

## **1: Introduction**

The effect of children with life threatening illness on the people around them, their families and on those that care for these children can be devastating and life-changing. A concept called paediatric palliative care was created to try and help lessen the effect on the child and families involved in such situations. There are however many people involved in the process of paediatric palliative care. Research has previously been conducted on general nurses' experiences with regard to their nursing role, specifically that of working closely with chronic and terminally ill patients (Figley, 1995). Yet little research has focused on nurses, and other health care professionals, working within the context of paediatric palliative care. This is a significant area of research, especially in South Africa where there is a high prevalence rate of HIV/Aids in children (the Joint United Nations Programme on HIV/Aids [UNAIDS/WHO], 2008).

The concept of palliative care originated out of the hospice philosophy. Hospice institutions developed in response to the gaps in care regarding chronically ill and dying patients. 'Palliate', the Latin origin for palliation, refers to alleviation or care without curing (Romesburg, 2007, as cited in Morgan, 2009). Palliative care can be traced back to the late 14th century, where it seemed to have existed as part of some of the European traditions (Morris, 1998, as cited in Morgan, 2009). In the 1960's hospice programmes were developed in the United Kingdom and in the 1970's hospice became adapted to meet the specific needs of paediatric patients in America and Europe. It seems that specialized palliative and paediatric palliative units were only introduced in South Africa in the 1980's.

The World Health Organization (WHO, 2004) defines palliative care as "an approach to care which improves quality of life of patients and their families facing life-threatening illness through prevention, assessment, and treatment of pain and other physical, psychological, and spiritual problems". The World Health Organization (2004) further describes palliative care for children as "the active total care of the child's body, mind, and spirit, as well as a means of providing support to the family". The World Health Organization (2004) further describes that it

is the process whereby “health providers must evaluate and alleviate a child's physical, psychological, and social distress”; and that “effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited”.

Paediatric palliative care provides care to children under the age of 20 years old. Common diagnoses of life-threatening illnesses in children include, prematurity; congenital anomalies; sudden unexpected infant death syndrome (SIDS); chromosomal defect; trauma; neurodegenerative disorders; acquired immunodeficiency syndrome (Aids) and cancer, with the latter being the leading cause of death in children and adolescents worldwide. Paediatric palliative care incorporates additional aspects of care that are distinct to the scope of paediatric palliative care. These include the need to individualise all of the care provided according to each child's specific developmental needs. Thus, communication and interaction must be delicately tailored to meet the child's ever changing needs. It is also essential that children are included in decision-making, and their care must constantly allow for open and honest communication (The Association for Children's Palliative Care [ACT], 2009).

Paediatric palliative care further requires an interdisciplinary team in order to ensure that all of the child's needs are met and creates a situation where team members provide patients with as much quality of life as possible (WHO, 2004; ACT, 2009). The interdisciplinary team try to provide both care and support to patients and their families. Paediatric palliative care nurses form a central part of this interdisciplinary team. These paediatric palliative care nurses are constantly witnessing the suffering and pain of children. As a result, they often experience emotional pain, feelings of helplessness, anger, sadness and anxiety. It is all of these feelings that can result in the experience of burnout or compassion fatigue (Morgan, 2009).

There is limited focus on paediatric palliative care throughout the world and South Africa is no different. Researchers have suggested that a possible reason for the lack of attention given to paediatric palliative care worldwide may result from the expectation that children outlive their parents (Morgan, 2009). As a result, the alternative eventuality is seldom considered. This does not however detract from the importance of and need for this type of care. This lack of attention given to paediatric palliative care may possibly create a situation where nurses may not be specifically educated to care for paediatric palliative patients. This may result in these nurses not being adequately equipped with the knowledge and necessary skills to deal with the severe impact this work can have on them.

### 1.1 Rationale

Paediatric palliative care nursing research is an area that is still in its infancy. A large body of literature exists regarding the experience of nurses in their relative fields (Ceslowitz, 1989; DiMatteo & Martin, 2002). Most of these studies focus on nurses' experiences of burnout or compassion fatigue, or how the nature of nursing impacts on nurses (Payne, 2001). Little is known specifically about paediatric palliative care nurses in terms of their experiences working with children, as well as the ways in which they manage the impact of their work. Furthermore, most research in palliative care has focused on adults, as terminal illness and preparation for death amongst child populations were construed as an unnatural part of the life-cycle (Morgan, 2009). With the HIV/Aids pandemic, childhood cancer and other life threatening illnesses, palliative care has evolved to include the needs of children and their families. Hence, paediatric palliative nursing care can be both stressful and rewarding and as such, requires coping skills, confidence and other attributes for successful patient care and nursing practice (Abendroth, & Flannery, 2006; Liben, Papadatou & Wolfe, 2008).

Nurses are of particular concern in South Africa, as they form the largest group of Health Workers in the country. Furthermore, palliative nurses are especially important, since South Africa has an extremely high mortality rate, particularly due to HIV/Aids (UNAIDS/WHO,

2008). Thus, it is important to explore how the nature of nursing and paediatric palliative care nursing in particular, impacts on nurses.

Palliative care has been recognized as a medical specialty since 1987 and has grown into an established field of practice for health professionals of all disciplines. Tens of millions of people worldwide are affected by life threatening illnesses such as HIV/Aids and cancer, which cause them and their families great suffering (Marlin, Sepúlveda, Ullrich & Yoshida, 2002). Yet the majority of the cases occur in the developing world, with the African continent having the highest prevalence rate of HIV/Aids and up to 280 000 South African children below the age of 15 being infected (UNAIDS/WHO, 2008). Yet in these areas there is little accessibility to effective treatment for these diseases (Marlin, Sepúlveda, Ullrich & Yoshida, 2002). Thus, the motivation for the study was to examine the various dynamics involved in paediatric palliative care nursing in the context of HIV/Aids in Gauteng, South Africa. This will be done by examining both the scope of paediatric palliative care; as well as the possible impact that working in paediatric palliative care may have on nursing staff.

## 1.2 Aim

Since paediatric palliative care requires individualistic care, that is tailored to meet the plethora of the needs of the child and family, health care professionals face numerous obstacles and challenges in providing such care to this unique population of clients. Hence the aim of this study is to examine the scope and nature of paediatric palliative care practiced in two facilities in South Africa, and to evaluate the impact of this work on paediatric palliative nurses.

## 1.3 Structure of the report

This research report begins, in chapter one, with an introduction to the area of paediatric palliative care nursing in context of nurses working with HIV/Aids in South Africa. Chapter two

consists of a thorough exploration of the literature and research relevant to the origins of palliative care; various elements specific to the scope of paediatric palliative care; general and palliative nurses' experiences of their jobs; as well as paediatric palliative care nurses' understandings of the scope of their work and studies on how this work impacts on them. Chapter three describes the methods that were used for this research. Chapter four describes the main themes that were found in the seven interviews that were conducted. These themes are organised according to the two research questions. Elements of the scope of paediatric palliative care nursing explored include holistic care and the importance of emotional care; communication and how culture may influence this; nurses' employment of a mothering role; as well as the importance of teamwork and the lack of a clear definition with regards to the nursing role. This is followed by an examination of the impact that this work has on nurses, with a focus on both the positive and negative impact that results from the emotional intensity of their work. This includes a discussion of nurses' witnessing of the suffering of their patients; nurses' experience of a grieving process upon the loss of a patient; as well as the ways in which nurses cope with this impact. Chapter five consists of a discussion of the themes found and their relationship with past or current literature or research. This section also explores the implications of these findings and provides recommendations for future research.

## **2: Literature Review**

Paediatric palliative care nursing, especially in the South African context, encompasses many different aspects of nursing. It is a distinctive type of care and its scope is vast and intense. Paediatric palliative care nursing provides a totality of care that includes medical, physical and emotional elements of care. Each element of this care must be tailored to meet each child's medical, developmental and emotional needs. Furthermore, nurses must offer support to both the patients and their family. As a result, nurses endure the gamut of experience from emotional reward to distress or burnout. Paediatric palliative care has many unique elements, but many of its foundational elements originate predominantly from general palliative care. Thus, it is helpful to look at some of the theories, literature and research that have focused on general palliative care. The scarcity of research in the paediatric palliative care further necessitates this.

### 2.1 The Scope of paediatric palliative care

“Paediatric palliative care is not about dying; rather it is about helping children and families to live to their fullest while facing complex medical conditions” (Himmelstein, 2006, p 163). Hence, Paediatric palliative care is care that is child-focused and requires nurses to provide a holistic level of care (WHO, 2004). Palliative care is less developed in the area of paediatrics, as it is less common and more diverse. Although paediatric palliative care is similar to palliative care, it does still differ from general palliative care with regard to its scope. When working with adults in a palliative setting, quality of life and alleviation of pain are the main goals, whereas when working with children nurses additionally offer curative or active care along with the palliative treatment (WHO, 2004). Furthermore with children, it is of the utmost importance to include the patient's family as part of the unit of care, with issues such as decision making as well as providing emotional and educational support. With general palliative care, a more standardized level of care is given. Yet with paediatric palliative care, treatment needs to be adapted to be developmentally appropriate for each child and must be carried out by an interdisciplinary team (Himmelstein, 2006). Working with children also requires nurses to provide opportunities of education and play, to allow for further growth while also allowing children to engage with their

youth (ACT, 2009). These additional or different aspects of paediatric palliative care place additional demands on the nurses. In the South African context, training and education are vital in preparing nurses for paediatric palliative care (Liben, Papadatou & Wolfe, 2008).

When working with children of all ages, nurses need to engage with each child's developmental understanding of death and illness. The child's understanding is often progressive and children's understanding of death progresses from death as a change, to the universality of death, to one's own mortality and the finality of death (Himmelstein, Hilden, Boldt & Weissman, 2004). Both Piaget (1965) and Kübler-Ross (1983) described the cognitive development of children as progressing over four stages. These stages progress from sensory experience of the world; to magical thinking or seeing death as temporary; to an intellectual understanding of death; and to understand death on an abstract and spiritual level. It is therefore essential that, when working with a child population, nurses need to be perceptive to both the verbal and non-verbal cues of children with regard to their emotional suffering, as well as to encourage each child to express hopes, dreams, or fears (Himmelstein, Hilden, Boldt & Weissman, 2004). Nurses must therefore identify and make use of body language and expressive methods of interacting (through play and other activities), in order to provide patients with appropriate outlets for feelings of frustration (Zengerle-Levy, 2006). Thus speaking with children about illness and death is another complex matter that forms part of the scope of paediatric palliative care, one that requires careful attention to the developmental issues relevant to children (Hynson, Gillis, Collins, Irving & Trethewie, 2003).

When working in paediatric palliative care, nurses provide both palliative and active treatment. Thus part of the nurses' role might include performing aggressive treatments (Morgan, 2009). Morgan (2009) reviewed current literature on paediatric palliative care to discover the needs of patients and nurses, as well as to identify the gaps in paediatric palliative care literature and training. In this comprehensive study, the researcher conducted interviews, clinical workshops and direct observations in paediatric palliative care, neonatal intensive care, paediatric intensive

care and oncology settings in America. This study illustrated that nurses found it difficult to still provide active treatment for palliative patients, as nurses were often left feeling guilty for letting terminally ill children experience more pain. Also, they feel that they were taking away time that the child could spend with family, or doing child-appropriate activities (Hynson, Gillis, Collins, Irving & Trethewie, 2003). Thus, nurses grappled with trying to provide quality of life, while concurrently trying to provide a holistic care to their patients (Morgan, 2009).

Nurses further need to provide care that is culturally fitting for the patient. Goepp, Meykler, Mooney, Lyon, Raso and Julliard (2008) conducted interviews with various healthcare professionals, in order to identify potential barriers or aids to inpatient palliative care at a large urban hospital centre in America. Barriers were noted when there was a conflict between a nurses' own cultural or religious perspective and those of patients and their families. Nurses further demonstrated that their own culture, religion, and ethnicity contributed to the way in which they approached palliative care nursing, such as providing a more protective care, as opposed to an unguarded and more open approach to patients. A possible implication of nurses employing guarded or closed communication styles that are influenced by their own cultures is that this may have been harmful with regard to the quality of care provided to the patients. This is due to the fact that sometimes nurses' cultural beliefs prevented them from attending to their patients in a way that best facilitated open and honest communication. It may also have led them to provide a type of nursing that was not necessarily sought after by the patient or their family. The institution was also a contributor to the way in which nurses approached cultural issues. This study, among others (Liben, Papadatou, & Wolfe, 2008), indicated the influence that culture can have on communication. It further showed the importance of individualizing care according to the patients' cultural and developmental needs, while still allowing for the possibility for open and honest communication. Thus nurses who are not aware of this may not consider patients' cultural preferences, employing their own personal or institutional cultural values, such as paternalism, to direct the care that they provide.



Liben, Papadatou and Wolfe (2008) reviewed literature and research in the area of paediatric palliative care, in order to identify the gaps and challenges in this field. One area that they explored was the impact that culture can have on the communication that occurs between nurses and patients. They found that the core principles of communication in relation to culture included open disclosure and honesty; patients' autonomy through their active participation in decision-making; as well as open expression of feelings, concerns, and needs. These were encouraged in the original principles of palliative care (WHO, 2004). Yet in some cultures open communication is not encouraged, especially when applied to a child population. Studies conducted in China, Japan, and Greece, all predominantly non-western cultures, have described a protective approach towards children, where open communication with regard to illness and death was disapproved of, and children's involvement in decisions about their own care limited (Martinson, Zhong & Liang, 1994; Sagara & Pickett, 1998; Kato, Yano, Ito, Yanagisawa, Hoshi & Eto, 2004; Papadatou, Yfantopoulos, Kosmides, 1996; Yam, Rossiter & Cheung, 2001, as cited in Liben, Papadatou & Wolfe, 2008). These cultures viewed honesty about dying as depriving the child from feeling safeguarded against anything potentially frightening or destructive, as well as threatening culturally prescribed autonomy roles or functions normally assumed by parents. In South Africa, African cultures represent the non-western sector of the country and all subscribe to a similar value system (Visser, 2007). The results of this study showed the importance of nurses being considerate of patients and their family's cultural preferences. As a result, research has recommended that institutions and training should assist nurses to adopt a culturally sensitive or individualistic approach to care (Gatrad, Brown, Notta & Sheikh, 2003; Weissman, 2002, as cited in Liben, Papadatou & Wolfe, 2008).

Communication is a primary component in the bonding of nurses with paediatric patients (Himmelstein, Hilden, Boldt & Weissman, 2004). It is essential that nurses form a personal relationship and develop a good rapport with the child, in order to gain the confidence and trust of the child, and to form a good nurse-patient relationship. Peplau (1962) and Hagerty and Patusky (2003), among others, write about the importance of the nurse-patient relationship. The concept of this relationship goes back to the universal need for human relatedness (Hagerty, Lynch-Sauer, Patusky, Bouwsema & Collier, 1992). This theory originates from the belief "that

relatedness is a functional, behavioural system rooted in early attachment behaviours and patterns” (Hagerty et al, 1992, p. 292). The concept of relatedness, which is evolving and complex, is based upon the person’s level of comfort and involvement with others (Hagerty & Patusky, 2003).

In the context of paediatric palliative care, the nurse-patient relationship needs to be adapted according to each child’s level of development (Betz, 2004). Within the scope of paediatric palliative care, a nurse-patient relationship consists of specific elements, including being a parent-minded nurse; sustaining human connections; as well as remaining cognizant of the fact that the patient is still a child. Zengerle-Levy (2006) interviewed and observed a group of nurses regarding the practices used when children were left alone in a burn intensive care unit. These nurses explained that they attempted to care for the paediatric patients as they would want their own child to be cared for, which the researcher referred to as caring in a parent-minded manner (Zengerle-Levy, 2006). The nurses reported consciously trying to alleviate the child’s fears of loneliness, pain and isolation through nurturing their emotional needs. This parent-minded role demonstrated that nurses occupied more than a nurse-patient relationship. They further indicated that personal parental experiences assisted them in recognizing children’s fears of dependency, as well as their emotional neediness (Zengerle-Levy, 2006).

This research further showed nurses to believe that the technological advances in the medical field were insufficient in sustaining life. Instead, human connections nourished the children’s whole being (Zengerle-Levy, 2006). As a result, nurses employ education, professional and personal experience to assist them in creating paediatric palliative care suitable to nurse-patient relationships. Presence, touch, listening and love were seen by the nurses as an essential aspect of their relationship with the children. These ‘caring elements’ were seen by the nurses as important communication elements that helped them to connect with the child in a way that allowed the child to express his or her suffering, to talk about it and to interpret it in a meaningful way (Fredriksson, 1999). The nurses focused particularly on love, believing that it

carried immense power. The nurses demonstrated that when working with children, it had potential long-term positive effects (Zengerle-Levy, 2006). Thus, nurses took on a mothering role, which linked with the nurses' deliberate engagement with the patient in a way that highlighted his or her being a child (Zengerle-Levy, 2006). These mothering elements seemed to be learned through the nurses' personal experiences of mothering. Nurses went beyond their regular nursing role or regular nurse-patient relationship, assuming a more mothering or nurturing role. Zengerle-Levy (2006) among other researches (Peternelj-Taylor & Yonge, 2003) postulated that this mothering role, although developed with good intentions, can lead nurses to go beyond a nurse-patient relationship and thus overstep professional boundaries. For instance, nurses may employ an overprotective parental role, preventing effective and honest communication with and understanding of patients and their families. The closeness and nurturing that resulted from this mothering attachment may have implications with regard to the ethical sensitivities inevitable in working with paediatric palliative patients.

Given that nurses emotionally invested beyond a regular nursing role, they created an intense bond or attachment. Bowlby (1969) wrote that attachment bonds have four defining features: proximity maintenance (desiring physical closeness to one's attachment figure); separation distress; safe haven (retreating to one's caregiver when one senses danger); and secure base (in order to explore knowing that your attachment figure will protect you from danger). According to his theory, attachment relationships evolve over the first two years of life and beyond. However, Bowlby (1969) did state that intimate attachment to other human beings is the focal point around which a person's life revolves, where he gave the example of one's therapist. Thus Bowlby believed that the therapist-client relationship, like the parent-child relationship, would manifest these same four characteristics. Again, this confirms prior literature that describes nurses' developing unusually intense relationships with paediatric patients, as well as nurses going beyond this and forming a mothering attachment (Zengerle-Levy, 2006). Bowlby further mentioned the significance of 'now moments' (Stern, 2004). These are brief interactions between nurse and patient, which have rich potential for change and growth for both the patient and the nurse-patient relationship. This too can be seen in nursing literature, regarding particular moments nurses feel are privileged, and feel to be a moment of intense connection with their

paediatric client (Fredriksson, 1999). Bowlby's theory of attachment is helpful in the context of paediatric palliative nursing in that it explains how the nature of attachment can have an intense impact, both positive and negative, felt by nurses as a consequence of the nature of such work.

Yet nurses also develop relationships with a patient's family members by providing them with support, as they form part of the unit of care in paediatric palliative care. This makes it important for nurses to identify the family's emotional state, while remaining cognisant of their own emotions and needs (Katzenberger & Ruesch, 2000). Achieving this balance, while still maintaining personal and professional boundaries, was presented by nurses to be challenging, particularly because they reported feeling compelled to take on the caregiver role (Katzenberger & Ruesch, 2000). However, if this was achieved, nurses showed that it could foster more open communication, effective teaching, and empowerment of the family and the nurse. Moreover, it could enhance the overall nursing care provided (Barnsteiner & Gillis-Donovan, 1990, as cited in Katzenberger & Ruesch, 2000).

Peternelj-Taylor and Yonge (2003) explored literature regarding the boundaries inherent in nurse-patient relationships, the importance of such boundaries, and ways in which nurses can maintain such boundaries. Nurses need to be aware that a nurse-patient relationship may leave them at risk of disregarding their professional boundaries. This is because this relationship creates an imbalanced or unequal relationship that may entice nurses into helping more than they should. Also, the intensity of patients' needs, as well as the strong relationship that nurses form with patients, can threaten the integrity of the relationship and ultimately lead to boundary violations (Peternelj-Taylor & Yonge, 2003). Thus, upholding professional boundaries is crucial in any nurse-patient relationship, but in practice it is not a simple task. The sensitivity of working with children makes the need for clear and definite professional boundaries even more significant.

Nurses employing a mothering role may confuse patients regarding the nature of the nurse-patient relationship. This is because nurses might take on an overprotective role that might discourage patients from approaching nurses regarding their emotional needs. Thus, nursing training needs to result in the creation and maintenance of therapeutic boundaries, whereby the patient and nurse are able to explore all elements needed from a position of empathy but still maintain neutrality (Peternelj-Taylor & Yonge, 2003). Peternelj-Taylor and Yonge (2003) thus described self-awareness, debriefing, institutional supervision and education as vital in empowering nurses to uphold their professional boundaries for the protection of both the nurse and the patient.

Another distinctive element of paediatric palliative care is that it is carried out by an interdisciplinary team. The complexity of paediatric palliative care makes it necessary for teamwork to be a vital part of the paediatric palliative care. It also makes it important for nurses to have a clearly defined scope of practice, as well as to have team co-operation (Goepf, Meykler, Mooney, Lyon, Raso & Julliard, 2008). Studies have shown how lack of team work often results in increased stress for nurses (Morgan, 2009). This is partly because lack of team work can result in nurses having to take on more than what is required of them. This may further influence nurses to disregard their professional boundaries. Nurses thus need to be cognizant of their professional limitations.

Nurses' attitudes may also influence their professionalism and maintenance of professional boundaries. For example, nurses' attitudes regarding working with HIV positive clients relate to the area of ethical issues that arise when working with such patients. The ethical and professional codes of practice guide professional nurses towards maintaining a trusting relationship and providing care that promotes the wellbeing of their patients. This includes the obligation to meet the health care needs of persons with HIV/Aids and apply ethical principles while caring for them. Ethical issues may include nurse emotions and behaviour regarding treatment, work environment or constraints, as well as issues regarding the therapeutic relationship. Nurses therefore need to be cognizant of their own attitudes towards HIV/Aids and how this might affect

the quality of care they are willing to provide their HIV infected patients (Berkowitz & Nuttall, 1996).

Due to the prominence of HIV/Aids on the African continent, it is important to consider research that has focused specifically on nursing within this context (UNAIDS/WHO, 2008). Several studies have been conducted on nurses' attitudes towards working with HIV infected patients, particularly within the South African context. However, most of these studies focused on nurses working predominantly with an adult population, examining their fears of contracting HIV as a result of their work (Reutter & Northcott, 1994, as cited in Deetlefs, Greeff & Koen, 2003). This fear can lead to avoidance of working with HIV positive patients, as shown in a study by Deetlefs, Greeff and Koen (2003). Deetlefs, Greeff and Koen (2003) interviewed nurses working in a hospital in the North West Province, South Africa. The researchers aimed to explore nurses' attitudes towards HIV positive patients, as well as to produce possible guidelines to help alter these attitudes for better care. This study's findings corroborated previous research that showed how negative attitudes led nurses to respond with fear, hopelessness, denial, blaming or unnecessary avoidance when working with HIV positive patients and thus negatively influencing the quality of care provided (Van Dyk, 1992, as cited in Deetlefs, Greeff & Koen, 2003). Despite these responses, nurses still used touch with patients suffering from Aids, which contrasted with findings from other studies that showed that fear to lead to avoidance, over-emphasis of universal precautions and little respect for HIV positive patients (Baylor & McDaniel, 1996, as cited in Deetlefs, Greeff & Koen, 2003). Nurses were further found to make value judgments regarding HIV positive patients. Nurses regarded the disease as a punishment for sin and a value judgment, depending on the method of transmission. For instance, nurses often viewed women and children as victims of men's irresponsible behaviour. Other nurses felt that younger people should be blamed if they became HIV positive in spite of health education. Nurses also felt that HIV-positive mothers should not have more children (Deetlefs, Greeff & Koen, 2003; Bester, du Plisses & Greeff, 2006). The latter is particularly relevant in paediatric palliative care for children who have HIV/Aids, as nurses' views seemed to change according to whether they are working with adults or children and in terms of the mode of transmission. These researchers concluded

that guidelines needed to be established and incorporated into nursing training, in order to counteract nurses' negative attitudes to care.

Other studies have also shown that nurses often view children with HIV infection as innocent victims (Novick, 1994). This is due to the fact that most HIV-infected children acquire their disease by being born to an infected mother. Although there are studies focusing on nurses working with children suffering from HIV/Aids, no studies seem to specifically focus on the nurses' attitudes regarding the mother to child transmission aspect of HIV. This is surprising, since the attitudes of nurses regarding HIV seems well documented. Yet the important area of paediatric nursing and the specific nature of mother to child transmission seem to be overlooked, including aspects of anger or blame towards the mothers, or issues of children being abandoned and thus having to be looked after at hospitals because of the mother's behaviour.

Yet nurses' attitudes to working with patients with HIV go beyond their views regarding mode of transmission. Berkowitz and Nuttal (1996) conducted a qualitative study on paediatric nurses from New York, Boston and Chicago, to explore the willingness of nurses to provide care to children with HIV/Aids. Here, a child population was chosen so that the mode of transmission with regard to the illness was not a factor influencing nurses' attitudes. This study found that paediatric nurses' experience with people infected with HIV usually resulted in more positive attitudes and rarely any negative ones. It further found that less than one fifth of the nurses felt that their job put them at high risk of exposure to HIV. Previous research has shown this relationship of nursing experience with the attitude of working with patients with HIV (Ficarrotto, Grade, Bliwise & Irish, 1990; Fredericks & Wilson, 1992, as cited in Berkowitz and Nuttal, 1996).

Thus, the various unique elements of the paediatric palliative scope, along with nurses own cultural or personal beliefs, reflect the complexity, intensity and impact of this type of care with regard to paediatric palliative nurses.

## 2.2 The impact of paediatric palliative care on nurses

The intensity and intimacy of paediatric palliative care work can lead nurses to experience both a positive or negative impact. Nurses may thus experience the work as fulfilling and emotionally rewarding, or as distressing and having a large emotional cost. Research in this area has primarily focused on the negative side of this spectrum, despite both being evident in studies.

Papadatou, Martinson and Chung (2001) explored both the positive and negative impact on nurses working with terminally ill children. They found that despite nurses explaining the difficulties of this type of nursing, they often still felt that it provided them with fulfilling experiences. This sense of fulfilment seemed to help them in dealing with the distress that resulted from their work. Nurses described a deep sense of satisfaction in feeling that they had provided something significant in their care of terminally ill children. Thus, they expressed that their job was extremely difficult, yet also meaningful.

Other researchers have focused more on the negative impact that paediatric palliative care can have on nurses. Morgan (2009) delved into various issues with regard to the negative impact that paediatric palliative care may have on nurses, such as moral and ethical distress. Moral and ethical distress were seen to occur when nurses were forced to act in a way that was not in line with their personal or professional ideals. Moral and ethical distress was found to result in leading nurses to feel helpless and angry. For instance, nurses expressed the difficulty in providing curative care, while also trying to provide the patient with comfort and quality of life (Davies, Clarke, Connaughty, Cook, MacKenzie, McCormick, O'Loane & Stutzer, 1996).



Barriers were seen to be either internal (communication skills or education) or external (being excluded by the institution in terms of decision-making) and these prevented nurses from acting in accordance with their own beliefs. This study further found that when nurses felt that they were no longer useful in assisting their terminally ill patients in their recovery, they often experienced sadness, ambivalence and helplessness (Yam, Rossiter, & Cheung, 2001, as cited in Morgan, 2009). Nurses further explained that witnessing the suffering of paediatric palliative care patients is very difficult for them, revealing some of the emotional impact of their work. These researchers concluded that these barriers need to be addressed, through education and counselling, in order for nurses to achieve job satisfaction.

Thus nurses suffer emotionally when working within the context of illness and death in a child population (Morgan, 2009). Nurses develop an intense connection with their patients and, as a result, experience an intense sadness when witnessing a patient suffer, or upon the loss of a patient. Thus, nurses find it difficult to witness the suffering of a child, including watching them miss out on their childhood. Nurses further struggled when they identified their patient with their own children, or identified themselves with the patients' grieving mothers. Sometimes, nurses try to keep themselves busy with the medical elements of their work, in order to try separate themselves from the relationship or attachment that they have formed (Morgan, 2009).

Various studies have been undertaken to explore the impact that working with chronic or terminal illness might have on nurses. Nurses working within these contexts experience a variety of emotional responses (Maytum, Heiman & Garwick, 2004). Most nurses describe feelings of uncertainty, fear, anxiety and guilt that are experienced as a result of witnessing the suffering of their chronically or terminally ill patients. These accounts have been elucidated upon in other studies. For instance, Copp (1997), through interviews and observations of hospital nurses, explored the ways in which nurses dealt with the impact of working within the context of death. Here, nurses described caring for dying individuals as extremely stressful, leaving them to feel inadequate and unable to cope with all of the elements of their job.

More recently, researchers have begun to focus more on the emotional impact of nursing, particularly nurses' experience of grieving upon the loss of a patient. Researchers have examined the emotional impact that the process of illness or death of a child can have on general nurses (Davies, Clarke, Connaughty, Cook, MacKenzie, McCormick, O'Loane & Stutzer, 1996). Saunders and Valente (1994) proposed a four-step model describing the grieving process as experienced by general palliative care nurses. This model described finding meaning; restoring or maintaining a sense of personal integrity and self-esteem; responding and managing personal feelings; and realigning relationships (Saunders & Valente, 1994). Some studies have gone beyond this, exploring the various ways in which nurses respond to grief (Davies, Clarke, Connaughty, Cook, MacKenzie, McCormick, O'Loane & Stutzer, 1996; Papadatou, Martinson & Chung, 2001).

Several studies have described general nurses' grieving experiences as having to be expressed in the form of hidden or unresolved grief. This was seen to be a result of nurses feeling as though they lacked a legitimate status as grievers (because they are not family members) and thus not being offered support from others (Rawnsley, 1990). Additionally, nurses may feel that they are discouraged by their institutions and by society to express emotions so as to maintain their professionalism (Feldstein & Gemma, 1995). Feldstein and Gemma (1995, p 229) wrote that nurses are subject to a "strong covert institutional message as well as peer pressure not to dwell on the loss" of patients. This pressure to move on after a loss of a patient may prevent nurses from acknowledging or expressing their grief responses, as well as preventing them from seeking out support (Shirk 2000). Yet the literature on grief identifies these as critical tasks of bereavement that, if left undone, can have an impact on one both emotionally and physically, as well as leading to work-related complications (Grove, 2003).

Little research has been conducted to explore the unique way in which paediatric palliative care nurses experience and express their grieving responses. Although studies from other areas of nursing can assist in an exploration of the experience of grief in nurses, it seems that the

complexities of paediatric palliative care may further impact on the way in which paediatric palliative care nurses experience and express grief. Furthermore, grieving is seen to be a universal experience, though it might be experienced and expressed differently. Papadatou, Martinson and Chung (2001) revealed both the similarities with palliative care and unique aspects within the scope of paediatric palliative care, in terms of the grief process of paediatric palliative care nurses. These researchers explored and compared the subjective experiences of nurses who provided care to terminally ill children in an oncology and a critical care setting in Greece and Hong Kong. These two cultures were chosen in order to explore whether there were differences in experience and expression of grief in western and non-western cultures. Using in-depth semi-structured interviews four major themes were explored, namely the motives that led nurses to decide to work in paediatric palliative care environments and personal experiences with illness, death and grief; the stressful and rewarding experiences resulting from their job; personal responses and meanings attributed to the death of children; and factors that affected their desire to stay or leave their current job, as well as their level of satisfaction with their current work (Papadatou, Martinson & Chung, 2001). It was found that 93% of the nurses identified experiencing grief upon the loss of a patient. Some nurses described being emotionally detached or distant as ways of trying not to grieve. These showed some of the defence mechanisms employed by nurses as a way of not engaging with their own emotional responses to the work of paediatric palliative care nursing. This study further revealed that these nurses experienced grief as an ongoing experience, involving constant vacillation between focusing on the loss and pain and avoiding or repressing it. Nurses described their grieving responses as resulting in their experiences of personal loss and pain. They further described this grief as resulting in the experiences of depression, recurring thoughts about the patients they have lost, the experience of guilt feelings, a need to cry, pray, briefly withdraw from daily activities, to share their experiences with colleagues or loved ones, or to attend the child's funeral to bring a closure to a relationship that was significant to them. Responses that helped them repress or avoid their grief involved attempts to try control their feelings; depersonalization of the lost patient; the experience of psychic numbing; or becoming involved with clinical duties and activities. Hence nurses reacted in two extreme ways, either by withdrawing or by overinvesting in their patient(s), both of which could be damaging.

This study found grieving to be a healthy and normal process that allowed the nurses to be aware of the impact the child's death has on them, without it overwhelming them (Papadatou, 2000). Yet it also showed that different cultures and the various types of nursing can influence the way in which nurses may express or react to grief. For instance, many of the Greek nurses openly expressed their anger, frustration, distress and sense of injustice over children's death. In contrast, many Chinese nurses experienced a sense of relief, as they perceived death as alleviating the patient from his/her pain and suffering. The majority of Greek and Chinese nurses attributed childhood death to sources outside themselves, such as religious or biological forces. Few nurses attributed death to their own inability to cure the patient, or to the child's futile attempts to fight the disease. These two groups reacted differently, in term of their emotional reactions. These findings indicate how religious and cultural beliefs may have an influence on nurses' world views, coping strategies, and communication patterns, and thus an influence on how nurses deal with and approach palliative patients. In the various South African cultures, many of the rituals and cultural experiences refer to issues regarding post death, such as burial and mourning. These post death rituals might influence how nurses deal with death and dying (Liben, Papadatou, & Wolfe, 2008; De Villiers, & Ndou, 2008). Thus, the current study proposes to explore how culture within South Africa influences the delivery of palliative care. Hence, it is imperative to acknowledge and understand the impact that working with dying children has on paediatric palliative care nurses. These understandings need to be incorporated into an appropriate approach to nursing education, so as to better prepare nurses for the nature of paediatric palliative care nursing (Papadatou 2000).

Grieving may go beyond grief over the loss of a patient and thus also relate to nurses feeling as though they have failed in the care that they have provided (Papadatou, 1997). Nurses may also grieve over missed opportunities (experience, education and so on) that they feel might have better equipped them in saving their patient. Nurses working with children may feel that as an adult, they have failed in their duty to protect children from harm. Nurses may also feel that they let the patients' family down, who trusted them in caring for their child (Papadatou, 1997). These feelings of failure may intensify nurses' experience of grief. As a result, nurses may feel helpless, guilty, angry or sad. These feelings form part of the negative impact of nurses working

with chronically or terminally ill children. Working with children who are chronically or terminally ill thus has a unique impact on nurses. As a result, nurses are challenged to develop their own philosophy on life and death. This will help them to cope with the illness or death of a child, something which is seen as out of the natural order and thus difficult to come to terms with (Papadatou, 1997).

Grief represents only one aspect of the negative impact of paediatric palliative care nursing. Nurses may also experience emotions such as helplessness, anger, sadness, and anxiety as a result of working with paediatric palliative patients (Morgan, 2009). Other negative impacts include grieving experiences in response to the patients, such as experiencing distress emotionally, morally, professionally and physically (i.e. burnout and compassion fatigue); as well as negative methods of coping (Joinson, 1992; Figley, 1995; Papadatou, 1997; Davies, Clarke, Connaughty, Cook, MacKenzie, McCormick, O'Loane & Stutzer, 1996). Such negative influences may not only impact on the nurse as an individual, but also on their workplace, where a nurse may not be able to work as effectively or efficiently; as well as on their home environment, where stress spills over into their personal life (Pffifferling & Gilley, 2000; Brosche, 2003; Lamson & Meadors, 2008). Thus, the impact of paediatric palliative care on nurses can be felt by nurses as a positive or negative impact. Several theories have been employed to explore why this impact is neither experienced nor dealt with by everyone in the same manner. Many studies have used Lazarus and Folkman's (1984) transactional model as a basis for explaining a more cognitive approach to the impact of stress (via appraisal) and how individuals cope with this impact (Lazarus & Folkman, 1984). Recently, this model has been applied to a number of populations, including nurses working with HIV/Aids patients (Bova, 2003; Pakenham & Rinaldis, 2001; Park, Folkman & Bostrom, 2001; Silver-Aylaian, 2003; Cronqvist, Theorell, Burns, Lutzen, 2001). The findings from such studies suggest that negative primary appraisals (i.e. threat, harm) are associated with negative psychological and physical adjustment, whereas positive appraisals (i.e. challenges) are associated with positive psychological and physical adjustment. Therefore, nurses' appraisals of whether their work is stressful, as well as whether they feel their personal and working environment offers them helpful ways in which to cope, was found to be vital in the understanding of how certain

elements of the job may have been seen as stressful. It further explained how certain nurses employ more productive coping mechanisms within the same working environments. This understanding was important for this study, as nurses' experiences of the impact of their work and methods of coping are an important part of the paediatric palliative care nursing experience.

Paediatric palliative care nursing requires a vast amount of personal and professional investment. As a result, nurses may experience various other stressors or frustrations that lead to them feeling drained and overwhelmed (Saunders & Valente, 1994). These issues may include: lack of time for each patients' needs; additional pressure from family members; constant pressure for physical and emotional attention by the patients; the wish to have the capacity to anticipate patients' needs; the feeling that patients' just die and thus nurses' efforts are never enough; as well as personal conflicts that add to work pressure and colleague conflict (Saunders & Valente, 1994).

Therefore, working with death affects individual nurses in different ways. The pressure from patients and the nature of palliative care may impact upon the nurses' personal viewpoints about death; regarding their role in comforting while still not giving up on curing the patient; their professional purpose, their own level of grief in response to patients; their reactions to emotions and conflict; and how they are able to cope (Davies, Clarke, Connaughty, Cook, MacKenzie, McCormick, O'Loane & Stutzer, 1996). Furthermore, working with HIV/Aids poses a unique set of factors that confront the patient, their family and the nurse. These include the nurses' fear of being infected; the individual's possible responsibility in contracting or spreading the virus; as well as the social stigma attached to HIV/Aids (Bester, du Plessis & Greeff, 2006; De Villiers & Ndou, 2008). These stressful elements may result in nurses experiencing distress, burnout or compassion fatigue.

Unexpressed or unresolved grief that results from nursing chronically ill children can result in the development of distress, burnout or compassion fatigue. Much research has focused on

compassion fatigue and burnout in relation to health professionals. Joinson (1992) suggests that nurses who may be likely to be empathetic and caring individuals, may absorb the traumatic stress of those they help. Figley (1995) referred to this phenomenon as compassion stress and later as compassion fatigue. Compassion fatigue is a result of prolonged exposure to trauma (such as working with death and dying, particularly working within the context of children) resulting in a variety of problematic symptoms, such as emotional and physical exhaustion. Caring for terminally ill patients and the realization that their patients may not recover may be extremely challenging for providers. Yet nurses need to continue providing individualized care to their patients (Figley, 1998). When a healthcare professional experiences a negative impact from work, such as compassion fatigue, this might additionally negatively impact both the workplace and the nurse's home environment (Pfifferling & Gilley, 2000). The former is because nurses who experience a negative impact from their work and thus experience compassion fatigue lead to decreased productivity, higher turnover and nurses requiring more sick days. Compassion fatigue may also have long-term implications for the care that health professionals provide to their patients and for themselves, as they continuously need to be prepared to assist the family of a chronically ill, traumatized or dying patient, as well as be prepared to deal with their own grief (Brosche, 2003).

Other studies have explored whether individuals who experience a negative impact at work will also do so in their home life. Thus, whether one appraises stress in a positive or negative manner may be more reflective of the individual than the work context. Lamson and Meadors (2008) conducted a quantitative study on 185 employees of a Children's Hospital, to determine whether compassion fatigue was experienced, as well as the type of coping strategies employed. Here, the researchers found that providers who experienced higher levels of personal stressors also experienced higher levels of clinical stress and compassion fatigue. They further found that those individuals who had a higher stress score, exhibited more negative behaviours, had a more difficult time separating work from personal life and tended to bring negative feelings from work to their home and family (Lamson & Meadors, 2008). In other words, those who were more stressed seemed to have evaluated the situation as stressful and seemed less able to find effective methods of coping. The reverse was true for those who obtained a low stress score. This group

exhibited higher positive behaviours, such as taking time for themselves to meditate; exercise regularly; have healthy eating habits; demonstrating self-assertive behaviours; as well as setting limits at work (Lindahl & Norberg, 2002).

The signs and symptoms of both compassion fatigue and secondary traumatic stress are well documented (Figley 2002). However the research that has been conducted on compassion fatigue primarily focuses on physicians and mental health providers (Figley, 2002). It is important to gain an understanding of how the nature of paediatric palliative care work can negatively impact nurses both personally and professionally. Since nurses are at risk of experiencing distress, burnout or compassion fatigue, it is important to explore what personal or environmental issues may leave nurses more at risk of experiencing a negative impact. Maytum, Heiman and Garwick (2004) conducted a descriptive qualitative pilot project on twenty paediatric nurses from a variety of paediatric settings in Minneapolis, Minnesota, in order to learn about their experiences with compassion fatigue and burnout. It was found that compassion fatigue was both commonly and frequently experienced by these nurses. These participants identified a number of distinct triggers that were of a work-related or of a personal nature. Thus, this study assists in discerning elements of paediatric work that may cause nurses distress. Nurses explained that caring for children with chronic conditions and their families was a primary work-related trigger leading to their experience of burnout. Nurses further described how their professional roles led them to experience immense pressure due to the load and intensity of their work. Another work-related trigger cited by the nurses in this study included work overload (Garwick, Heiman & Maytum, 2004). The most commonly cited examples in this study were seeing too many painful procedures done to children, experiencing sadness, as well as witnessing many deaths and a great deal of suffering. Approximately two thirds of the participants described lack of support as a crucial element leading to feelings of being distressed. In terms of personal triggers, the most prominently cited was becoming overly involved or crossing professional boundaries (Garwick, Heiman & Maytum, 2004).



Paediatric palliative care is a complex and intense job. Thus, any additional pressures on the staff, such as difficulties with communicating with both the patient and his/her family, may increase the risk on nurses experiencing a negative impact, or excessive stress. Cohen, Contro, Larson, Scofield and Sourkes (2004) conducted a study to assess both family and staff opinions about the quality of palliative care in a Californian hospital. Staff felt inexperienced in communicating with patients and families regarding end of life issues (Cohen, Contro, Larson, Scofield & Sourkes, 2004). Communication difficulties, in terms of how to best communicate with the patient and their family on issues of death and/or support, are just one of the many identified obstacles to good care found in several studies. Thus communication problems and inexperience or lack of preparedness seemed to further escalate the nurses' experiences of stress resulting from their work.

Payne (2001) conducted a quantitative study focusing on stressors, coping and demographic variables as predictors of burnout in a sample of hospice nurses from nine hospices in the United Kingdom. This study used the Maslach Burnout Inventory, The Nursing Stress Scale, Folkman and Lazarus's (1986) Ways of Coping (revised), as well as a demographic questionnaire. The evidence from this study and previous research (Ceslowitz, 1989) suggests that although some problem-focused strategies are negatively related to burnout (e.g. planned problem-solving); others are positively related (e.g. confrontative). Similarly, some emotion-focused strategies are positively related to burnout (e.g. escape) but some are negatively related (e.g. positive reappraisal). Hence research concluding that problem-focused coping is positively related to burnout and emotion-focused coping is negatively related (Ceslowitz 1989) is oversimplifying the relationship. Thus, viewing nursing as stressful may not necessarily lead to an experience of nursing work as having a negative impact, nor will the use of emotion-focused coping strategies always culminate in the experience of burnout. This seemed to reflect that defence mechanisms and ways of coping can be both helpful and harmful, depending on how they are used.

Thus nurses try to deal with the emotional pain of their work in a variety of ways. McNeely (1996) studied, through the use of questionnaires, the impact of stress and coping strategies in a group of 308 palliative, psychiatric and general nurses. According to this study, nurses were aware of the need to separate work from home. Respondents gave a variety of ways of establishing boundaries needed to help them in avoiding the negative impact of their work stress effecting their home lives. Nurses described informal chats or group meetings and socializing after work with colleagues as important relational or interactive ways of coping. Furthermore, the frustration felt by the nurses was generally expressed privately through crying, listening to loud music, screaming or loud outbursts. These coping strategies were employed in order to release and relieve nurses from the pressures of work so that when they got home, these tensions were not carried over into their family time (McNeely, 1996). Additionally, coping strategies were employed by nurses, which either aggravated the negative impact or protected nurses from it. Coping strategies that led to nurses experiencing a negative impact included the defence mechanisms of avoidance, distancing or denial regarding the impact of their work. This was done by occupying themselves with other things and keeping busy. Also, nurses employed techniques that helped them in reducing the negative impact that they experienced, such as exercise or shouting (used by 50 per cent of the sample but given as most effective by only 25 per cent of those listing these methods of coping) (McNeely, 1996). Since paediatric palliative care nursing can be a stressful and demanding occupation, it is imperative that nurses learn how to deal with this negative impact. There are many ways in which paediatric palliative care nurses learn to cope with the demands of their work, including a variety of emotional, psychological, physical and social processes and strategies (Payne, 2001; Pakenham, & Rinaldis, 2001; Park, Folkman & Bostrom, 2001).

Support is highlighted in many studies as an imperative part of preventing or lessening the impact of nursing. In a study by Cohen, Contro, Larson, Scofield and Sourkes (2004), which used both qualitative and quantitative methods, over half the nurses researched explained a feeling of lacking both informal and formal types of support in the hospital setting with regard to end-of-life care. Participants were staff from one children's hospital in Stanford. Almost half of this sample consisted of nursing staff, with 20 percent of the nurses from various specialty

paediatric units. Here, nurses explained the importance of emotional, psychological and social support, with most of them feeling that there was an inadequate amount of support available to them. Nurses also described a lack of support from friends, family, colleagues and other health professionals (Morgan, 2009). Cohen et al (2004) concurred with past studies in that inadequate support for nurses often led to depression, emotional withdrawal, as well as many other symptoms (Bagatell, Meyer, Herron, Berger, Villar, 2002, as cited in Cohen, Contro, Larson, Scofield & Sourkes, 2004). Hence, support was highlighted in the relevant literature as a major contributor towards stress and the prevention of stress (Abendroth & Flannery, 2006; Cook & Oltjenbruns, 1998).

Research has found that professionals who listen to clients' stories of fear, pain and suffering may feel similar fear, pain and suffering because they care (Figley 1995). This can impact on paediatric palliative care nurses emotionally, physically and psychologically, as well as on personal, relational and occupational levels. When working within the context of HIV, paediatric palliative care nurses need to develop self-awareness, self-care (including setting boundaries and expressing grief), as well as making use of available support systems (including both personal and institutional support).

Since paediatric palliative care nursing requires teamwork, it is important for there to be collaboration (Morgan, 2009). A cohesive team provides further support for nurses, allowing them to experience less of an impact as a result of the intense and intimate nature of their work. Education and experience are also important in preparing nurses for the impact of paediatric palliative care (Morgan, 2009). In addition, several studies have focused on whether one's educational preparedness or experience can impact on nurses' ability to cope with the negative impact of paediatric palliative care (Contro, Larson, Scofield, Sourkes & Cohen, 2004). Nurse educators have identified that historically, nurses have not been sufficiently prepared to care for dying patients (Mallory, 2003). Yet several studies have highlighted the potential positive impact that educational preparation can have on nurses' attitudes towards death, communication, pain

and symptom management, ethics, caregiver distress and most importantly on nurses' abilities to cope (Degner, 1985; Karnard, 1999, as cited in Mallory, 2003). Despite these studies, paediatric palliative care nurses have described feeling inadequately prepared to deal with issues that have arisen due to the nature of paediatric palliative care nursing, particularly focusing on their attitudes towards suffering or dying and effective communication.

For instance, a study by Mallory (2003) explored whether there were any positive effects resulting from an end-of-life educational nursing experience. This was done using a pretest-posttest, with two groups completing the Frommelt Attitude Toward Care of the Dying (FATCOD) scale and a demographics questionnaire, with the intervention group additionally participating in an educational training component. It was found that education could have a positive effect on nursing students' attitudes toward care of the dying, in that these students had a significant positive improvement in their attitudes and ability to cope following the intervention. This study and other studies have indicated the constructive impact that education can have on nursing attitudes and ability to cope with their work, thus supporting the recent trend to integrate end-of-life content into nursing education (De Graves & Aranda, 2005). Furthermore, Feudtner, Santucci, Feinstein, Snyder, Rourke and Kang (2007) conducted an internet survey with 410 paediatric nurses in a major children's hospital. Their study further indicated that nurses with more years in practice, more hours of palliative care education and/or experience, as well as those who indicated higher levels of hope or comfort in caring for dying children and their families found it easier to talk about death and dying, reported higher levels of palliative care competency and better ability to manage their job (Lange, Thom & Kline, 2008). This conclusion is confirmed by several other studies (Gow & Williams, 1971). These results indicate that nurses who are more prepared for this type of work seemed to be able to cope more easily with the uniqueness and intensity of the work. Thus education and experience have been shown to have a positive and powerful impact on nurses' abilities to cope.

In conclusion, paediatric palliative care nursing builds on the elements of general palliative care, adding its own unique elements. Paediatric palliative care nurses must provide individualistic care, tailoring the care to the child's emotional, medical, developmental, communicative and relational needs. This must be done while focusing on the patient and their family as the unit of care. Paediatric palliative care nurses thus provide holistic care. Yet the immensity of work required necessitates a cohesive interdisciplinary team.

The vast scope of paediatric palliative care nursing work, as well as the intimacy that results from the attachments formed with patients, often results in both positive and negative impacts on the nurses. This impact may leave nurses feeling emotionally fulfilled or drained and may have accompanying physical consequences. Part of this impact is the grieving experience that nurses go through. The impact of paediatric palliative care on nurses is dealt with in various ways, some more helpful than others. Key areas of support with regard to this impact included self-care, emotional support, as well as social and institutional support.

### **3: Methods**

This chapter describes the methods applied to the current study. The research questions, research design and participants are described. Also, the procedure, measures, data analysis and ethical considerations are discussed.

#### 3.1 Research Questions

- a) What is the scope of paediatric palliative care nursing?
- b) How does paediatric palliative care impact on nursing staff?

#### 3.2 Research Design

In order to achieve the aims of this research, a qualitative, non-experimental study was chosen. A qualitative research methodology was chosen for this research as it lends itself to the exploration of and insight into subjects experiences of their work. Qualitative research allows for exploration of issues in their natural setting (Holloway & Todres, 2003). Furthermore, the researcher forms part of this examination, which differs from the objective standpoint employed in quantitative research. Qualitative methods allow the research more flexibility with regards to the parameters of what is being investigated. The goal of qualitative research is to achieve understanding of the subjects and the context that they are in. As a result, this type of research allows for responses that are meaningful and rich (Holloway & Todres, 2003). Thus A qualitative framework was employed.

#### 3.3 Participants

This study used convenience and non purposive sampling. The sample comprised of seven nurses working with paediatric palliative care patients from either The Soweto Hospice or the

Cotlands Baby Sanctuary. Three of the interviews took place at The Soweto Hospice, with the remaining four at the Cotlands Baby Sanctuary. At the time of the interviews, all of the interviewees were full time nurses at either the Soweto Hospice or Cotlands Baby Sanctuary. All of the full time paediatric palliative care nurses at both of these institutions responded to participate in this study. All of these nurses had previous nursing training and worked within the specialized area of paediatric palliative nursing training. These nurses had varying years of experience in the general nursing field, palliative nursing field and paediatric palliative nursing field. Interviewees described their general nursing experience as ranging from three to thirty years, while their paediatric palliative care experience ranged from a less than one year to eight years. All participants had a minimum of six months experience in the paediatric palliative care field. Gender, age and race were not excludable criterion in this study.

### 3.4 Procedure

The researcher contacted both The Soweto Hospice and Cotlands Baby Sanctuary, in order to obtain permission to conduct this research. The Facility Manager or Childcare Manager sent a letter granting this permission (Appendix E, F and G). After this, ethical approval was gained from the medical ethics committee of the University of the Witwatersrand (Appendix H). Once ethical clearance was granted, a subject participation form (Appendix A) was given to each paediatric palliative nurse beforehand, explaining the purpose of this study. Consent forms (Appendix B and C) were also given to each care worker at Soweto Hospice and Cotlands before conducting each interview.

This research was conducted over several months, from July to October 2009. The interviews were held at the Soweto Hospice and Cotlands premises, respectively, at the convenience of the participants. Each interview took less than one hour to complete. Each interview was audio recorded and transcribed. This data was then repeatedly examined to facilitate the formation of codes and themes, as specified by Braune and Clarke's (2006) method of thematic content analysis.

### 3.5 Instrumentation

This study used a self-developed, semi-structured interview (Appendix D). Semi-structured interviews were used to explore both the scope of paediatric palliative care nursing and the impact that it has on nurses. The use of open-ended questions allowed participants to answer in their own words, without limit. The semi-structured questions put forward in interviews also maintained a structure, thus allowing for consistency of data (Whitley, 2002). In this way, using a qualitative study and using interviews allowed for the collection of information, as well as allowed for exploration. This research merely observed what existed, without trying to control or manipulate any of the relevant variables (Whitley, 2002). The fact that this study aimed to explore and describe the subjective experiences of the participants suggests that a qualitative approach would be most useful.

The researcher engaged with relevant literature regarding the various elements of paediatric palliative care, the impact that work can have on nurses, as well as the ways in which they cope with this impact. This guided the researcher with regard to the formation of this semi-structured interview. Each of the interviews were audio-recorded and transcribed, to accurately encapsulate all of the information gained from the interviews.

### 3.6 Data Analysis

Braun and Clarke's (2006) thematic content analysis method was used in order to analyze the information collected from the interviews. The researcher identified and analyzed the patterns or themes emerging from within the data set (Braun & Clarke, 2006). Braun and Clarke's (2006) method of thematic content analysis method allowed for both the systematization of the data, and for a detailed and meaningful description of that data. Thematic content analysis differs from other analytic methods in that it is not bound to a theoretical framework, thus allowing for flexibility. According to Braun and Clarke's (2006) method, the researcher read the data



repeatedly, so as to become familiar with the content. This included transcribing the audio-taped interviews, as well as the writing of brief notes on initial themes.

Thereafter, a list of all possible codes was generated, in order to identify important features of the data and to assess the data in a meaningful way. These codes were then used to search for themes. This was done by using the initial codes (from the previous step) to discover potential themes and relationships between these codes, as well as to classify significant main themes and sub-themes. These included training and experience; feeling adequately prepared for the job; aspects of the job; finding outlets to release or express distress; institutional culture; working with HIV/Aids; how paediatric palliative care is different from other nursing; professionalism; skills needed for this job; involving the patient's family; parental attachment; boundaries; witnessing suffering and the impact of this; hope; grieving; religiousness; discussing illness and death with children; nurses felt there was an impact; attitude to the work and appraisal; ability to separate work from life outside of work; shortage of staff or lack of resources; personal support; personal coping strategies; psychological support; institutional support; teamwork; and culture. These themes were then grouped according to the research questions, to allow for the discussion and analysis of the results to have more consistency and flow.

These themes were then collapsed into more concise themes, where some themes required being split up into separate themes. For instance, issues of attachment were integrated with the area of the nurse-patient relationship; and appraisal and coping were reformulated to focus on the positive and negative impact of paediatric palliative care on nurses. Following this the researcher examined whether all the themes appeared to form a coherent and connected picture, as well as whether these themes corresponded with the raw data. This allowed the researcher to construct a thematic map of the data, as well as further refine the significant themes of this study. Finally, a research report was produced, containing all the concise and relevant themes (Braun & Clarke, 2006).

### 3.7 Ethical Considerations

Participants were given a subject information sheet explaining the aim and purpose of this study, in order to inform them of their rights as participants prior to being interviewed. The participants were also told of their right to withdraw from the study at any time, without any negative consequences. The voluntary nature of participation was also emphasized. When choosing to participate in the interview, the participant gave his or her consent to participate in the study, to allow for the audio-taping of the interview, as well as the use of direct quotations from the interview in the research report.

Only the supervisor and researcher had access to this material, thus ensuring limited confidentiality. No identifying information was used in this study, as each interviewee was assigned a numerical code to ensure anonymity. Upon completion of this study the audio tapes, as well as the transcribed material will be kept for six years, after which they will be destroyed.

Due to the nature of this study and of paediatric palliative care work, some risks were anticipated. Thus, nurses were given the contact numbers for both Lifeline and the Emthonjeni Centre for free counselling and advised to contact either of them, should they experience any emotional difficulties as a result of the interviews. Upon completion of this study, the results were made available to the Soweto Hospice and the Cotlands Baby Sanctuary, in the form of a summary. It was hoped that by sharing information and suggesting possible practical implementations of such information, the present study was not merely be an academic exercise, but one that may impact positively on the population from which the sample was drawn.

## 4: Results

The findings of this study were based on the two primary research questions, namely the scope of paediatric palliative care nursing and the impact that paediatric palliative care has on nurses. The scope of paediatric palliative care nursing focused on how prepared nurses felt regarding all the elements of paediatric palliative care. Also investigated was the mothering, nurturing or intimate role that the nurses employ in relation to their patients. The impact of paediatric palliative care was explored through examining how nurses experience their work, as well as the impact of their work. This impact included how nurses may disregard their professional boundaries. Lastly, the way in which nurses dealt with the impact of their work was examined.

### 4.1 The scope of paediatric palliative care

Paediatric palliative care requires nurses to provide a holistic level of care. Nurses explained the various elements of care.

*“My work mainly entails taking care of sick children holistically - psychologically, physically and medically (Nurse [N] 4)”.*

The main physical and medical areas involved administering medication, monitoring the children for any signs of sickness, as well as bathing and feeding the children. Every nurse described the element of psychological care as an important aspect of paediatric palliative care, but their explanations of what constituted this type of care differed. Furthermore, nurses seemed to understand the emotional needs of children according to two stages, younger and older children. Nurses described playing with younger children; reading to them; spending time with them; and talking to them about child-related issues as ways of providing appropriate psychological care for younger children. For the older children, nurses described talking to patients, or allowing them the space in which to express their fears and wishes.

*“When you play with them...you break that barrier between nurse and patient. Then there’s this interaction...and they begin sort of like trust you (N 4)”.*

Thus, nurses explained the importance of emotional care, which in paediatric palliative care comprised of physical closeness, physical comfort, non verbal communication, as well as attending to the plethora of needs expressed by each child. It was also part of the nurses' job to provide support for the patients' family, educating them on the child's condition and prognosis, as well as providing emotional support for them. Nurses tailored their care for each of their patients according to the developmental needs of the child. This also included the way in which nurses communicated with their patients, as well as what nurses were focused on in terms of the patients' communication to them. Thus, working with children made non-verbal communication very important. Nurses expressed the need to understand non-verbal communication in order to better understand the physical and emotional pain of their patients.

*“If you’ve worked with [children] for a long time, you understand the child; you understand what’s happening with the children because they can’t talk for themselves (N 7)”.*

*“The challenges we have, like any other Paediatric nurse, is communication... we have to try learn about...communication. Especially... gestures, non-verbal communication (N 4)”.*

Nurses also showed how communication was an important accompanying element while nurses performed aggressive treatments. For instance, nurses felt that they needed to tell every patient, regardless of their age, ‘I love you’, as a way of comforting them through physical and emotional pain.

*“You just tell them ‘I love you’, you tell them before you do it, because it’s sad just to prick [them]. When you say it, it helps them, even if they can’t respond, to understand before you do it. And if it is old[er] kids, from 8 years and above you can talk to them, and you can explain and support [them] (N 6)”.*

Nurses also commented on the cultural influence on communication. Nurses described African cultures as discouraging open and honest communication and collaboration with children.

African cultures, as referred to by the nurses, were shown to limit the opportunity of open and honest communication with children regarding illness and death, as well as discouraging patients, their families and the nurses from emotional expression. Several studies have focused on the impact of culture on communication regarding the topic of death and dying in relation to children (Liben, Papadatou, & Wolfe, 2008). It seems that in some Eastern cultures, there is a 'protective' or closed communication approach, where children are not openly spoken to regarding dying and decisions regarding palliative care (Liben, Papadatou, & Wolfe, 2008). However, although nurses were open to discussing their African culture and its influence on communication, it appears that the influence of culture is not necessarily considered, or incorporated into palliative care or paediatric palliative care training.

Furthermore, channels of communication from within the cultural context are generally hierarchical, with children being protected from open and negative communication. This was highly prevalent within the South African context (DiMatteo & Martin, 2002).

*"In the African traditions, it's so difficult, you know. [Patients and their families], don't like really showing their feelings, you know. They sort of like hide [their feelings] (N 4)".*

Nurses felt that African cultures promote a more parental or paternal or overprotective type of care, where children are not spoken to about death and dying and adults are not encouraged to express their emotions in response to death and dying. However, it seemed that when the children initiated a discussion with nurses regarding these issues, nurses were able to support them. Yet the nurses did not initiate or provide a further forum for their patients to openly discuss and engage with these issues.

*"According to our culture, we are not supposed to tell the child that you are going to die... So, I don't do it.... I still maintain that ...I don't think it's right to tell the child that the child is going to die. Because when a fourteen year-old child dies or a ten year-old, when she's very sick, I think they do feel that they will die. They can tell us, they do not need me to tell them. They do ask... Am I going to die? They do ask. Then I will ask them: What do you think? And then either*

*she will say: I think I will die or I will get better. But I don't tell them that they're going to die (N 3)''.*

Thus nurses seemed able to provide patients with a safe space to talk about their views of death, but the nurses were aware that their cultural and personal beliefs discouraged them from engaging openly with the issues of death and dying in the context of children.

It seemed that nurses were aware that it should be their role to encourage patients regarding feelings or thoughts they are having about missing out on childhood, their fears, family issues, terminal illness, death or other areas of concern. Yet their cultural beliefs seemed to prevent this from occurring and instead, results in nurses preventing open communication and honesty.

*''You can sit down, and ask their fears, ambitions, and their aspirations and all things like that. So you sit down and you discuss [all of these issues] with them. Mostly, it's not for a long time (N 4)''.*

All of these elements of care resulted in nurses spending a significant amount of time with their patients. This, along with the emotional elements of care, seemed to lead nurses to provide a very personal or intimate level of care. As a result, nurses developed a relationship with their patients that transcended a typical nurse-patient relationship. Attachment to paediatric patients seems inherent in a job requiring nurses to provide holistic care to young children. Yet the maternal attachment described by these paediatric palliative care nurses seemed to go beyond that. Regardless of the gender of the nurse, nurses seem to foster a nurturance with the patient that went beyond emotional support provided by a nurse.

*''You cuddle them, you talk to them, tell them 'I love you' (N6)''.*

Nurses seemed to draw on their own personal experiences of being parents as the primary source of knowledge pertaining to their employment of a role that went beyond a standard nurse-patient relationship in the paediatric palliative care context. This is evident in their developing nurse-patient relationships that resulted in a parent-child dynamic, with nurses employing a mothering role. In this regard, nurses appeared to identify themselves more as mothers than nurses. It seemed nurses not only incorporated their own experiences of mothering as part of the care offered, but also practically took on a more mothering role than a regular nursing role. The level of intimacy, as well as the frequency of contact formed part of the incentive for nurses to assume this mothering role.

*“They don’t look at us as nurses, that’s why we don’t put on uniforms. They actually call us moms...So by the end of it we are so attached (N 1)”*.

Furthermore, since many of the patients were abandoned or orphaned, as well as plagued with social problems (e.g. in need of social grants), nurses felt it became part of their job to incorporate the mothering role into the many functions of care that they already provided.

*“We are their mothers...because their mothers are not here. We give them love, we make them happy, we say, we do everything. We take them like our own children (N 7)”*.

The institutional culture lent itself to nurses employing the mothering role. Nurses tried to make the hospice feel homely, with the staff and patients being referred to as a family.

*“We end up being a family, so they end up being our children (N 2)”*.

As has been shown, paediatric palliative care nurses occupy more a mothering role than a nursing role. This mothering role is evident in the way in which nurses viewed and approached their patients. Nurses referred often to their fantasies of seeing their patients grow up; reflecting nurses maternal desires for their patients. Nurses also incorporated the concept of love into the care that they provided.

*“Our children just need love...Because most of them...don’t have anybody to love them (N 7)”.*

Yet the unique elements of going beyond the nurse-patient relationship and the attachment that nurses formed with their patients were some of the elements that did not seem to form a sufficient part of the nursing training. Nurses thus highlighted this disjuncture between the importance placed on emotional care or involvement of paediatric palliative care nurses in practice and the minimal attention paid to this in training. Thus, there seemed to be disparity between nurses’ formal training or educational input and their job description. It seemed that as a result, nurses turned to both their nursing experience and personal experience to assist them in the emotional or psychological elements of care. In this regard, general paediatric care was mentioned as a key source that nurses made use of when working in paediatric palliative care.

*“You can never be prepared when dealing with children... It’s more experience...than reading [about it] in the book or something (N 4)”.*

*“As long as you get the paediatric experience, you are able to deal with the paediatric cases (N 6)”.*

It seemed that general paediatric care taught nurses, among other aspects, about the importance of identifying and responding to nonverbal communication regarding physical pain or needs of patients and how to create a nurse-patient relationship.

*“When you are in paediatric [care settings], you land up knowing the cries” (N 2).*

Inherent in paediatric palliative care is working with chronic illness, as well as death and dying. In the South African context, HIV/Aids is the primary terminal illness presented by paediatric palliative care patients. Participants felt that they were not influenced by the primary diagnosis of HIV/Aids.



*“Sickness is sickness. The only thing [is] you have to protect yourself. [Otherwise] they’re just the same to me (N 7)”.*

*“HIV is just like any other illness...I don’t have that stigma any more....We just treat every patient...regardless of their illness (N 4)”.*

Thus, paediatric palliative care nurses described treating all patients in the same way, with the exception of performing different medical care, such as administering antiretroviral (ARV’s) medication and using medical protection (i.e. gloves). Due to the fact that most paediatric HIV/Aids is caused by mother-to-child transmission, the nurses viewed their paediatric patients as victims.

*“With our children, there are [some] that have been abandoned by their mothers...others their parents passed away, they don’t have anybody to look after...At times I feel pity for them... Because most of them, they don’t have anybody to love them. [So] They need love from us (N 9)”.*

This seemed to further encourage nurses to employ an overprotective or mothering role.

Nurses explained team work as an essential aspect of paediatric palliative care nursing, since the range of care is vast.

*“It’s not that one person has a specific duty...[in paediatric palliative care] we work as a team...you depend on each other more than when you doing the curative part, in palliative you really really depend on each other, you cannot do it alone (N 2)”.*

Despite an interdisciplinary team set up, there seemed to be some role confusion with regard to the role of the nurse in relation to these areas and the role of the other team members.

*“Sometimes we undermine each other, you feel like you are doing more than the other person. Each and every person has got the part in that care (N 2)”.*

Furthermore, it seemed that the scope of practice of paediatric palliative care nurses was unclear. Nurses spoke about medical issues, social issues, psychological issues, administrative issues and educational issues that formed part of their job, while simultaneously being part of the doctor's, social worker's, counsellor's or psychologist's job. Thus, it seemed that nurses were unsure what elements of these areas of care fell under their scope or whether they were part of the role of other members of their team.

*“[In paediatric palliative care] It's not that one person has a specific duty (N 2)”.*

As a result, it seemed that nurses disregarded certain professional boundaries when performing some tasks that would normally be done by the social worker, doctor, and so on. Further, nurses also seemed to carry out care that went beyond any of the team members' role, such as taking the children for outings. Here, nurses were almost trying to fulfil the wishes of their patients, or were trying to provide them with opportunities that would allow patients to experience childhood. Nurses were the permanent members of hospice staff, with most of the other team members, such as social workers and doctors, either being part time workers or were part of other companies and thus only visited hospice for a certain number of hours per week. Thus, even when some areas were specific to doctors or social workers, nurses were sometimes left to substitute for other team members.

*“When they come the doctor and the social worker are not here... [So] I am the one who will advise [on whatever is needed] (N 2)”.*

Thus nurses described that paediatric palliative care nursing incorporated many different job demands. Thus it was important to understand how adequately nursing training prepares nurses for all these elements of paediatric palliative care. Training was defined in this study as education that formed part of the nursing degree, any additional training, as well as any ongoing training, in the form of workshops that took place at the various institutions. Training or education was described as a vital step in preparing nurses for paediatric palliative care.

*“[Paediatric palliative care training] has prepared me so much because I can try and handle all [paediatric palliative care] situations... you become a little bit brave after you have done [paediatric palliative care] nursing (N 3)”.*

*“[You] also need some education to add on your experience, to give you more knowledge. [Then] you can know more about how can you take care of the sick...children (N 7)”.*

Nurses also felt that paediatric palliative care training was particularly important because the paediatric palliative care was different from palliative care or other forms of nursing.

*“You can say that the nursing part of it is the same, but there is a great difference. Because now we are taking each patient to be an individual, we are treating that child as an individual; individual needs. Not as a group, clustering them together (N 1)”.*

Thus, nurses illustrated that the scope of paediatric palliative care is vast and complex. They seemed to describe many elements of the scope, though they seemed unclear about some of their roles and responsibilities. Furthermore, communication and use of their instinctual experiences of mothering seemed of vital importance to fulfilling their role that went beyond the basic nursing role.

#### 4.2 The impact of paediatric palliative care on nurses

In order to meet the comprehensive level of care required in paediatric palliative care, the nurses were required to attend to a broad range of needs for both patients and their families, despite an unclear scope of practice. Paediatric palliative care nurses also developed a deep level of care that culminated in an attachment, or unusual level of intimacy with patients. This bond, along with nurses responding to the plethora of needs of each child, often resulted in nurses experiencing their job as emotionally rewarding. Furthermore, nurses worked within the context of high workloads and a lack of crucial resources. As a result of these demands, paediatric

palliative care nursing also had a high emotional cost, namely distress, burnout or compassion fatigue. Thus nurses experienced both a positive and negative impact resulting from their work. Some of the participants in this study described paediatric palliative care nursing as fulfilling, while others experienced it as draining.

*“At the end of the day, I’m not even halfway stressful, that’s how I feel. Actually, there is no stress in it, there is fulfilment in me. I enjoy it, I really enjoy my work. It’s special looking after these children, it’s a challenge (N 1)”*.

Many of the nurses explained that the negative impact they felt primarily arose from them witnessing the suffering of their patients. Some of the nurses explained that this emotional pain stemmed from them watching their patients missing out on their childhood. Others vicariously felt the suffering of their patients.

*“At times you become so emotional; [because it is difficult] to look at a child who is suffering and not know what is happening to him or her. The child, you know, expects to be like the other children, but she’s bedridden or she can’t move. [So] you actually feel that pain in you (N 1)”*.

The emotional impact that working with chronically or terminally ill children had on nurses could be clearly identified through the variety of nurses’ grief responses upon the loss of a paediatric patient. The attachment that formed with patients resulted in this experience of grief upon the loss of a patient.

*“You actually feel the loss...inside you. When you walk inside the cubicles and say, so and so would sleep on that bed...you actually miss that space that is missing (N 2)”*.

The grieving experience of paediatric palliative care nurses often remained hidden or unexpressed. Nurses felt that they needed to appear strong for the family and for fellow

healthcare workers. They also felt that it was inappropriate for them to express their distress over the loss of a patient.

*“As a nurse, it is hurting, but because you are a nurse you are not supposed to show the others because...you have to tell the care workers to be strong (N 5)”*.

Thus nurses described themselves as needing to be strong and being strong meant not expressing emotion, or showing one’s possible distress.

*“You just need strength for that part, [because] if you’re not strong sometimes you can also break down (N 6)”*.

*“You have to be strong, for them to be strong, for them to survive (N 1)”*.

This impact also resulted from nurses feeling as though they had failed in their job of providing quality of life, and that they should have done more to help save their patients.

*“You feel that you have failed. You were supposed to do something, besides giving the treatment. There was something you were supposed to do and you didn’t do [it]-you feel guilty...You know with the next... child, when they ask for something impossible, you [would] jump (N 2)”*.

*“At times you would think that you have given your best to that child, and then you see that that child is really recovering and you go off. The next morning you come you hear that child passed away. You become so down... [You think] maybe I didn’t do my best. Maybe I should have done ABC (N 1)”*.

The impact that nurses experienced from their work was exacerbated by stressors at home or at work. Nurses explained how the workload impacted on their work. Nurses also explained that working 12 hour shifts left them more susceptible to experiencing a negative impact from their

work. Furthermore, nurses found it difficult to separate themselves from their patients, as well as from the emotions of their work.

*“It’s really draining. Because when you go home, when you’re sleeping, you still think that “Oh, I left that child, she was very, very sick. I wonder if he’s going to make it tonight”. So you don’t rest even at home. You just think about the children that you are nursing. So, even when you are home, you are not off officially (N 3)”*

Nurses explained the importance of separating work from home life, in order to maintain a sense of fulfilment from their work, as well as to prevent this negative impact from having a harmful impact on their home life.

*“When you get home... you end up being irritable. And yet, it’s not their fault that you ...had a lot of work to do, and something happened at work...You [need to] just say to yourself: Hey, let me leave anger here at work, let me just go home and forget about everything that happened at work (N 7)”*

Almost all of the nurses seemed to use their belief in G-d and prayer as a way of trying to understand and to give meaning to death. It seemed that this helped nurses to achieve a more positive impact from their work.

*“It is G-d’s will that the child passed away. And sometimes you even tell yourself that...the pain that the child had, G-d helped him by, taking the child [and stopping the pain]. Though, it’s not nice...You end up accepting that, oh, well, it’s just one of those things you can’t do anything if it’s time for her or for him to go, there’s nothing we can do (N 7)”*

*“You look at them and the number of years they’ve been sick, and when they die, you just say at least they have managed to get rest and peace, because they were in pain (N 6)”*

The institutions offered support that further helped nurses to give meaning to death through memorial rituals, such as memorial services, or remembrance gardens. These seemed to provide nurses with ritualistic closure and assisted nurses in dealing with the close bond that they had formed with their patient.

*“If the babies have died, we just prepare some butterfly cards-we write our messages [on those cards]. There’s a tree...with some colourful butterflies for all the babies who have died, you write [on the butterfly cards] and you pin it on the tree. You write down messages, whichever message you want to express, we write it there and then you stick it there. And then we also have a remembrance garden at the back for all the babies that have died, there are some stones with [their] names...You [can] just go there...just to remember so and so was here...we go there and pray (N 6)”.*

Nurses described the personal ways in which they tried to deal with the impact of nursing in the context of paediatric palliative care. Nurses seemed to employ a variety of defence mechanisms in an attempt to manage this impact. Yet some of these defence mechanisms seemed to prevent nurses from properly dealing with the impact of their work. Nurses described the difficulty of working within the context of chronically or terminally illness and death. The notion that is unfair for a child to have a serious illness left nurses feeling they had to maintain hope throughout the process of providing care. This element of hope seemed to represent an unrealistic optimism that nurses used as a way of avoiding or denying the reality of a patient’s impending death. This resulted in nurses maintaining an unrealistic hope, rather than a realistic or honest perspective of the child’s position. Nurses also tried to rationalize by trying to find logical reasons for feeling distressed over the loss of a child, such as the fact that death brought an end to their suffering, or it was their time to die.

*“You still have got that hope that things will change... Every time that you nurse them there is still that hope that maybe they will turn around (N 2)”.*

*“When you look at a child, you look at her positively, you reason this and this, maybe in a few hours this child will be much better (N 1)”.*

Some nurses employed 'death humour' to try and make the sombre subject of terminal illness and death in children feel less grave. Also, in general nurses were taught to maintain a level of detachment, so as to refrain from excessive involvement or emotional expression. However, paediatric palliative care nurses seemed to achieve a level of intimacy that prevented this type of detachment. Instead, nurses seemed to use detachment as a way of trying to disengage from their emotional responses to the loss of a child, which had resulted from the attachments that they formed with their patients (for instance).

*"It hurts quite a lot. And you know. But then you try to detach yourself. You try and say, okay these are [just] patients (N 4)".*

Sometimes, nurses displaced their anger or frustration from work onto people at home, or outside of work.

*"You know you get angry-you shout and get angry with someone. You realise when you just sit down and you look at yourself.... You come back to your senses and think to yourself no, I'm not supposed to do this. If I go to work angry, if I come home angry, it's not fair to be like that, to the kids (N 6)".*

In response to the impact of paediatric palliative care on nurses, nurses employed a variety of methods in order to cope. Most nurses seemed to have coping strategies that were personal and beneficial in the short term, such as self-care activities (example exercise, or prayer). These were employed to try relieve tension, to help distract them, or even to try to forget the stress of their work.

*"I enjoy music and then I forget everything-after the music I am just a different person, forgotten everything (N 6)".*

*"[When] I'm so stressed, just taking maybe a weekend [to go away, that is helpful for me], just to go and relax and forget about everything...Maybe just for a picnic, taking a*



*family for a picnic just to get your mind off your work, or off your stress, or anything (N 7)”.*

*“I go out with my friends for a few drinks, and movies. Go to recreational areas, to the zoo, you know to places just to relax and forget about everything and take care of me (N 4)”.*

Yet few of the nurses seemed to have a long term strategy regarding self care, such as developing a personal philosophy of care, engaging in self-reflection and self-awareness, or committing to taking care of one’s self. This seemed to be linked to a lack of emphasis on self-care or the need for self-reflection in nursing training.

Nurses also described social support as a vital way for them to deal with the impact of paediatric palliative care. Nurses stated that their families were their primary support, providing them with the opportunity to talk, being understanding, or offering opportunities to distract them.

*“When you talk about these things [with your family], they really feel it with you... [Even] if you don’t relate [exactly] what happened at your work, by being there for you...that is the supportive part of the family that you need (N 6)”*

*“You talk [to your family and friends] if you have a problem [at work] ... they’ll just say: don’t worry, cheer you up. [They help you to see that] you must go out for a party, or you talk, go to church, or go for a walk, just whatever you need to do to relieve whatever you’re feeling (N 6)”.*

Other coping strategies focused more on work-related solutions, with the most important being the development of supportive professional relationships that promoted debriefing and enhanced mutual support. The nature of this support focused on the exchange of information (informational support) and the clinical collaboration to meet patient needs. Nurses felt that their

colleagues were a large part of their support system. Nurses further described the importance of teamwork, which included providing support to each other.

*“We discuss the problems that we have had with the children, or whatever encounters we have encountered that week. We sit down, we talk, and we give each other support” (N 1).*

However it seemed that little emphasis was placed on the sharing of personal feelings and experiences (emotional support) and the reflection and attribution of meaning to one’s work experiences (meaning-making support) in these forums.

*“Only when you feel it’s needed. Because it’s very busy here you don’t even have time. We do like to see them {counsellors} maybe like weekly but it’s not possible (N 3)”.*

Yet these seemed important elements that should form part of the support offered to paediatric palliative care nurses, as nurses still experienced feelings of helplessness and despair, as well as strain and burnout.

*“Because you really got burned out here, especially when we lose a lot of...patients. Because sometimes we get attached to them, you know emotionally (N 4)”.*

Nurses thus described the immensity of and emotional investment required by the scope of paediatric palliative care left nurses feeling both emotionally rewarding and emotionally draining. As a result of this impact, nurses employed defence mechanisms, self care activities, as well as social and institutional support.

## **5: Discussion and conclusions**

Paediatric palliative care has a scope that deviates from the normal standards of general nursing, paediatric nursing, and palliative care nursing roles. Yet the scope of paediatric palliative care nursing has not been thoroughly investigated, especially in the South African context. Paediatric palliative care research is an area still in its infancy, worldwide and especially in South Africa. Furthermore in this country, there is a lack of much needed resources and basic infrastructure that would allow for a more uncomplicated execution of paediatric palliative care (Harding, Powell, Downing, Connor, Mwangi-Powell, Defilippi, Cameron, Garanganga, Kikule & Alexander, 2008). Related to this scope is the impact that this type of care has on the nurses themselves. The clinical phenomenon of burnout and compassion fatigue has been thoroughly researched in relation to health care professionals. However, few studies in general have focused on the grieving process that paediatric palliative care nurses experience, as well as other issues such as the negative effect and impact of witnessing the suffering of children that these nurses may have. These studies are of particular importance as paediatric palliation may leave nurses vulnerable to experiencing a negative impact due to an intense and intimate bond they may develop with their patients, the frequent contact they have with their patients, and their often recurrent exposure to loss of their patients. Understanding the scope and impact of paediatric palliative care in relation to the paediatric palliative care nurses could empower nurses and institutions to make use of measures that promote better nursing. This may help improve patient outcomes, as well as help nurses maintain job satisfaction while avoiding burnout or compassion fatigue.

Although the nurses in this study described the importance of individualised care, they seemed to be administering this care within two broad categories. They classified these two categories as younger and older patients. Nurses seemed to focus on whether the patient could verbally communicate or not and therefore were not necessarily considering other significant developmental issues. Literature confirms the importance of tailoring nursing care to paediatric patients' specific developmental level, using appropriate communication and interaction (WHO, 2004; Himmelstein, Hilden, Boldt & Weissman, 2004). Yet the nurses in this study did not seem to

conform to the full definition of individualized paediatric palliative care. The use of two broad categories, as opposed to considering several different developmental levels, did not seem to significantly impact on the quality of care that the nurses felt they were able to provide for their patients. Using these broad categories nevertheless allowed the nurses to consider communication development, along with growth towards independence.

Nurses described the importance of utilising, as well as demonstrated their use of both verbal and non-verbal communication with their patients. They further discussed their ability to understand the verbal and non-verbal communications of the children. The importance of non-verbal communication has been confirmed in previous studies to be a key element in developing a connection with paediatric patients. It furthermore plays a crucial role in helping nurses identify and respond to paediatric patients' physical pains and emotional needs (Zengerle-Levy, 2006). Though nurses in the current study discussed communication with regards to emotional care, they used their communication skills primarily to respond to their patients' medical and physical needs. This lack of emphasis on emotional care could be a result of nurses having a vague understanding of their ability to use their communication skills for emotional care, as well as how to carry out emotional care, though this is only one possibility. This became apparent when the nurses emphasised emotional care as an indispensable part of paediatric palliative care nursing, but did not demonstrate it as a main area of their practical nursing. Himmelstein, Hilden, Boldt and Weissman (2004) described the importance of using communication not only for medical insight, but also as a way of gaining access into the child's emotional world. Since emotional care is identified in the literature as a vital part of paediatric palliative care, it is noteworthy that nurses in the present study did not use communication skills to carry out emotional care.

Despite the nurses in the current study acknowledging the importance of supportive communication with the patients under paediatric palliative care, they did not seem to encourage open and honest communication with patients. Nurses seemed to use communication to reassure

the patients, rather than using it in order to actively interact with them. This seemed to relate to the nurses' own cultural beliefs. Their own cultural constraints in talking about death in general, as well as in particular, talking honestly about the idea or reality of dying with the children, may have prevented the nurses from communicating honestly with the children, and particularly with regard to conveying difficult information to the children (Liben, Papadatou, & Wolfe, 2008). Many of the nurses referred to their African culture as the leading cause of their difficulty in communicating openly and honestly with children. African cultures are mainly described as collectivistic, whereby "a person exists by virtue of and in service to his or her community" (Lambo, 1973, as cited in Visser, 2007, p 71). It is because of this collectivistic nature of African cultures that communication with and involvement of the patients' family in paediatric palliative care is very important and further emphasizes the need for open and honest communication. It was however also through this collectivistic culture that an overprotection of family members toward the child was evident. This hampered the ability of families and nurses to communicate in an open and honest manner with the child. These paternalistic and protective elements of the collectivist culture therefore seemed to sway nurses to create a more protective and guarded interaction with the children, rather than allowing for more open and relational interaction. Thus, nurses seemed to impress their own cultural values onto patients rather than allowing the patients' cultural perspective to dominate. Goepf, Meykler, Mooney, Lyon, Raso and Julliard (2008) emphasised the importance of open communication in facilitating useful interactions that result in patients feeling satisfied with their care and nurses feeling able to provide appropriate care to their patients. Nursing training should encourage nurses to offer patients support that is in line with the patients' cultural preferences. Given the fact that South Africa is a multicultural country, the importance of sensitivity to different cultural beliefs therefore seems especially important. Lack of understanding in this regard will have consequences in terms of the quality of care that nurses are able to provide.

Communication does not only occur between patients and nurses. Nurses also needed to respond to and allow for easy communication with each of their patient's family members. As the nurses in the current study did seem to allow for discussion of children's medical prognosis with the family members, they also seemed unsure of how to honestly engage and appropriately deal with

the family's responses to the situation. Again, this seemed to highlight the interference of the nurses' personal and cultural beliefs, where they felt the need to be protective over patients' families, offering them hope and belief in G-d, instead of offering the family members the appropriate support. This seems to further demonstrate the complications that may arise when nurses employ a mothering role when patients' families were still involved. Communication is moreover essential between staff members, in order for all members of the team to attend to all of the patients' needs accordingly (Himelstein, 2006). Yet the nurses' lack of role clarity seemed to prevent straightforward peer communication. These communication complications seemed to often result in nurses experiencing their role as stressful. Thus nurses seemed to provide comprehensive care despite lacking clarity in terms of their nursing duties. Yet the quality of care given did not seem to be as valuable as it could be, thus having potentially harmful consequences for both patients and nurses. This is because nurses seemed to cross over their professional nursing boundaries, caring for their patients' almost as pseudo-children.

The nurse-patient relationship is important in all forms of nursing. However, the paediatric palliative care nurses in this current study described a relationship with their patients as one that went beyond this basic nurse-patient relationship as they seemed to have performed more of a mothering role. This seemed somewhat expected, given the fact that they are nursing children during a vulnerable period of their lives, thus creating a parent-child dynamic in which one would expect the patient to look up to the nurse for care. Literature supports the parent-mindedness of nurses working with ill children (Zengerle-Levy, 2006). However, the nurses in the current study went beyond being parent-minded, taking on a more overprotective mothering role. Thus, nurses went beyond the expected standards and norms of paediatric palliative care nursing. This may have been because they were primarily working with children who have been orphaned or neglected. It may also have been because these children were chronically or terminally ill and thus vulnerable and in need of nurturance. This reality however seemed to further increase pressure on nurses to do absolutely everything that they felt was needed for the child. The lack of clearly defined roles and therefore responsibilities may have accounted for the nurses believing that they needed to carry out every task. These issues, along with the reality of limited healthcare resources in South Africa, further complicate the nursing job and consequently

add an even more complex dynamics to an already extensive nursing role. This pressure will almost definitely result in nurses feeling overwhelmed or distressed from their job.

Nurses did not seem to learn this mothering role from their nursing training. Rather, they learned this method of care by using their own professional experiences and more specifically their personal experiences of being parents. Literature shows that the nurturing role that paediatric nurses occupy often results from nurses being guided by their own experiences of parenting (Katzenberger & Ruesch, 2000; De Graves & Aranda, 2005). Thus, nurses seemed to intuitively fill the disparities between their training and the patients' demands by utilising their own personal resources, epitomising the fact that nurses were going beyond their professional boundaries and duties. When nurses disregard professional boundaries, they take on roles beyond their nursing function and therefore overstep their responsibility. This adds pressure to an already demanding job and thus may result in nurses feeling distressed or burned out. Research agrees with the importance of defining and maintaining professional boundaries in order to protect patients from feeling unsure about what to expect from their nurses. This will also protect nurses from overstepping their professional boundaries, which could lead to burnout (Peternelj-Taylor & Yonge, 2003).

Teamwork was also shown to be an important element of the paediatric palliative care nursing scope. Goepp, Meykler, Mooney, Lyon, Raso and Julliard (2008) confirmed teamwork as a vital aspect of the paediatric palliative care nursing scope. Furthermore Morgan (2009) illustrated the importance of team co-operation and a need to clearly define the varying team members' roles in order to help nurses cope more efficiently with their work. Despite the current study's nurses being aware of the importance of teamwork, there seemed to be a lack of team role definition. This was evident in that the nurses did not have clearly defined roles and responsibilities; there was a lack of clarity with regard to their job description; as well as unclear peer communication which seemed to have further impeded cohesive teamwork. Teamwork is an aspect of paediatric palliative care that is relied upon in order to provide an all-inclusive and comprehensive level of

care. Therefore, collaboration and clearly defined roles are of great important. Defining and clarifying each team members' role, as well as promoting collaboration, would help to achieve a better form of care, while also preventing nurses from experiencing such an intensely negative impact and such immense distress from their work. These results highlighted the need for more clearly defined job roles and responsibilities for paediatric palliative care nurses. This would assist nurses in having a clearer understanding of the elements that form the scope of paediatric palliative care nursing.

As a result of these various elements of the scope of paediatric palliative care nursing, nurses experienced both a positive and negative impact from their work. Literature has explored both the positive and negative impacts that nursing has had on nurses working with chronically or terminally ill children (Papadatou, Martinson and Chung, 2001). Though studies have shown that nurses view their role in paediatric palliative care as a deeper calling, research has primarily focused on the negative impact of nursing, with regards to nurses' experience of burnout and compassion fatigue (Papadatou, Martinson and Chung, 2001; Morgan, 2009). This seems expected, since paediatric palliative care nursing requires continuous empathy, active involvement and personal investment from the nurses, which leaves nurses vulnerable to the experience of burnout or compassion fatigue. All of the nurses cited hospice as a good institution to work for and explained that they experienced pleasure from their work despite it being demanding and challenging. However, it appeared that the nurses were not given the space in which to discuss this impact that their work had on them, with institutional support focusing mainly on assisting nurses with medical advice. This lack of focus on nurses' experiences of their work could be harmful, as nurses were not being given the opportunity to deal with the negative and positive impact that this work had on them which may be seen to be beneficial, both for their personal growth and for the quality of their work. Furthermore, it may be reasonable to assume that integrated supervision that is inclusive of emotional debriefing for the paediatric palliative care nurses would serve to model the appropriate emotional support required by their patients.



Nurses described witnessing the suffering of their patients as one of the primary causes of their experiencing a negative impact as a result of their work. Studies that confirm this have observed how painful and difficult it was for nurses to witness the suffering of their patients (Copp, 1997). Some literature focused specifically on the affliction of watching children suffer and how this may have resulted in nurses suffering serious distress (Morgan, 2009; Papadatou, 1997). In this study, witnessing suffering left nurses feeling helpless and as though they had failed in their job to provide quality of life for their patients or had failed to save the life of their patients. South African nurses contend with the additional factors of poverty and insufficient parental support, which seemed to have led nurses to feel an even deeper responsibility for the wellbeing of their patients. This seems an interesting and relevant issue, even though it does not seem to be engaged with in the literature. When working within the context of chronic or terminal illness in relation to paediatric patients, it is inevitable that nurses will be exposed to the suffering of their patients. However, it is the additional mothering role that paediatric palliative care nurses took on that may have caused the negative impact of paediatric palliative care nursing to be even more extreme, which was further complicated by poverty and insufficient parental support. As a result, it is critical that paediatric palliative care nurses' be given more clearly defined roles in the scope of their duties, as well as more specific guidelines in terms of their professional boundaries in this regard. It also seems that these nurses require more opportunities to discuss their experiences, in order to develop more understanding and skills regarding their own responses to paediatric palliative care work. It seems to yet again highlight the absence of sufficient emotional or psychological support for nurses in both training and ongoing institutional support.

Nurses also experienced a grieving process upon the loss of a patient. There have been several studies that have explored the experience of grief in health-care professionals (Feldstein & Gemma, 1995). Nurses in the current study described their grieving process as unique to paediatric palliative care. As such, the nurses seemed to feel that they had to hide their grief in order to remain useful in their protective, mothering role. Even though only a few studies have focused on grieving within the specific context of paediatric palliative care, this distinct grieving experience has been confirmed by previous research (Papadatou, 1997). Studies have explained that this hidden grief, that nurses from all areas of health-care experience, arises from their

feeling that society and institutional values discourage them from expressing and resolving their grieving responses (Rawnsley, 1990). So, not only did these nurses have insufficient outlets in which to express their grief, they furthermore felt that their expression of grief rendered them unprofessional. This left them unable to find a way to deal with their grief. Literature shows the importance of nurses working through the grieving experience, in order for it not to continuously negatively impact on the nurse, who might, as a result of such grief, experience burnout. It may further leave nurses having to suppress their emotional pain, resulting in them being reserved and closed off in their interactions with other patients (Grove, 2003).

The ways in which nurses dealt with this impact had branching implications for the individual nurse, their patients and the institution. Nurses' employed several types of defence mechanisms that prevented them from managing this impact. Some of these defence mechanisms employed seemed essential to preserving nurses' sanity in the face of poor preparation and support structures. McNeely (1996), who studied impact and coping strategies among palliative, psychiatric and general nurses, elucidated upon the variety of coping mechanisms that nurses employed as a response to experiencing a negative impact from their work. Avoidance, denial and distancing, along with distraction and activities that helped relieve tension were seen to be the most common methods of defending against this impact. This consistent and ongoing use of unhelpful defences as a result of the negative impact on the nurses due to their work, seemed to indicate nurses' increasing lack of managing the emotional aspects of their job. This downward spiral prevented nurses from remaining engaged in their work. If continued for long enough, this job dissatisfaction and emotional exhaustion would not only leave nurses demotivated to provide the best care, but may even have implications for staff turnover and institutional efficiency.

Nurses attempted to cope with this impact through the use of self-care, and alternative social support and institutional support. Literature has emphasised the importance of each of these elements as vital for nurses to avoid job dissatisfaction, burnout or compassion fatigue. Cohen, Contro, Larson, Scofield and Sourkes (2004) discovered the importance of both social and institutional support. Studies have further shown the detrimental effect that lack of support can have on nurses' ability to avoid burnout and work dissatisfaction (Abendroth & Flannery, 2006).

However, the nurses in the current study did not seem to be aware of the consistent need to employ these methods in order to be effective in managing the impact their nursing role had on them. This seemed to additionally reflect the lack of preparing and educating nurses prior to working in paediatric palliative care, especially with regard to the significance of their personal care.

The nurses in the current study seemed to show that their experience of paediatric palliative care nursing was similar to other paediatric palliative care nurses in other geographical areas of the world. Besides the generalised nursing responsibilities that all nurses have, paediatric palliative care nurses have additional demands. However it seemed apparent that specific South African issues, such as cultural beliefs with regard to communication and poverty and the prevalence of HIV/Aids, resulted in these nurses' experiences to be somewhat unique. The intensity of the nurses' maternal attachment to their patients was an interesting and distinguishing finding, given the paucity of literature in this area. This study revealed the lack of clarity for nurses of their nursing roles and responsibilities and the fact that this lack of clarity created a situation where paediatric palliative care nurses took on more than their paediatric palliative care-nursing role demanded. Despite finding their job to be rewarding and fulfilling, nurses that took on too many functions without clearly defined roles or sufficient support and resources experienced a severe personal negative impact, namely distress, burnout or compassion fatigue. The imprecise nature of their jobs seemed to result in nurses being insufficiently equipped with the knowledge and skills to suitably deal with the realities and inevitabilities of their jobs. Nurses were also not properly cared for in terms of their own emotional responses to their work.

Nurses further seemed to experience a disjuncture between the training and the delivery of care, which may spill over into the organisational sector (Morgan, 2009). These results thus indicated the need for nurses to be provided with more precise guidelines, both in their initial training and through ongoing input, in terms of the scope and professional functions that they are required to perform. Also, nurses illustrated their need to be better equipped with regards to communication

skills and understanding developmentally appropriate care. These issues could be addressed through continuing and regular education aimed to advance nurses' knowledge and skills with regards to paediatric palliative care. Should palliative care become more formalised and address quality assurance issues, then nurses may experience greater clarity in terms of how education and training, service delivery, continuing education and organisational structures can be aligned (Papadatou, 1997; Mallory, 2003; Morgan, 2009). Furthermore, nurses need to be offered ongoing emotional or psychological support in order to acknowledge, understand and engage with their own responses to the impact of their work. In addition paediatric palliative care nurses need to have access to the skills of stress management as another way of preventing burnout. Perhaps it is relevant to consider training groups that allow for self-awareness and personal growth. This would facilitate an understanding by the nurses of how their cultural paradigms and belief systems impact on their ability to perform their job effectively. This will provide them with better skills, which in turn will lead them to provide a better quality of care to their patients. This will have the result of nurses having the ability to better manage the stress of their work, thereby allowing them to experience more job satisfaction.

### 5.1 Limitations of the Study

This study used a small sample, which is expected when conducting a qualitative research study. Both hospices had a limited number of paediatric palliative care nurses, thus preventing the possibility of a larger sample. Moreover, the limited number of nurses specialising in paediatric palliative care in Gauteng further prevented a larger sample. This also resulted in using nurses from only two institutions. This, along with the lack of standardised paediatric palliative care nursing training in South Africa, may have influenced the results of this study and may thus also have implications for the replication of these results in future research. Furthermore, all of the nurses in this study were of an African culture. This may have restricted the cultural aspects of this study. As a result, the generalisability of this study may be limited.

## 5.2 Recommendations

The current study identified gaps in current research and thus helped provide a guide regarding directions for future studies. Firstly, nurses in this study highlighted the lack of clarity with regard to their scope. Furthermore, nurses emphasized the importance of teamwork, while illustrating the current lack of team collaboration. Thus, future research needs to further investigate what is needed in order to develop guidelines that clearly define and outline paediatric palliative care nursing role, as well as to delineate each team member's function. It is hoped that this clarity will result in higher job satisfaction, while also creating more team cohesion. This will also assist in nurses not overstepping their professional boundaries. The success of these changes should be assessed in future research. Secondly, nurses described the need to provide individualized care regarding medical, physical and emotional elements of care. However, nurses did not seem to have a comprehensive understanding of what this entailed. Thus, training should also include teaching nurses all of the elements involved in each aspect of paediatric palliative care, especially emotional care. Future research needs to investigate the role of such training and how this will assist nurses, as well as to further elaborate on how the lack of preparation in this regard might impact on both the nurse and the patient. Thirdly, nurses' cultural preferences were found to interfere with the type of care that nurses were able to provide. Thus, research should be done regarding culture in South Africa and whether this has a large influence on nurses' ability to provide individualized care. This too will have consequences for nursing training, as nurses may need to be educated in terms of how to let the patient's cultural values guide the type of care provided.

Fourth, nurses in this study did not express and explore their own responses to the impact of their work, which seemed to often result in distress, burnout or compassion fatigue. Nurses also described their experiences of the positive impact of their work. Yet they did not seem to have the space in which to express this. Thus, nurses need to be given a space that allows for legitimate room for expression and understanding of these experiences. Furthermore, more research needs to be done focusing on the positive impact that paediatric palliative nurses experience as a result of their work. Thus, it seems imperative for research to further explore, in

depth, the intricacies of the specific impact that paediatric palliative care has on nurses, as well as the ways in which they cope. This gap again highlighted the need for training to include psychological support for nurses, in order for them to learn self awareness and self understanding with regard to their responses to their work. It would be valuable for future research to explore the impact of the suggested changes with regard to training, by conducting a pretest-posttest study. Fifth, the nurses in this research had all been in paediatric palliative care for less than 10 years. Since the impact of the work can lead to burnout, it seems important to explore the staff turnover, as well as the long term effects of this negative impact on nurses. Sixth, the mothering role that the nurses in this study employed needs to be further researched, with regard to the South African contextual elements, such as the impact of African culture. These are just some of the needs in paediatric palliative care nursing and research.

### 5.3 Conclusion

This study focused on an exploration of the gaps in literature and research with respect to the scope and the impact of paediatric palliative care on paediatric palliative care nurses. There was little research that related specifically to the distinct nature of paediatric palliative care and how this impacts on nursing staff. Nevertheless, the research that existed was helpful in identifying the key elements of the paediatric palliative care nursing scope. This study found the importance of individualized care, applying this with respect to a comprehensive level of care. Nurses also described that despite paediatric palliative care being mainly about medical and physical care, emotional care was equally as important. Additionally, it was found that culture plays an important role with regard to communication. This study further found that the intensity of the attachment nurses develop with their patients is strong.

This research also helped to ascertain the primary elements of paediatric palliative care nursing that positively or negatively impact on nurses. Nurses described the positive impact of their job, which left them feeling emotionally fulfilled. The nurses also experienced emotional pain from witnessing their patients suffering. They also struggled to come to terms with their experiences

of grief upon the loss of a patient. In response to this impact, nurses sometimes employed defence mechanisms in an absolute and unhealthy manner, illustrating their inability to manage this impact. Helpful coping strategies included self-care, social support and psychological support, all of which were highlighted by the literature to be crucial in preventing job dissatisfaction, burnout or compassion fatigue and to maintain the positive effects of their job.

The findings of this research indicated the need for training to include more clearly defined nursing roles. It also showed the importance of guiding nurses in how to provide comprehensive emotional care. Other areas where training was required included explaining to nurses what constitutes individualized care, as well as how to employ communication skills in a way that would be most beneficial for the patient and their family, the nurse and all members of the team. This could assist nurses in providing a high quality of care, while still maintaining their professional boundaries. Nurses also seemed to require psychological debriefing or ongoing training with a focus on their own self-insight.

Care provided by paediatric palliative care nurses is complex and vast. Thus, nurses need to be offered continuous support and education to help them learn how to habitually care for themselves. This will allow for nurses to provide more valuable care, as well as for nurses to experience more fulfilment with less distress, burnout, or compassion fatigue.

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