other studies revealed that health professionals' pain assessment does not always correlate with parents' assessments as the primary source of information or with child-patient self-reports of pain pain[125, 126].

5.4.2 SELF-RATED KNOWLEDGE ITEMS WHICH NEED ATTENTION

5.4.2.1 KNOWLEDGE IN MANAGING PAIN IN CHILDREN WITH INCURABLE CONDITIONS

Pain is considered the fifth vital sign[128.] Addressing pain is an issue of great concern among health professionals[128] and inadequate pain management is regarded as a poor medical practice which impacts negatively on patients and families according to Brennan et al [70].

In South Africa pain and in particular cancer pain "*is common, it is a problem, and it's not well-managed*" as revealed by Beck's study[129].In this study knowledge of pain management compared with confidence in pain assessment was rated lower by participants. More than half of participants rated their knowledge in managing paediatric pain as poor to fair and this finding indicates the need for more education and training.

Among the job categories the study found significant differences: nurses rated their knowledge in managing pain in children with LL and LTIs' better than doctors (57% nurses versus 22% doctors). A possible reason for poor pain management among doctors at DNH might be the lack of formal training and this finding is similar to a study conducted among 368 doctors from different area of

practice in Michigan[131]. Green et al found that one third of them reported lack of formal education or minimal education in pain management during medical school, residency training or via continuous medical education program [130]. On the other hand, nurses' confidence to assess pain correlates with their closer relationships with the patients while their knowledge in pain management might be related to their existing theoretical knowledge, experiences, attitudes and practices.

An Italian survey among doctors and nurses from different clinical practice areas revealed knowledge deficit with regard to paediatric pain and its management with no significant differences between doctors and nurses[131].

Dora Nginzas' study did not show any significant difference between knowledge in pain management and categories of experience or area of work and this finding is similar with Salanterä's study[132].

A positive Relationships between health professionals 'knowledge in pain management and years of experience was found in a study among doctors in New York [133.] Manworrens' study among nurses found a positive relationship between pain management and area of work: ICU and emergency department nurses having better knowledge of pain management[134.]

Paediatric nursing staff in DNH who reported their knowledge in pain management as very poor to fair might not have enough experience of nursing children in pain as very few of them are caring for children with cancer pain and they do not rotate through oncology. On the other hand the question was asking about knowledge in managing pain generally and did not measure how they applied the knowledge in practice which is a subject for further research

As the results regarding pain management are based on a self-assessment further research is required in order to establish the real level of knowledge and how knowledge is applied in daily practice.

An international survey which included South African nurses working in paediatric oncology wards in two hospitals in Pretoria revealed that the level of knowledge among South African nurses is adequate but highlighted that the management of pain is suboptimal[135].

The reason for this finding is not the nurses' theoretical knowledge but their ability to apply their knowledge appropriately in practice as showed by Lic et al' study[136].

However pain management deficiencies continue even among oncology nurses who perform better in the area of pain management compared with greater deficiencies found among non-oncology nurses[137].

Studies on pain knowledge and management among health professionals showed surveyed nurses felt they were doing a better job than the doctors in managing patients' pain and nurses evaluated the physicians' role in pain management as very poor and poor[121]. Results of studies done in countries such as: USA, Israel, Tasmania revealed lack of experience, knowledge deficits in area of pain management as well as inadequate knowledge of analgesia to be amongst barriers to adequate pain control[57,138,139].The situation is acute settings is not much different: and pain control is still suboptimal[140].

Results in relation to pain management among paediatric staff in DNH revealed some inconsistencies between nurses and doctors confidence in assessing pain and managing pain in pediatric population. These findings indicate that gaps of knowledge in relation to pain management need to be addressed through educational programs and training.

Inconsistencies between pain assessment and its management were observed by Jacob and Puntillo in a survey among nurses from Children's Hospital in Ohio[142]. Other studies found knowledge deficits[123] of pain tools and pain protocols or failure to appropriately apply theoretical knowledge in practice[135] as barriers to effective pain management.

5.4.2.2 CONFIDENCE IN PRESCRIBING MORPHINE IN CHILDREN

A large number of participants (86%) rated their confidence level in prescribing morphine in children low and this finding ranked as the lowest among the questionnaire's knowledge items. Only a small percentage (14%) of medical staff perceived their confidence in prescribing morphine as good and excellent.

Research on health professionals' knowledge and confidence, attitudes, practices and beliefs revealed similar findings with those found at DNH' study. Inadequate knowledge of pain assessment and management during the medical school education was highlighted by numerous studies[139, 142]. Other studies found among the barriers to prescription of opioid analgesia the following: poor knowledge of

pharmacologic properties and use of opioids [138], resistance to the use of opioid analgesia [143] and fears of addiction (opiophobia) or titration [144] ,[145] ,[138,146,142], respiratory depression, fears of overdosing as well as personal judgments[147] .

Surveyed doctors exhibited greater confidence of prescribing opioids in children compared with nursing staff and this finding wasn't unexpected.

Confidence in prescribing morphine in children was found to be higher for doctors compared to nurses and this finding is further discussed and compared with literature. Among doctors population, less than one third (28%; n=12/42) perceived greater confidence in prescribing opioids in children and they may have been experienced doctors. Two thirds of doctors who weren't confident could have been interns and junior doctors who may have the theoretical knowledge but lack the clinical experience and confidence and therefore they need consultants' and senior doctors' supervision to prescribe morphine. The results are rather similar with those obtained by Sheetz and Sontag Bowman among physicians at Primary Children's Medical Centre in relation to their confidence to use opioids [110].

Large number of pediatric nursing staff (91%; n=99/108) rated their confidence in prescribing opioids in children from very poor to fair and only a few of them reported feeling confident. The results among nurses are not unexpected; South African nurses are not trained to prescribe opioids but doctors are and they are expected to have appropriate knowledge and competencies regarding opioids prescription.

Traditionally nurses are not trained to prescribe morphine and "*they regard their role synonymous with the administration of drugs* "[148].

There are exceptions, in countries like Uganda, where the hospice has convinced the government to allow palliative care nurses to prescribe morphine to cancer or HIV patients [149] .Nurse prescribing opioids in South Africa is currently being explored by the nursing council and the national alliance for Palliative Care (personal communication).

Some discrepancies were found between participants' confidence in morphine prescription (MS=2.31), WHO analgesia step ladder (MS=2.83) which were perceived among inadequate knowledge items and pain management (MS=3.31) which was rated higher. These findings may indicate that participants overestimated their knowledge which was self-reported. Theoretical knowledge does not always translate into improved practices as revealed by other studies[136, 150.]

Knowledge deficit in the use of opioid analgesia seems to be of a greater concern among health professionals[151, 152.] This needs to be addresses through formal education and training that will increase health professionals 'knowledge and expertise.

Research showed that irrespective of working experience, health practitioners may encounter different barriers related to gaps in knowledge, communication with patients or institutional regulations[119].

Opioid prescription for non-malignant chronic pain reported even more negative feelings, attitudes, misconceptions[14] and concerns compared with malignant conditions causing pain and this was shown in a number of studies.[153, 154,155].

Barriers with regard to analgesia and in particular to opioid analgesia continue to hamper the efforts to manage pain effectively to achieve complete relief.

5.4.2.3 CONFIDENCE IN ADMINISTERING PRESCRIBED DOSES OF MORPHINE

More than half of participants (59%; n=89/102) indicated having very poor and fair confidence in administering opioids to children. Nurses confidence in administering morphine to children was higher compared to doctors' (44%; n=47/108nurses versus 32%; n=14/42 doctors). This finding was to be expected due to the fact that administration of drugs, including morphine, is one of the major duties of the nurse as doctors very seldom administer drugs to patients[148.]

The fact that 56% of nurses (61/108) rated their confidence in morphine administration as low is raising a serious concern and this finding needs further exploration and warrants for education of staff.

5.4.2.4 KNOWLEDGE OF PAEDIATRIC PALLIATIVE CARE

Level of knowledge with regard to PPC was found in the fair interval .No significant difference was found between doctors and nurses.

Among the participants only a quarter rated good and very good knowledge of PPC. It is possible that they were junior staff who received undergraduate education and training with introduction of palliative care curriculum in South African medical schools.

The Paediatric Department in DNH does not provide specialized paediatric palliative care services and most of the patients with LL and LTI's are cared for by health professionals without specialist palliative care training and they are still expected to have knowledge of PPC. The results indicate the need for palliative care teaching in order to assist paediatric staff to face the challenges of care for patients with LL and LTIs.

Lloyd et al' findings highlight that despite palliative care teaching within undergraduate training, a lack of knowledge and skills still continues among health practitioners[156].

Globally, the first commitment to palliative care education was made in the UK in 1994 by publishing the first generic palliative care curriculum and the USA followed suit in 2000.

In South Africa palliative care learning was initiated by the Hospice and Palliative Care Association of South Africa (HPCA) which offered a training program to nurses.

As a result of the increasing burden of diseases[157] Bradshaw et al in line with World Health Organization[158] recommendations, advocated to include compulsory Palliative care training in the medical schools and nursing colleges curricula. Palliative care teaching and training started in 2000 at UCT by postgraduate program, followed by the undergraduate teaching [117, 159] while a basic nursing degree in palliative care is offered at The Cape Peninsula University of Technology and Tshwane University. However there is still an urgent need to improve palliative care knowledge, skills and competencies among South African health professionals.

WHO recommends that all students and health professionals be provided with teaching and training in palliative care together with the integration of palliative care services at every level as part of universal access to care[158].

Evaluating outcomes of the postgraduate educational program at UCT, Ens et al found significant progress with regard to professional's knowledge and confidence in providing palliative care and it appeared that the training had beneficial effects in all areas in which the professionals perform their duties[118].Another study revealed that basic in-service training among newly qualified doctors, increased confidence in medical management and communication skills with most valuable teaching being on pain control[151].

Despite these recommendations Hyson et al found that PPC services still remain underdeveloped in paediatric settings[25] and there are significant deficits in provisions of adequate education in palliative care both at under-graduate and post-graduate level [151] resulting in a lack of confidence and ability to provide palliative care by many professionals[110]

Research among diverse population of practitioners (who deal considerable number of patients who require palliative care) such as paediatric oncologists [162] paediatric residents[118], haematology-oncology fellows [163] and general practitioners[158]revealed that lack of formal education [160] in PPC curriculi are barriers to palliative care [156].

Studies of an undergraduate didactic curriculum found no real improved comfort and competencies despite increased educational efforts. This may be due to the perception among professionals that palliative care is synonymous with advanced cancer and care for dying [156] while others do not regard palliative care as core competency and they view palliative care as "*low-tech or soft*". Therefore don't seek skills and competencies despite the growing evidence [118,162].

Some professionals felt that learning palliative care on the job requires good mentorship in addition to knowledge acquisition[163].

Implementing palliative care programs within medical facilities requires consultancy, collaboration and coordination between the interdisciplinary team and the primary care team which will allow

continuity of care for the child and family. Achieving this goal is a challenging task due to barriers such as: lack of formal training, role modeling, feedback and mentorship and negative perception that palliative care moves away from curative treatments [164,163].

It is rather difficult do identity which of the challenges faces the paediatric staff in DNH right now. However it is the institutional, departmental and health professionals' task to identify and overcome the barriers of care but this requires further research.

5.4.2.5 WHO PAIN LADDER

The question with regard to knowledge of the WHO pain ladder was rated in the fair interval. A large number of participants, 75% rated their knowledge as poor to fair. No significant differences were found between nurses and doctors.

The WHO analgesic ladder was developed in 1986 as a three- step guideline as an approach to the management of cancer pain matched with pain severity. Research shows that most cancer pain can be effectively controlled (70-90%) by using the WHO three step pain ladder. The same ladder is also recommended for use among paediatric patients.

This development was praised by WHO a few years after the inception of the pain ladder: "*Nothing would have a greater impact on the quality of life of these patients than the dissemination and implementation of knowledge already available in relation to pain and symptoms"*[165].

Research showed that after more than twenty years since the introduction of WHO pain ladder and despite palliative care teaching within the undergraduate training the lack of knowledge and skills among practitioners continues and this is also a valid finding for our study [156.]

WHO standards recommend the use of strong opioids for moderate-to-severe cancer pain, orally, around the clock, and make provision for the treatment of breakthrough pain and also for medications to be prescribed concurrently to counteract the side effects of opioids (nausea, constipation, sedation) [166].

A South African study exploring the knowledge, attitudes, practices and beliefs among registered nurses providing palliative care found that half of the respondents had good knowledge about the WHO pain ladder guidelines with regard to combination of drugs.

The same study highlighted that knowledge level was higher among nurses providing palliative care compared with the nurses working in the general wards, and a link between the degree of qualification and the clinical practice setting [150].

A study in palliative care conducted among different categories of doctors (interns, medical officers, specialists) at Polokwane/Mankweng hospital complex, in Limpopo Province revealed that two thirds of doctors were not familiar with the WHO guidelines and only one third of the surveyed doctors were aware of WHO pain ladder guidelines[167]. DNHs' results in relation to knowledge of WHO pain ladder are similar with those obtained in Limpopo Province

Lack of knowledge and expertise, limited access and understanding of the WHO analgesic ladder are not limited only to Limpopo or the Eastern Cape Province.

In his report to WHO, professor Kumar revealed that there is "*little support for paediatric pain management available in most South African hospitals, mainly due to lack of knowledge and expertise*"[168] .

Unfortunately the same situation has been reported in Sub-Saharan Africa by Harding et al [169].

Similar knowledge deficits in relation to WHO analgesia basic principles and recommendations were found among nurses in developed countries. Researchers found that in countries with longer exposure to palliative care, nurses' level of knowledge was higher than in countries without traditions in palliative care. The authors of the study, McCaffrey and Ferrell concluded that improving education alone is not enough [121].

Research conducted in South Africa revealed that in order to promote adequate pain management and to achieve effective pain control education should be complemented by other key factors (such as communication, patient- health professionals and interdisciplinary team working) and the necessary human and financial resources [170].

African countries have the lowest morphine consumption in the world at 0.7mg/capita and South Africa has the highest consumption at 3.4mg/capita among African countries.

In contrast industrialized countries use of morphine is 20-75mg/capita. Limited opioid analgesia combined with the lack of knowledge is a huge challenge in treatment of cancer and HIV pain[171].

South Africa served as an international example by improving drug availability with the introduction of paracetamol, codeine, and morphine on the Essential Drug List (EDL) for primary health care [172].

The results of this study did not find correlation between knowledge of the WHO pain ladder, pain management and morphine prescription. The findings support the assumption that health professionals with appropriate knowledge of WHO analgesic guidelines will have the ability to apply their knowledge in managing pain using appropriate pharmacological options to the benefit of their patients.

The strategy to address medical professionals' knowledge deficits about the WHO pain ladder within the framework of the "ladder and the clock" requires consistent educational and training programs [173].

5.5 RESULTS RELATED TO THE EMOTIONAL COMPETENCE

Emotional competence will be discussed in specific areas: emotional status, personal coping mechanisms and the ability to make EOL decisions.

Among categories of experience, HCP with >9 years' experience rated their emotional competence in the lower interval compared with less experienced staff (Table 4.14, p 61).This finding reveals that longer exposure to children with incurable pathologies results in burnout and compassion fatigue among HCP making them less able to cope emotionally. In contrast junior staff with limited experience in caring for children with LL and LTI's rated their emotional competence higher and this finding will be discussed in the following chapter.

Opposed to nurses, doctors in this study reported their emotional competence better than nurses. This finding is due to doctors' poor self-awareness. Study found that often doctors under report emotional distress and they seldom seek emotional support compared to nurses[101].

Two of the surveyed emotional items: professionals' emotional status and their coping mechanisms were rated by the participants in the good interval, while EOL decision was rated in the poor interval.

Health professionals caring for children with LL and LTIs' cannot avoid getting "emotionally involved"[5]. Circumstances surrounding children with malignant, chronic and terminal conditions are stressful and in response to patients 'illness, health professionals develop their own emotions such as: sense of failure, frustrations, fears, or cross the boundaries and become deeply involved [163]. Unresolved emotions and exposure to death and dying affect the coping patterns and may result in professionals' distress, avoidance, disengagement, poor judgment and burnout [174].

5.5.1 EMOTIONAL STATUS refers to emotional skills at handling emotional situations. Certain conditions such as LL and LTIs have an indisputable emotional impact and predispose health professionals to risks of over or under engaging which can affect the quality of care to patients.

Nearly half of participants perceived their emotional status as adequate. Amongst job categories, more nurses (47%; 51/108) perceived their emotional status as good compared to doctors (26%; 11/42). This finding reveals that nurses exhibit better emotional skills possibly due to the fact that they spend more time with patients and families than doctors do. No significant relationship was found between emotional status, categories of experience and working areas.

Reidinbaugh et al' study found that emotional status varies among categories of doctors with the level of training, with interns being more affected than registrars or consultants [175].Inadequate training in communication skills affects professionals 'emotional status and does not get better with more experience as found by Fallowfield and Jenkins' study [89]

It is possible that participants to this study introduced desirable bias with respect to their degree of emotional status. The results are subjective participants' measure their own status that may not be the general pattern of emotional behavior which would require further research.

A recent study concluded that exposure to chronic or terminally ill patients may also have positive influence on medical professionals including personal growth and finding meaning in life. Nurses reported higher level of personal growth than doctors as a result of their closer, more intimate and longer involvement with the patients [176].

5.5.2 COPING MECHANISMS were rated good by more than one third of the participants. Among job categories, doctors (50%; n=21/42) rated slightly better than nurses (41%; n=44/108).Only few participants among doctors and nurses indicated poor coping mechanisms when dealing with children with LL and LTCs. The finding is similar with those of Redinbaugh et al study, where majority senior doctors were equipped with coping mechanisms compared with the interns and the registrars who indicated their need for support from the senior doctors in order to cope with the emotional issues around death and dying [176].

Coping mechanism or emotional survival is a core concept and key skill in managing emotional aspects of the work. It may involve strategies such as: shielding, processing and emotional postponing. Sandgren et al found that palliative care nurses achieved their emotional survival by using shielding strategies in order to avoid emotional overload and to protect themselves in relation with the patients [177]. Paediatric oncology nurses used strategies such as: emotional expression, reflection, problem solving, spirituality and religion, as well as social support[178]. It is rather difficult to assume what types of strategies are employed by the staff in the paediatric department at DNH. Findings of studies done in palliative care or oncology units in the developed world may not be transferable to our setting due to a different philosophy of care, high workload, limited time and a lack of training.

5.5.3 A**BILITY TO MAKE END-OF-LIFE DECISIONS** was the second lowest item (MS=2.39) after debriefing support.

EOL decisions in paediatrics are sensitive and often emotionally charged. Decisions not to use aggressive therapies, withdraw or withhold life-prolonging treatments represent *"the most challenging and morally driven decisions"* [179].

EOL training is guided by a number of principals in relation: to appropriate communication with children, information sharing, patients' best interest, and treatment of physical and emotional symptoms, partnership with families and health providers and personal challenges [180].

Participants of the study perceived a lack in their ability to make medical decisions towards the end of life phase.

This finding raises a serious concern as health professionals' inability to make EOL decisions has the potential to affect not only patient's care, but also families and professionals alike. In view of these results, further formal training, mentorship and development of departmental policies with regard to EOL decisions are urgently required.

Insufficient formal training and mentorship, sense of failure, fears and minimal exposure to death and dying may be the reasons for these findings, which are supported by previous researches done globally [16, 179,181].

Only few participants perceived their ability to make EOL decisions to be good. No significant differences were observed among the job categories.

In reality nurses are not supposed to make decisions to limit care, this task being doctor's ultimate responsibility; however, this does not preclude nurses' involvement in the decision to limit care.

EOL decisions should be a collaborative process between doctors and nurses. In this process nurses are important collaborators for the doctors and facilitators for the patient and family by, helping them to deal with high levels of emotional distress [182, 183].

Participants' poor ability to EOL decision making is reflected in their increased learning need about EOL issues, which was ranked among their greatest learning need by almost half of participants.

No significant relationships were found between the ability to make EOL decisions, category of experience or the area of work.

Research among paediatric oncologists showed that despite not receiving any formal EOL training, they were comfortable to deal with EOL psychological issues and with EOL pain. This finding is not unexpected among oncologists who deal on a daily basis with pain, complications of treatment and

many psychological issues. Learning from experience, mentorship and increased time in practice may be factors associated with their increased comfort in dealing with EOL issues [184].

Numerous studies found that professionals' inability to make EOL decisions resulted in suboptimal patient care during the end of life phase with regard to pain and symptom control[115]. Research found that lack of EOL decisions may result in difficulties in bereavement issues for staff as well as for family members[179] and avoiding of patients at the end of life phase could lead to a sense of abandonment on the part of the families [181.]

Poor or inadequate undergraduate training [118, 100,185,187], and lack of basic competency and skills among paediatric staff, who received some training [99] were found by different studies .The absence of role-models and lack of institutional EOL policies[56] combined with the culture in many hospital setting which does not encourage the learning about this subject are demonstrated as barriers towards EOL decisions[186]. Prognostic uncertainty, relationship between curative and palliative management and the transition of care, limited experience with death in childhood, combined with ethical issues such as: fears of litigation, patients' role in decision making, best interest and the appropriate course of care may affect health professionals EOL decision making **[16]**.

Furthermore, late communication with families [98,162] and lack of communication between doctors and nurses with regard to the treatment plan, unnecessary prolongation of life and lack of EOL practices affect doctors and nurses competence to make the final decisions[188].

The barriers identified by other studies are relevant to our setting and require further exploration.

The essence of providing good EOL according to Dame Cecily Saunders-the founder of modern hospice movement, is not only professional competence but professionals awareness of their own humanity: "*The dying need the friendship of the heart—its qualities of care, acceptance, vulnerability; but they also need the skills of the mind—the most sophisticated treatment that medicine has to offer*"[189.].

5.6 RESULTS RELATED TO COMMUNICATION COMPETENCE

Three specific items pertaining to communication were rated by the respondents: communication and counseling of the parents, confidence level when delivering bad news to the parents and confidence level in BBN to the child-patient. Only BBN to the child-patient was perceived as low. Communication skills and BBN to parents of children with LL and LTI were rated higher by participants.

5.6.1 COMMUNICATION SKILLS WITH PARENTS OF CHILDREN WITH LLI AND LTI

The results were found adequate (MS=3.51) without significant differences between nurse and doctors.

More than half of respondents indicated as having good and excellent communication and counseling skills with the parents of children with LL and LTI. These results being self-reported reflect participants' perception and are not a real measure of their performance.

Training in communication skills is usually acquired through the formal training at the undergraduate level or are acquired on-the-job or through self-directed learning.

Contro et al' study reported that majority of paediatric staff felt inexperienced and inadequate in communicating with families and that poor training was the reason for the lack of communication competencies[57]. Poor communication results from the fact that medical curriculum puts little emphasis on developing communication skills. Paediatric residents participating in Kolarik et al' study expressed their needs with regard to communication skills such as BBN and talking to the children about EOL issues and discussing prognosis [118].

Communication is regarded as an essential core competency and as an essential skill involves supervised practice, feedback and mentoring [190].

Effective communication involves not only making information available (cognitive dimension) but requires interpersonal sensitivity (emotional dimension) in discussing emotional and distressing facts, as well as building partnership with the child and family [192].

5.6.2 CONFIDENCE LEVEL WHEN BBN TO THE PARENTS

Results showed that half of participants feel confident in communicating bad news to parents of children with LL and LTCs and no significant differences were found between job categories, area of work or category of experience. These results reflect participants' perspective and not a measure of their skills in BBN. Research showed that self-assessment with regard to BBN is not always accurate. Leventown's study found that respondents tend to overestimate their skills and when the skills are inadequate the strategy is to avoid or disengage from difficult conversations[190].

Meert et al' study found that doctors at all levels self-reported discomfort in communicating bad news had limited training and a need for further education. Parents and families dissatisfaction with doctors' communication supported the finding[194].

BBN is not an easy task even among the oncologists who are dealing only with patients LTCs' and they are expected to have better ability in BBN [193].

Barnett et al' study found that senior consultants (qualified before 1980) lacked formal training compared with the younger consultants. Both groups expressed a need for further training in communication skills as the majority of them acquired skills through on-the job-learning [195].

BBN is a difficult task and critical skill which requires planning and training and is associated with considerable distress, as highlighted by previous studies [87, 90,193].

5.6.3 CONFIDENCE LEVEL WHEN BBN TO THE CHILD-PATIENT

The lowest scored item among the communication skills was BBN to the child-patient.

Only one third of participants reported good confidence level. Among job categories, doctors rated slightly better than nurses but not significantly.

More respondents (27%) reported poor confidence level in relation to BBN to the child compared with confidence in BBN to the parents (16%) and this finding is similar with those of Rider et al [198].

Zwaanswijk and colleagues observed that the task of BBN to a child is difficult and communicating upsetting news is left to the parents, unless the child is a teenager or there is a lack of a parent/caregiver. Parental shielding hampers the efforts to establish a good relationship between professionals and the child-patient and leads to the child's marginalization. Therefore reassessing communication preferences should be a continuous process, in accordance with changes in the disease status and balanced between parents and patients preferences [197].

The Child has the right to information, to get involved in treatment choices even if his decision does not determine the treatment plan. Health professionals have the ethical and moral obligation to involve children in communication about their health and health decisions based on the self-determination principle and with respect to their capacities; where older children and teenagers have bigger role to play [190.] A significant relationship was found between all three items (communication with parents, BBN to parents and BBN to child-patient) and categories of experience: most experienced staff (> 9 years) ranked their communication skills higher than the least experienced category: 0-3 years. The significance of this relationship ($p=0.042$) indicates that longer professional experience results in improved communication skills. As revealed by research, longer experience may increase basic communication skills but not necessarily advanced communication competencies such as BBN [197].

Good communication helps professionals to handle their own emotions and affects patients' satisfaction with their care, quality of life, adherence to treatment and helps patients to understand and accept their condition [89].

5.7 RESULTS RELATED TO LEVEL OF SUPPORT

The questions pertaining to the level of support required by HCP was the main aim of this research. Support was ranked the lowest item in the questionnaire [MS=2.85], and this finding is illustrated by Figure 4.5.

5.7.1 EMOTIONAL SUPPORT STRUCTURES

Two thirds of participants (65%) rated low the emotional support received in the paediatric setting. A significant statistical relationship (p=0.015) between job category and support level was found: nurses rated support structures better than doctors. The finding reveals that nurses in paediatric department support each other better than the doctors in the absence of formal support system. These differences may be explained by their different roles within the department and the findings are supported by previous research. Keene et al found that doctors seldom sought emotional support [101] while nurses seek and rely strongly on support from their colleagues and the institution [198].

5.7.2 DEBRIEFING SUPPORT

Debriefing support available in DNH, paediatric unit, was rated by more than half of participants (83%; n=123/150) as the lowest surveyed item (MS=2.27).

Nurses and doctors almost equally found the debriefing support poor.

This finding raises serious concerns as debriefing is seen as an important coping mechanism among professionals caring for children with LL and LTIs' towards the terminal stages of illnesses[99]. Poor rating of the debriefing in the paediatric setting in DNH might indicate that support structures are inefficient, inconsistent or inexistent.

Limited debriefing opportunities among the staff working in the outpatients departments compared with the staff dealing with the inpatients death [100] less on-going support [181]were identified in previous studies. Even health professionals working in academic setting reported that debriefing was infrequent and their training and coping with the death of the patient was inadequate [200].

The death of a child is a dramatic event which has a powerful impact on health professionals involved in caring for the child. Professionals' reactions, feelings (sadness, loss) and concerns (personal competence) around the death of the patient need to be acknowledged and addressed and support should be offered.

Recommendations for formal support include: professional counsellor or psychologist and debriefing after each death [99], peer support and mentorship to the junior staff as well as providing an environment where health professionals can freely express their feelings and concerns[179]. Informal support from friends, family and colleagues or time-out for discussions depends of the philosophy of care of each work setting while others rely on friends, family and colleagues for support [179].

Debriefing support is equally important among health professionals irrespective of their experience and previous exposure to dying children as many still find the loss of a child a distressing and difficult experience to handle[16].

5.7.3 BEREAVEMENT SUPPORT

Among participants to this study, 71% (n=106/150) rated bereavement support as the second lowest item (MS=2.61) after debriefing support.

The results show that majority of participants feel that the bereavement support is inadequate and this finding suggests that the institution needs to give consideration and to address the lack of support. Comparing the results among the job categories, nurses (31%) rated the bereavement support higher compared to doctors (9.5%).Those participants who rated bereavement support as good may make use of informal support such as: support from colleagues or the team which helps professionals to achieve closure[100.] Research found that doctors and nurses grieve differently: doctors seldom seek support while nurses often seek support from their colleagues [198]. Nurses more often make use of support groups or a counselor and accept more training on how to deal with their own grief and bereavement [199].

The reason for inadequate bereavement support might be directly linked with the expression of grief which is not always expressed among health professionals. Both society and institutions expect professionals to remain strong and invulnerable in dealing with dying[103]. The grieving process' fluctuations (grief and loss, repression and moving forward) may prevent professionals from being submerged by their grief and helps them to adapt, to achieve personal growth (meaning) and to support bereaved families.

Grief and bereavement support structures should be recognized and made available on an ongoing basis as recommended by Papadatou [200]. Studies found that the benefits of the bereavement and debriefing sessions proved beneficial and meaningful in assisting health professionals to explore their emotions, fears and anxieties[201] and to maintain their professional integrity[101].

5.7.4 THE ROLE OF MULTIDISCIPLINARY TEAM

Health professionals understand that caring for patients with LL and LTIs' exceeds any single expertise and that only collaborative multidisciplinary teams of professionals with diverse training can provide independently the complex support which will improve the quality of life of patients and families[202].

In fact, MDT concept varies from one setting to another by its role definition, team composition and dynamics, collaboration, communication, shared vision and combined knowledge, skills and expertise [203].In this study the role of MDT was rated the highest among all the items related to support.

More than two thirds of participants rated the role of MDT good and very good. It will be rather difficult to assume if the concept of MDT as seen by the participants is similar with the same as often discussed in PC literature, where team work is "*integral part of the philosophy of palliative care since its early days, enshrined in its standards and embedded in its practice*"[204].

This study did not find significant differences between nurses and doctors' perception with regard to the effectiveness and role MDT plays within the paediatric department. However, a Japanese study found the perception about MDT differed considerably between doctors and nurses, doctors rating higher than nurses. The negative perception among nurses was attributed to the possible gap between ideal team and the existing one and the differences in perception could have an impact on decision making, according to the researchers [205].

How the MDT in our paediatric setting delivers the care and evaluating the outcomes of care to children and families deserves further research.

5.8 STAFF'S EDUCATIONAL NEEDS AND LEARNING MODALITIES

5.8.1 EDUCATIONAL NEEDS IN PALLIATIVE CARE

Asked to rank-order their learning needs, nearly half of the participants indicated the EOL issues as their greatest educational need, followed by debriefing and pain and symptom control while ethical issues and communication skills were reported as the fourth and fifth educational needs respectively.

It is not surprising that EOL issues were ranked as one of the most important learning needs as this will assist paediatric staff in DNH to improve their knowledge and their ability to make EOL decisions which will positively impact on their patients [16] and their families' (decreasing the sense of [183], quality of care during the EOL phase. Numerous studies identified similar educational needs in palliative care among health professionals, the only difference being the ranked-order of their learning needs.

As revealed in the literature, pain and symptom control and communication play a central role in the care of children with LL and LTIs'[94]. Research found that only few health care professionals received training and teaching in palliative care and the lack of knowledge and skills is a barrier to delivering effective PPC[195].

Pain and symptom control and communication skills on subjects such as: discussing prognosis, BBN, discussing code status and including children in EOL discussions were among the most important educational needs in palliative care in Kolarik et al's research[118]. Other studies indicated that EOL issues were the most important areas of learning [100, 185, 94.]

In this study the learning need in communication skills was ranked as the forth greatest need. By contrast, communication skills were found by Amery to be the most pressing need among Ugandan professionals[111].

The fact that communication was not a priority of the participants may be supported by the significant relationship (p= 0.05) found between communication competence and categories of experience in paediatrics. Category with the higher paediatric experience, > 9years, which represents almost half of the participants felt more confident in communicating with patients and families compared with less

experienced category: 0-3 years. The results are based on participants' perception and one cannot assume if they are indeed good and competent communicators.

Caring for children with LL and LTIs and families presents health professionals with multiple ethical issues, implications and dilemmas. The perceived learning need about ethical issues wasn't ranked as very significant by the participants despite the complexity of these dilemmas. Ethical issues require a multidimensional approach and the team collaboration in negotiating ethical issues helps health professionals in the paediatric department to avoid conflict and provides much needed support for child and family[206.]

5.8.2 STAFF'S PREFERRED LEARNING MODALITIES

The participants indicated their preferred learning modalities in both formal and informal education and training from the greatest to the least.

More than half of the participants indicated the need for formal education such as workshops and lectures and less than half opted for informal teaching such as bed side teaching and group discussions and lastly, role play.

Similar learning formats such as: seminars conferences or online learning were identified in a study among Canadian nurses [207.]

Participants in the research are aware that participating in formal education and training requires financial support and guaranteed time off (study or special leave) which may be difficult due to financial difficulties and staff shortages. On the other hand informal education format such as: bed side teaching, group discussions, role play might be a more practical way of educating health professionals providing that there is available mentorship and expertise to achieve this goal [195, 208,]

The results of our study highlight the need among health professionals for further education in areas of palliative care, in order to meet the challenges of caring for patients with LL and LTIs and families.

5.9 QUALITATIVE DATA RESULTS

The last two qualitative questions were of particular interest to this research and the results highlighted the directions towards improving quality of care for these categories of children at both levels: staff (paediatric nurses and doctors) and the institution (by acknowledging and addressing staffs 'perceived needs).

Open-ended questions presented the participants with the unique opportunity to make their challenges and concerns, views and experiences, known as they were documented in this study and to identify the most stringent needs in caring for children with LL and LTIs.

5.9.1 PERSONAL SUPPORT NEEDS

The first question was in relation to participants' perceived personal support required to care for children with LL and LTIs.

Narrative text analysis showed that the participants have a clear understanding that dealing with complex LL and LTIs' requires specialized knowledge and skills which can be achieved through education and mentorship. Themes such as: education and training, emotional support and communication skills with particular interest in BBN, debriefing and bereavement support needs dominated the participants' personal support needs.

Fewer participants expressed the need to improve their knowledge about spiritual and ethical issues.

5.9.1.1 EDUCATION AND TRAINING NEEDS

More than half of the respondents identified as a specific need for education and training more knowledge about LL and LTI's.

Education and training are essential for all health professionals caring for children with LL and LTIs' and these needs are justified even among health professionals working in palliative care settings, who expressed their need for further educational programs, due to the challenges of care[209].

5.9.1.2 EMOTIONAL SUPPORT

Respondents identified the need for emotional support in areas such as: debriefing and bereavement support services, EOL, spiritual and MDT support. The results of the questionnaire informed that debriefing and bereavement support were poorly rated. Allowing the expression of grief and offering formal to all professionals caring for terminal patients is an institutional task which should be addressed.

Currently the debriefing and bereavement support network is informal and patchy and there is an urgent need for formal support, debriefing, bereavement support groups and counseling. These needs resonate with the findings of other studies in which participants indicted their need for additional emotional, informational, practical and appraisal support [57, 99,223.]

5.9.2 NEEDS FOR INSTITUTIONAL SUPPORT

The second open-ended question was in relation to the institutional support required by paediatric staff in order to provide better care to children with LL and LTIs'.

Participants indicated that additional institutional support was needed that included a greater focus on the work environment (paid study days, higher levels of pay to reflect higher qualification, time for in-service training not during working hours when staff should look after their patients).

Two main themes were identified from analysis of narratives: educational needs in palliative care and the establishment of a PPC unit/team within the paediatric department. Other themes, less prominent were: support for families and the MDT.

5.9.2.1 EDUCATION AND TRAINING IN PALLIATIVE CARE

A high number of respondents suggested that the institution-DNH should acknowledge the importance of education and training in PPC and its value in caring for patients with LL and LTIs. The aspects of palliative care learning and the learning format were ranked in the questionnaire.

The reality is that senior staff had not received any formal training as palliative care was included in the curriculum only in the recent years. These findings and comments highlight that it will be

worthwhile for the institution to promote further education of its paediatric staff, by making training opportunities available for interested professionals and granting time-off in order to achieve better knowledge, skills which will improve the standards of care for patients. Even with the introduction of palliative care in the universities and nursing colleges' curricula, studies continue to document deficiencies in formal palliative care education at undergraduate level [118, 161,211] and postgraduate level[160].

5.9.2.2 NEEDS FOR PALLIATIVE CARE UNIT/TEAM

Caring for children with life limiting and life threatening conditions in a specialized PPC unit and the development of a PPC Team was suggested by respondents. It is not clear if the participants refer to a separated PPC or a unit integrated into the paediatric department and this issue is debatable.

The development of a separate PPC unit has financial implications in terms of costs and staff while an integrated unit will be more cost effective, especially in the current financial climate.

Integration of PPC services in the mainstream South African hospitals 'practice has already been a proposed by Henley [122]. In fact this follows the WHO guidelines and similar recommendations and proposals to implement PPC in hospitals caring for children with LL and LTIs have been made worldwide[15, 211].

Many children with LL and LTIs' will require hospital admission at some stage of their disease. The benefits of having specialized PPC units for these children will decrease the burden of admissions on the general paediatric wards, could reduce the cost of care substantially by utilizing less intensive care resources and address their care needs in a more holistic manner.

. Studies demonstrate that admissions to palliative care units result in decreased hospital costs and increased support for patient and family. Identifying patients and families' goals of care will result in less overtreatment especially towards EoL phase. There is evidence to supports the hospital efforts to invest in PC services. Research showed that in USA the cost of care decreased by 66% after transfer to PC unit [212.]

Unfortunately there is very small available body of data with regard to PPC in Sub-Saharan Africa.

The only available data about the children with LL and LTCs who require PPC has been extracted from a population census in Western Cape in South Africa [213].

Based on the existing data evidence and our own statistics of children with LL and LTIs there is an increased need for establishing PPC services. To start with the development of a PPC Team which will be integrated in general paediatric wards, outpatients, ICUs' and specialized clinics will be more cost effective.

This goal cannot be achieved without support from DNH management which has the responsibility to respond holistically to these children's needs and to facilitate their access to such services. Finally, advocacy and access to a NGOs' support will facilitate and speed this process.

5.10 LIMITATION OF THE STUDY

Several limitations of the study were identified and outlined.

1. The survey-questionnaire was purpose designed for this study. As its validity and reliability haven't been tested in other settings, these preclude the generalization of the findings outside the study 'site.

2. Piloting the questionnaire was done on a very small sample to verify face and content validity.

3. Using Likert-scale has the advantage of simplifying respondents' task, minimizing time to respond and facilitates statistical analysis; however the results should be treated with caution as self-rating the questions reflects respondents 'perceptions and not a real measure of their knowledge.

4. Transition from the Likert-scale to the ranking questions format: from the greatest (1) to the least need (5) might have confused participants.

5. The study did not sufficiently explore emotional aspects encountered including issues such as burnout and compassion fatigue with regard to needs of the carer.

6. The qualitative, open-ended questions in the questionnaire were regarded as time consuming and difficult to complete by some of the participants who choose not to reply. The difference between personal needs and institutional needs has different meanings resulting in similarities.

7. Participants knew the principal investigator and her field of interest and this may have prompted the answers that they considered desirable or applicable to the researcher's field of work.

8. The study was limited to doctors and nurses. It will be interesting to explore the needs and issues confronting allied care workers (rehabilitation therapists, social worker, psychologist, and nutritionist) who are involved in caring for these patients as well.

9. The Principal investigator's lack of previous experience with research was among the first limitations of this study. As the study unfolded, the understanding of the research process contributed to the expansion of researchers' knowledge and personal growth.

5.11 STRENGTHS OF THE STUDY

1. This is the first palliative care research conducted with Paediatric Department in Dora Nginza hospital which aimed at providing some insight into the support needs for nurses and doctors caring for this special category of children with LL and LTIs'. The findings are unique for paediatric setting in DNH, useful in designing and planning future support and are valid despite the limitations.

2. The results of the study reveal that both nurses and doctors who are engaged in caring for children with complex conditions identified the strengths and weaknesses and indicated areas where further educational and training and emotional support is needed.

3. Participants' willingness to partake to the research and their efforts to complete the questionnaires despite their heavy workload was remarkable. The 75% overall response rate is a good indicator and may have practical implications regarding further education which will enhance professionals' fund of

knowledge and skills and in the design of departmental protocols. The high response rate also strengthens the reliability of the results that they are representative of the study site.

4. Finally, this findings of this research laid the foundation for further studies, might increase awareness and encourage other researchers to embark on new studies regarding different needs of care of children with LT and LLIs', their families and health professional's needs.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This study aimed to evaluate the support required for staff in the paediatric unit of Dora Nginza Hospital in caring for children with LL and LTIs. The findings provide an insight into the staff's support needs and identified areas where further education, training and support are required.

The summary of the findings and the conclusions of this research as well as the recommendations are discussed further.

6.2 CONCLUSIONS

This research succeeded in identifying the self-perceived level of knowledge and communication skills of the paediatric staff as well as their identified needs for further education and training.

Caring for children and young people with LL and LTIs can give rise to strong emotions and the emotional impact on staff highly involved increases the risk of developing burnout, stress and compassion fatigue. There is increasing evidence that without adequate support, health providers experience emotional distress and painful memories[222]. Recognizing the professional distress for health care professionals caring for the children with complex chronic conditions and implementing support strategies can help care providers to fulfill their difficult task of providing compassionate care to those in need [35] and can assist staff to redefine their goals[59].

A need for more education and training in aspects of paediatric palliative care was documented by this study. The stake-holders: peadiatric staff and Dora Nginza hospital management will be informed about the findings of this research.

Dora Nginza hospital, as part of the Port Elizabeth Hospitals Complex and the Eastern Cape Department of Health will need to address the issues raised by the surveyed paediatric health professionals. Developing strategies to educate staff and improve existing support structures or create new ones to provide better paediatric palliative care services needs to be dealt with and recognized as a priority. A follow up on the outcomes of this study, monitoring of future developments and re-visiting the study setting are objectives which are envisaged by the principal researcher and this will be the subject of further research.

The level of knowledge as perceived by the participants with regard to items such symptom assessment, formal training and pain assessment was found to be higher than in other studies[57, 39,168]. As this was a self-evaluation further research would be required to more objectively assess this.

Knowledge items such as: pain control in particular prescribing morphine, knowledge of PPC and WHO pain ladder were found to be low and these results are comparable with other studies[57, 118,161, 168,169.]

The confidence **level in delivering the bad news** to the child-patient was found to be low and this has been recognized by other research as being a difficult task[90] and a critical communication skill among health professionals [89,190].

With regard to **emotional competence**, more than half of the participants struggle to make to EOL decisions (either emotionally or practically) and this finding is similar to other studies [98.162,179].

Our results with regard to debriefing and bereavement support show a greater need for the debriefing and bereavement support structures than other researchers have shown [99, 181]. This may also be because of the higher death rates experienced in a resource constrained setting.

Two significant statistical relationships were found between demographics: 1) experience in paediatrics and communication skills and 2) job category and the level of support. The findings confirm that with more experience of working with children, the better the communication skills and nurses support each other better than the doctors in the absence of formal support systems.

Among the **perceived learning needs,** EOL issues were recognized as one of the greatest learning needs, followed by debriefing and pain and symptom control. Making EOL decisions is a difficult and sensitive task for health professionals and research confirms this finding [94,100,118].

The doctors and nurses in this study indicated as their most **preferred learning format** workshops, lectures and bedside teaching and this finding differs from other studies[208].

A high number of the participants indicated that they needed more education and training, about LL and LTIs', more emotional support and debriefing, as well as assistance with bereavement and EOL decisions.

Regarding **institutional support** required by health professionals, the participants recognized the importance of palliative care learning and proposed the development of a palliative care unit within the department be advanced.

6.3 IMPLICATIONS

The findings of this research provide unique insight and valuable information and may have practical implications for those working in the DNH Paediatric department in relation to their further educational and support needs.

The results of this study found that there are many potential areas which deserve attention and future research such as:

1. Training senior staff (who had good retention rates) in palliative care will influence the knowledge, skills, attitudes and practices of junior, rotating staff
2. To identify further the attitudes, practices and barriers among doctors in prescribing morphine in children.
3. To explore the challenges and understanding of allied health workers (psychologists, social workers, dieticians, occupational, physiotherapists, speech therapists, and art therapists) when dealing with children with LL and LTIs', their families or carers.
4. To measure what impact bereavement and debriefing support services will have on and health professionals and families.
5. Implications of EOL decisions on families and health professionals.

6.4 RECOMMENDATIONS

Key recommendations arising from this study:

I. Education and training of healthcare professionals should include aspects such: improving pain and symptom management, knowledge about LL and LTIs', communication skills (BBN), EOL care and ethics.

Actions:

1. Formal education such as courses, workshops and lectures require institutional financial support and granted time off for the professionals.
2. Informal education such as bedside teaching and role play requires experienced mentors. This can be achieved by identifying motivated professionals who can undergo further training to provide ongoing, sustainable education programs in the department.
3. Continuous medical education for all health professionals and training of trainers.
4. Developing and implementing guidelines and protocols for pain and symptom assessment and management based on reliable evidence that is reviewed regularly as new information becomes available.
5. Promotion and dissemination of good practice. The universal ethical requirements should consider the following issues: informed consent as an ongoing process rather than a once-off event, fair selection and respect for the participants: protection of privacy, anonymity and monitoring of their well-being, minimizing the risks and enhancing the benefits, scientific validity and added value to the existing body of knowledge[214].

II. Identifying risk factors and preventing stress, burnout and compassion fatigue among HCP

Identifying stressors at the work place, developing training courses, establishing mentoring programs to guide staff, and improving clinical care facilities are few interventions which can protect staff from stress, burnout and compassion fatigue[59].

Actions:

1. Addressing staff shortages, role expectations and work conflicts
2. Address inadequate environment and philosophy of care :avoid overcrowding in the units and increased workload
3. Replacing/repairing malfunctioning equipment
4. Increasing opportunities for staff in decision- making processes
5. Recognition of skills/competencies and appropriate promotions
6. Offer adequate psychological and institutional/administrative support for staff

Implementation of the above strategies will assist the department to recruit newcomers in paediatrics and to retain experienced staff– who are happy in their vocation as, a valuable resource.

III. The development of debriefing and bereavement support structures. The lack of these structures raises serious concerns. Staff rely on peers, friends and family for support in order to deal with their patient's death and own bereavement issues.

Actions:

1. The department and the institution should recognize that dealing with staff's grief and bereavement requires specialized support structures which should be made available on an ongoing basis[200]. Counseling and debriefing sessions will assist health professionals to maintain professional integrity and validate their emotional difficulties [100].

IV. Implementation and development of PPC services (programs, team, unit) unit within the Paediatric Department was deemed necessary.

The unit will care for children with pain and other symptoms for short periods, for children who cannot be cared for in the community and for EOL care. The aim of admission of these children is the supportive care, psycho-social, spiritual and developmental care and to return them back to the family or community as soon as their symptoms and quality of life are improved. This need is supported by the Report of the 2nd Global Summit of National Hospice and Palliative Care Associations 15-16th March 2005, Seoul, Korea [214,] which stated that:

"*Children and adolescents with life-limiting conditions have very specific palliative care needs which are often different to those of adults. If these children's physical, emotional, spiritual and developmental needs are to be met, the carers require special knowledge and skills. We ask that the voice of these children and adolescents is heard, respected and acknowledged as part of the expression of palliative care world*-wide."

Actions:

1. Familiarize multi-disciplinary staff members with the concepts and principles of paediatric palliative care.
2. Source funding to develop palliative care services, starting with a PPC team which will attend to all inpatients and outpatients needs.
3. Learn from the experience of hospices in caring for the patients with life limiting and life threatening illnesses and outline the achievable goals.
4. Approach the decision makers: hospital medical superintendent, members of the hospital board, Port Elizabeth Hospital Complex CEO, the Head of the Paediatric Department, Eastern Cape Provincial Department of Health through lobbying, direct communication (including regular newsletter) and research.
5. Further research including a good knowledge of the current situation, supportive materials, and statistics: number of patients, diagnosis, total number of admissions, and length of admission, risk assessment and costs involved).

In conclusion this study documented the expressed needs of support of staff caring for children with LL and LTIs' in paediatric unit in DNH. It identified a need for further palliative care learning and increased personal and institutional support for staff. These deficiencies should be addressed: 'as it is the right of the child'; and the time to act is Now!

"*We are guilty of many errors and many faults,*

But our worst crime is abandoning the children,

Neglecting the fountain of life.

Many of the things we need can wait,

The child cannot wait.

Right now is the time his bones are being formed,

His blood is being made,

And his senses are being developed.

To him we cannot answer 'tomorrow'

His name is Today."[216]

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APPENDICES

I: Participants' information letter and the Questionnaire

Research title: ''**To evaluate the support required for staff in the paediatric unit at Dora Nginza Hospital, in caring for children with life limiting and life threatening diseases''.**

Principal Investigator: Dr F. Ureche

Organization: University of Cape Town, Faculty of Health Sciences, School of Public Health &Family Medicine, Division of Palliative Medicine.

Information: The researcher, Dr F. Ureche is registered for the Master Degree (MPhil) in Palliative Medicine at UCT. This letter is designed to give you information about the research and to enable you to decide if you would like to participate, or not. The participation to the study is voluntary. There will be no negative consequences for participants in case of refusal or withdrawal from the study at any time, and no risks involved.

Purpose: The Department of Paediatrics in DNH has considerable numbers of children affected by life limiting or life threatening disease from the time of diagnosis through to death if this is unavoidable. These are children diagnosed with cancer, congenital anomalies, and children with chronic organ failure like heart failure, renal failure and hepatic failure, children with progressive neurological conditions, genetic and metabolic disease and HIV/AIDS. Caring for these patients and their families is often challenging for health professionals: doctors and nurses.

The aim of this research is to evaluate the support (in a broad sense of the concept) needed by the paediatric staff (nurses and doctors) in managing these patients who are undergoing complex treatments and require specialized, long term medical care and support.

Ethical Approvals: the research has been approved by UCT Faculty of Health Sciences- Human Research Ethics Committee (UCT FHS HREC) protocol no HREC REF:432/2010, and by Walter Sisulu University- Health Research Ethics & Bio-Safety Committee, Clearance Certificate 015/2011. Permission to conduct research has also been granted by Dora Nginza Hospital acting Medical Superintendent (Internal Memorandum 02.03.2011) and by the Head of the Paediatric Department.

Confidentiality: all the information obtained during the research will be kept confidential locked up with lock and key. The information about the participants will not appear as the questionnaire is anonymous (coded).Confidential information will be shared only with the supervisor and the Ethics Committee (HREC).

Participant selection: The researcher invites all doctors and nurses who work in the Paediatric Department in DNH to participate to this research by completing the questionnaire.

Procedures/protocol: The participants are asked to answer to each question in the questionnaire.

Benefits: the results of this research will assist the investigator to identify the gaps, if any and to assess the health professionals need for support. Based on this research results, specific education and training programs will be designed to assist the health professionals working in DNH in caring for patients with LT and LTC's and their families, resulting in better quality of care for these patients. The research may contribute in planning care in the country and more specifically in developing new strategies to support the staff's needs in caring for the patients with complex chronic conditions.

Incentives: no money or gifts will be offered for the participation to this research.

Sharing the results: The results and will be shared with the participants before it is made available to the public, in a departmental meeting. Only thereafter the results will be published in order that other interested parties may learn from our research.

Who to contact: for any queries related to the research at any point in time, even after the study has started, the participant may contact any of the following:

Dr F. Ureche

Department of Paediatrics Dora Nginza Hospital

Tel: 0414064292, cell: 072 196 7844

Email: floristel@vodamail.co.za

Or designated member of HREC, FHS, UCT

Ms Lamees Emjedi

Faculty of Health Science Human Research Ethics Committee

E52-23 Old Main Building, Groote Schuur Hospital

Observatory, 7925

Tel: 27 21 4066492, Fax: 27 21 4066411

Email:lamees.emjedi@uct.ac.za

Participant's signature

……..

QUESTIONNAIRE - SECTION A: DEMOGRAPHIC INFORMATION

Please indicate your answer in the appropriate box

1. Gender	1.Female	2. Male

2. Ethnicity	1. Asian	2. Black	3.Coloured	4. White	5. Other

3. Experience in Profession	<1 Year	>1-3 Years	>3-6 Years	>6-9 Years	>9years

. Experience in Paediatrics	<1 Year	>1-3 Years	>3-6 Years	>6-9 Years	>9years

5. Job Title	1. Enrolled-Assistant Nurse	2. Intern	3. Medical Officer	4. Prof. Nurse	5. Registrar	6. Spec. Paeds.

6. Clinical Area	1. General Wards	2. NICU	3. Nursery	4. Paeds out Patients	5. PICU	6. PREM Unit	7. Spec. Clinics

QUESTIONNAIRE - SECTION B

Please indicate HOW WOULD YOU RATE YOUR ANSWER to the following questions by circling the appropriate number on a scale from 1 to 5	**Very poor**	**Poor**	**Fair**	**Good**	**Excellent**
1. Your formal **training** in caring for paediatric patients with complex illnesses?	**1**	**2**	**3**	**4**	**5**
2. Your **knowledge** in managing pain in children with incurable conditions?	**1**	**2**	**3**	**4**	**5**
3. Your confidence level in **assessing pain** in these children?	**1**	**2**	**3**	**4**	**5**
4. Your ability to **assess symptoms** other than pain in paediatric patients with life threatening or limiting disease?	**1**	**2**	**3**	**4**	**5**
5. Your ability in safe **prescription of morphine** in children?	**1**	**2**	**3**	4	**5**
6. Your ability in **administering prescribed doses of morphine** to children?	**1**	**2**	**3**	4	**5**
7. Your knowledge of the use of the World Health Organization (WHO) **Pain ladder?**	1	**2**	**3**	4	**5**
8. Your knowledge about **paediatric palliative care**?	**1**	**2**	**3**	**4**	**5**
9. Your **emotional status** when caring for children with life threatening and life limiting diseases?	**1**	**2**	**3**	**4**	**5**
10. Your **personal coping mechanisms** in caring for children with life limiting and life threatening conditions?	**1**	**2**	**3**	**4**	**5**
11. The emotional **support structures** available in your current work settings?	**1**	**2**	**3**	**4**	**5**
12. Your ability to make **end of life decisions** in caring for children with incurable disease?	**1**	**2**	**3**	**4**	**5**
13. Your current **communication skills** when having discussions with the parents of children with life limiting or life threatening illnesses?	**1**	**2**	**3**	**4**	**5**
14. Your confidence level when **delivering bad news** to **the child patient** (where appropriate)?	**1**	**2**	**3**	**4**	**5**
15. Your confidence level when **delivering bad news** to **the caregivers/family**?	**1**	**2**	**3**	**4**	**5**
16. The role the **multidisciplinary team** plays in your current work setting?	**1**	**2**	**3**	**4**	**5**
17. The **bereavement support** available in your institution?	**1**	**2**	**3**	**4**	**5**
18. The **debriefing support** available for staff in your department?	**1**	**2**	**3**	**4**	**5**

19.1. Please **rank your learning needs in the following aspects of palliative care** on a scale of 1 to 5, **with 1 indicating the greatest need, and 5 the least learning need.**

	Pain and symptom control
	Communication skills
	Ethical issues
	Debriefing
	End of life issues

19.2. Please **indicate the preferred type of training** to assist you in caring for patients with life limiting and life threatening conditions on a scale from 1 to 5, **with 1 indicating the greatest preference and 5 the least preferred type of training.**

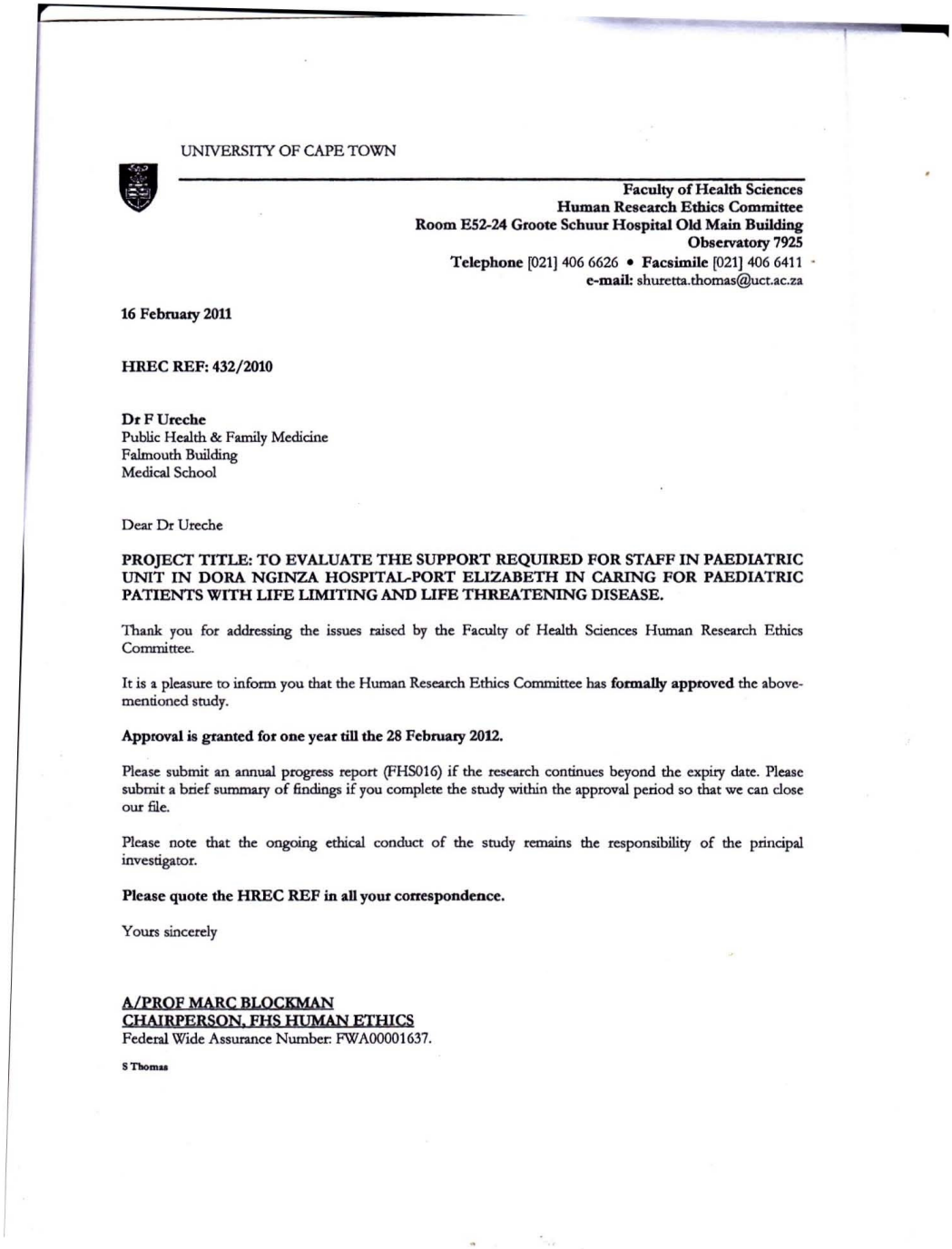
	Work shops
	Lectures
	Group discussions
	Role-playing
	Bed side teaching

19.3. Please outline the **kind of support you personally need** to assist you in caring for children with life limiting and life threatening illnesses

19.4. What **improvements do you envisage in your institution** in order to offer better quality of care for the children with life limiting and life threatening illnesses?

Thank you for completing this questionnaire

II: Human Research Ethics Committee- University of Cape Town



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • **Facsimile** [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

16 February 2011

HREC REF: 432/2010

Dr F Ureche
Public Health & Family Medicine
Falmouth Building
Medical School

Dear Dr Ureche

PROJECT TITLE: TO EVALUATE THE SUPPORT REQUIRED FOR STAFF IN PAEDIATRIC UNIT IN DORA NGINZA HOSPITAL-PORT ELIZABETH IN CARING FOR PAEDIATRIC PATIENTS WITH LIFE LIMITING AND LIFE THREATENING DISEASE.

Thank you for addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the Human Research Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 28 February 2012.

Please submit an annual progress report (FHS016) if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

A/PROF MARC BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.

S Thomas

III: Clearance: Walter Sisulu University

WSU
Walter Sisulu University

HEALTH RESEARCH ETHICS & BIO-SAFETY COMMITTEE

CLEARANCE CERTIFICATE

PROTOCOL NUMBER	:	015/011
PROJECT	:	TO EVALUATE THE SUPPORT REQUIRED FOR STAFF IN PAEDIATRIC UNIT IN DORA NGINZA HOSPITAL- PORT ELIZABETH, IN CARING FOR PAEDIATRIC PATIENTS WITH LIFE LIMITING AND LIFE THREATENING DISEASE
INVESTIGATOR(S)	:	FLORENTINA URECHE
DEPARTMENT	:	PALLIATIVE MADICINE (UNIVERSITY OF CAPE TOWN)
DATE CONSIDERED	:	05 APRIL 2011
DECISION OF THE COMMITTEE	:	APPROVED THROUGH EXPEDIATED REVIEW

N.B. You are required to provide the committee with a progress or outcome report of the research after every 6 months. The committee expects a report on any changes in the protocol as well as any untoward events that may occur at any time during the study as soon as they occur.

Walter Sisulu University
Academic Health Service Complex of the Eastern Cape
Postgraduate Education and Training
Faculty of Health Sciences
Walter Sisulu University
P/Bag X1, WSU, 5117, E.C.
Tel (047) 502 2100 / Fax (047) 502 2101

11/04/2011
Date

CHAIRPERSON

DECLARATION OF INVESTIGATOR(S)
(to be completed in duplicate and one copy returned to the Research Officer at Office L311, 3rd Floor, Old Library Building, NMD Campus, WSU)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Research Ethics Committee. I/We agree to a completion of a yearly progress report.

.....
Investigator

.....
Date

N.B. Please quote the protocol number in all enquiries.

Institutional Review Board (IRB) 00007448 **HREC 1202009-020**

Prof CD Mwesigwa-Kayongo (Chairperson), Prof G Wright (Deputy-Chairperson), Mrs N Dabata (Secretary), Prof Longo-Mbenza, Ms P Nakani, Prof EL Mazwai, Prof G George, Ms Z Dotwana, Dr L Mpahlwa, Prof P Yogeswaran, Dr NS Magenuka, Prof TX Maluleke Prof N Mijere, Prof JE Iputo, Prof GAB Buga and Dr NV Nombekela-Madiba.

IV: Internal memorandum- medical superintendent DNH

Province of the
EASTERN CAPE
HEALTH

Room DG15 •1st Floor • Dora Nginza Hospital • Spondo Street • Zwide • Port Elizabeth• Eastern Cape
Private Bag X11951 • Algoa Park • Port Elizabeth • 6005 • REPUBLIC OF SOUTH AFRICA
Tel.: +27 (0)41 406 4428 • Fax: +27 (0)41 464 4551 • Website: www.ecdoh.gov.za

INTERNAL MEMORANDUM

To:	To whom it may concern
From:	Mrs N.G. Mtshake Acting Medical Superintendent
CC:	
Subject:	**Permission to conduct research – Participation of staff, Doctors and Nurses**
Date:	2 March 2011

Permission is hereby granted to Dr F. Ureche to conduct research in the Paediatric Department of Dora Nginza Hospital.

The research study is entitled to evaluate the support required by the staff in the Paediatric Unit at Dora Nginza Hospital, in caring for children with life limiting, and life threatening disease.

The research proposal was submitted to the Human Research Ethics Committee(FHS – HREC) at UCT for ethical approval.

Informed consent will be signed by the participants and confidentiality will be observed by all means.

Kind Regards

MRS N.G. MTSHAKE
ACTING MEDICAL SUPERINTENDENT (DNH)

V: Permission to conduct research in Paediatric Department- HOD

PROVINCE OF THE EASTERN CAPE
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH
Tele/Fax 041 4064327/0414064097
DORA NGINZA HOSPITAL

Private Bag 11951, Algoa Park 6005. SA

email: daphne.terblanche@impilo.ecprov.gov.za

To: **Dr F. Ureche**

Date: **18.04.2011**

Re: Permission to conduct research in Paediatric Department-Dora Nginza Hospital

Research Title: " To evaluate the support required by staff in paediatric unit in Dora Nginza Hospital-Port Elizabeth in caring for paediatric patients with life limiting and life threatening disease"

The permission is hereby granted to Dr F. Ureche to carry out the above mentioned research in the Paediatric Department in Dora Nginza Hospital.

The research protocol has been approved by the HREC of University of Cape Town and Walter Sisulu University and the permission was granted by the Medical Superintendent of DNH.

The researcher should ensure compliance and adherence to the ethical requirements for the entire duration of the study. A copy of completed research will be expected for the hospital's resource centre and the researcher should be available to assist with the interpretation of the results and the implementation of recommendations where possible.

Dr L. Pepeta

Head of Department of Paediatrics-Dora Nginza Hospital