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# Nurses' Experiences of Paediatric Palliative Care

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## **Nurses' Experiences of Paediatric Palliative Care**

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Pediatric palliative care is an emerging specialty in the field of nursing which involves elevating the social, psychological and physical well-being of the patient. Conditions requiring palliative care are mostly life-limiting or life-threatening. Caring for these patients can be very demanding and emotionally draining for the nurses who work closely with these children and their families.

The purpose of this thesis was to describe nurses' experiences of pediatric palliative care. The research question was: What are nurses' experiences of pediatric palliative care. To achieve this, a literature review was conducted. In order to retrieve recent materials, two complimentary online academic databases (LaureaFINNA and EBSCOhost) were searched using search words associated with the purpose and the research question. The articles were then subjected to two stages of pre-determined inclusion and exclusion criteria followed by data appraisal using John Hopkins research evidence appraisal tool. 12 articles were found suitable and relevant. Inductive content analysis was used for data analysis.

From the findings, five major themes emerged: emotional burden, coping with own emotions, a sense of meaning and purpose for work, learning at work and lastly, challenges in provision of care. Nurses' encounter in provision of pediatric palliative care was filled with a lot of emotional suffering resulting from varying circumstances and difficulties emerging from working with limited resources and insufficient knowledge. Despite the challenges nurses found it rewarding working in pediatric palliative care. For future studies, it was recommended that further research should be carried out to determine how paediatric palliative care training and education for nurses can be improved.

Keywords: registered nurse, paediatric, palliative care

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## 1 Introduction

Technological advancements in the healthcare field have significantly minimised the number of children dying annually, as a result, there are a lot of children living longer with life-limiting and life-threatening conditions. This situation has resulted in a widespread inception of paediatric palliative care services which are provided in the hospitals, hospices or at home. Paediatric palliative care extends beyond enhancing the quality of life for patients into also caring for the wellbeing of the patients' family, thus making its provision tasking and challenging for nurses who are in frequent and constant contact with the patients. (Crozier & Hancock 2012; Christian 2013.)

Due to the complexity in nature of life-limiting conditions, children living with them are in intense threat of death. This can be emotionally overwhelming for the family and the nurses. Due to close bonds formed between nurses and patients, nurses caring for a dying child have a difficult time watching them and their families in distress. More often than not, grieving and attachments pose ethical dilemmas for the nurses. (Charlotte, Norberg, Strandberg & Dahlqvist 2014.)

Pearson (2010a) acknowledges that a lot of research has been done on palliative care and affirms that however, little attention has been given to the effect a child's death has on a nurse. Administering palliative care to children can be rewarding and challenging to a nurse (Pearson 2010a).

Having experienced the provision of adult palliative care, the writer was interested in finding out the experiences of nurses providing paediatric palliative care. This would shade some light on the needs of nurses who are involved in the provision of paediatric palliative care. The information obtained would be beneficial to nursing students, nurses, other healthcare workers, patients, families and even law makers. The purpose of this thesis is to describe nurses' experiences of paediatric palliative care using previously documented research.

## 2 Paediatric patients living with life-limiting and life-threatening conditions

English Oxford living dictionary (2018) defines a child as, "a young human being living below the age of puberty or below the legal age of majority". For the purpose of this study, the definition of a child will be limited to persons between ages 0-19 (Upper limit being 19 because most of the articles used for this thesis have applied the same limit) and the word child will be used interchangeably with young person, dying child, baby and patient to refer to paediatric patient.

In a traditional setting children do not live alone, they are brought up and cared for in a family context, which varies in structural composition for example, single parent family, adoptive

family, grandparent-led family and so on. Every child is raised and has their needs provided for differently depending on the family's culture, religion, race, and ethnicity. These are important elements that a care provider has to relate to and consider when caring for a child in order to provide the best possible care that identifies and responds to the needs of an individual and the family. (De Sevo 2015, 1-2.)

The number of children living with life-limiting and life-threatening conditions is on the rise, for these children it means that their condition is incurable or at a risk of remission and therefore, they are likely to die before adulthood or they have a narrow possibility of living into adulthood (Fraser, Lidstone, Miller, Aldridge, Norman, Mckinney and Parslow 2014). Noticeably, most of these conditions are rare and the symptoms are greatly individual thus creating a huge challenge for the healthcare professionals (Cari, Liz, Gillian, Faith & Richard 2011). The medical care for these children considerably includes life-prolonging therapies and comfort or therapies geared towards enhancing the quality of life. Some of these therapies often result in emotional and physical pain. It is therefore important that the needs of these children are not overlooked or underestimated. (Rome Luminais Bourgeois & Blais 2011.)

Children with life-limiting conditions and complex chronic functions need a lot of support from their families and caregivers due to their complex physical and psychological needs. Understanding the needs of these children and their interpretation of death from the healthcare perspective can help healthcare providers deliver better care by being able to effectively plan and evaluate children's needs. (Donnelly, Huff, Lindsey, McMahon & Schumacher 2005.)

Death is understood differently all over the world. While some people deem it important to keep death-related facts from children, others find it useful when children are knowledgeable about it. This results in a huge variation of understanding of death amongst children. The differences are influenced by aspects such as age, culture, religion, emotions, experiences and many other factors. For children with life-limiting/life-threatening conditions, their understanding of death is influenced by their response to illness, families' values and their needs. Children's emotional and intellectual comprehension of death expands as they grow in age. (Field and Behrman 2003.)

The conditions resulting to the need for palliative care in children are different and much rare in comparison to those of adults and they are mostly genetic. The childhood conditions have been categorised into four categories (Table 1). Conditions in category 1 are likely treatable but curative treatment may be practical but the success is not totally guaranteed for example cancer and irreversible organ failures. Category 2 represents conditions whereby untimely death is probable, characterised by lengthy periods of intensive treatment focused at extending life (for example cystic fibrosis HIV/AIDS). Category 3 displays progressive, in-

curable conditions which require exclusive palliative care from the time of diagnosis (for example batten disease). Lastly, category 4 represents irremediable, non-intensifying conditions that cause severe disability resulting in increased vulnerability to health complications and a great risk of early death. (Development of health and children (Ireland) 2009.)

CATEGORY 1	<p><b>Life-threatening conditions for which curative treatment may be feasible but can fail.</b></p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
CATEGORY 2	<p><b>Conditions where premature death is inevitable.</b></p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Example: cystic fibrosis</i></p>
CATEGORY 3	<p><b>Progressive conditions without curative treatment options.</b></p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses, Duchenne muscular dystrophy.</i></p>
CATEGORY 4	<p><b>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</b></p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

Table 1: Categories outlining the four types of illness trajectory which will require paediatric children's palliative care provision (Development of health and children (Ireland) 2009)

### 3 Registered nurse in paediatric palliative care

Paediatric nursing is a specialized branch of nursing that involves caring for neonates, children, youth and their families across the healthcare chain (Barnsteiner et al 2002). A key factor to paediatric nursing is teaching and educating families about health matters, illness and also child growth and developmental needs (Christian 2013).

Nurses in Finland are trained at universities of applied sciences for about 3.5 to 4.5 years with 210-270 ECTS. Registered nurses are required to achieve 210 ECTS, public health nurses and paramedics require 240 ECTS and midwives require a little more at least 270 ECTS for successful completion of their degree (Finnish Nurses association 2018). Nursing training in Finland is characterised by a lot of clinical placements which involve different nursing environments, amongst them is nursing involving neonates and children. This enables nursing students to train or work in any paediatric environment of their choice. After graduation, one can apply for a license from Valvira (The national supervisory authority for welfare and health in Finland) in order to work as a nurse. Unlike in countries like UK and USA, in Finland one does not require a 4 year nursing degree program geared specifically towards neonates and children in order to qualify as a paediatric nurse (No specialization), the minimal requirement is for one to be simply a registered nurse.

It could be said that nurses are part of the multidisciplinary team that provides paediatric palliative care in which they play a crucial role. They promote togetherness and organize the efforts of the multidisciplinary team. As stated earlier, nurses are the ones in most close con-



tact with the patients compared to other healthcare professionals and they are often present at the patient's bedside, making nurses strategically placed to recognise the needs of the patients and hence making it possible for them to alleviate suffering and effectively provide palliative care. However, research shows that nurses have insufficient knowledge and skills required for the provision of quality paediatric palliative care and very few of them have been trained to provide palliative care. Commonly used textbooks for paediatric nursing curriculum have insufficient information to assist paediatric nurses efficiently care for a dying child and the family. As a result, a majority of the nurses develop and advance their palliative care skills through working life experience and personal development. (Dochert et al 2012; Malloy, Ferrell, Virani, Wilson & Uman 2006; Forster and Hafiz 2015. )

Nurses working in paediatric palliative care settings require qualities and skills such as compassion, professionalism, confidence, coping skills and good communication skills, this is so due to the nature of their work (Barnard, Hollingum, and Hartfiel 2006, cited in Darla 2009).

Being witnesses to the pain and suffering encountered by paediatric patients and their families makes nurses be susceptible to the same feelings of pain and suffering and go through emotions such as vexation, helplessness, sorrow and uneasiness (Darla 2009). The death of a child can be emotionally draining for nurses due to the vast amount of effort put in by nurses to save and prolong the life of a child. They may feel like they failed in their role as nurses and as adults to protect the child from harm and also that they let down the families because they (families) put their trust in them (nurses & other healthcare professionals). The feeling of failure results in nurses having a burden of guilt and they end up stressed out. These experiences may result in burnout and nurses quitting their jobs from the healthcare setting. (Weigel, Parker, Fanning, Reyna & Gasberra 2007, cited in Darla 2009; Darla 2009.)

The immensity of the emotional impact experienced by the nurses providing palliative care demands for some form of support for the nurses to deal with their personal pain, thus ensuring continued provision of standard care and in turn lessening turnover. Colleagues are an important support network as they have experienced the same situation. Healthcare professionals acknowledged the importance of discussing death experiences amongst each other. For some people discussing their feelings is beneficial while for others it may worsen the shock and anguish that they are experiencing. Some caring environments provide pastors and other organisations to provide counselling. Despite the much needed support, there are instances when nurses felt unsupported by their colleagues, administration and other healthcare professionals. Lack of support was a stressor for the nurses. (Pearson 2010a; Forster and Hafiz 2015; Darla 2009.)

It could be argued that nurses play a key role in educating and supporting the parents of their patients when it comes to withdrawing or withholding treatment and enhancing informed

decision by parents. However, nurses are required to be advocates for their patients when they realise that there is no longer any need for aggressive treatment which only causes more suffering to the patient. By playing the advocate role, nurses often harmonize palliative care services. More often than not, discussions between nurses-family and nurses-multi professional team on matters concerning discontinuity of care bring about tension and frustration whenever there was a difference of views. (Beckstrand et al 2009, Darla 2009.)

#### 4 Paediatric palliative care

Palliative care emerged from the field of oncology and was first presented in 1959 by Cicely Saunders a researcher at St. Josephs Hospice in London, UK (Clark, 2007). According to Morgan (2009), the history of palliative care dates back to the 14th century and the first paediatric palliative care unit was set up in 1982 in England. For a long time palliative care was geared towards hospices caring for adults dying from cancer. Over the years its role has transformed into caring for people of different age groups with life-limiting and life threatening illness. (Tornquist, Anderson & Edberg 2012.) However, paediatric palliative care is rare compared to adult palliative care maybe as a result of more adults dying than children or that, the reluctance in adaptation of paediatric palliative care could be because the society has more difficulty accepting the death of a child as opposed to that of adults (Darla, 2009).

WHO 2014 describes palliative care as specialized multidisciplinary approach of care whose main focus is to minimise pain, relieve suffering and regulate symptoms for patients facing serious life-threatening illnesses. This type of care maximises on family-centred care. The intention is to make the patient and his/her family understand that death is a normal process and to encourage them to make the most of the time that they still have together. (WHO 2014).

WHO further defines palliative care in relation to children as care that is provided by a multidisciplinary team which seeks to promote the child's physical, social and psychological well-being. This care also incorporates the patient's family. The delivery of this care does not have to be very sophisticated and it can make use of the available resources. Moreover, the care can be dispensed in any healthcare setting and even in the child's home from the time the illness is discovered. (WHO 2010.)

From the definitions above, it is important to note that palliative care is not a replacement for curative treatment, both can be given simultaneously for the best possible outcome. Currently, the most developed countries have laws protecting integrated palliative care approach as recommended by American Academy of Paediatrics (Huang et al 2010). After the diagnosis of life-limiting or life-threatening condition or enervating injury or disease, cure-oriented

options are started at the same time as palliative care. The role of palliative care intensifies when the options for disease-modifying treatment shrink. Figure 1 summarises the provision of palliative care and its consolidation with curative treatment. (Docherty, Thaxton, Courtney, Barfield, Tamburro, 2012)

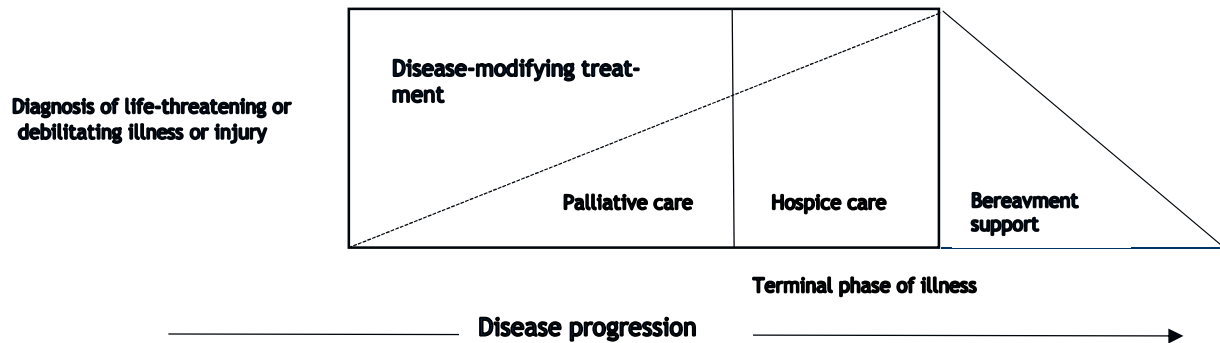


Figure 1 : Disease progression for life-limiting diseases  
(Docherty et al 2012)

Life-limiting and life-threatening conditions are very intricate and unpredictable, therefore challenging to predict the time a child has to live, in turn, making it difficult to determine when efforts to save a child are only prolonging the child's suffering and death (Field & Behrman 2003). According to Bergstraesser (2012), palliative care could last for only a few hours or even up to many years depending on the severity of the condition at hand. Based on issues such as regulations, staffing and funding, the services provided by various palliative care team vary from each other (Crozier & Hancock 2012).

It could be said that most families are actively involved in the palliative care of their children from the point of diagnosis to the end of life and for them, it is a journey accompanied with a lot of emotions such as loneliness, hopelessness, and grief. One cannot fully comprehend the loss of a child unless they experience it first-hand (Stephens 2015). One of the major goals of paediatric palliative care is to enable children with life-limiting medical conditions together with their families to lead a normal life as much as possible by creating a possibility for the children to participate in similar activities as their age mates, for example, playing, visiting friends and going to school (O'Quinn and Giambra, 2014).

O'Quinn and Giambra (2014) report on studies showing improved quality of life for paediatric patients and their families as a result of palliative care, the children reported less pain while the family members reported less suffering and less grief in dealing with the end of life care. Despite the positive outcome and the exemplary palliative care services provided, paediatric

palliative care provision is still faced with challenges such as, difficulty identifying who or when a child will need palliative care, incorporating culture and spirituality, insufficient research for guidance, communication difficulties, transitioning from paediatric palliative care to adult palliative care, health professionals' personal discomfort and scanty knowledge (Price, Jordan & Prior 2013).

5 Purpose of the study and research question

The purpose of this study is to describe nurses' experiences of paediatric palliative care.

The study question is:

-What are nurses' experiences of paediatric palliative care?

## 6 Methodology

Arguably the amount of information that can be accessed by healthcare professionals is vast and constantly increasing, this can be attributed to the increasing emphasis on evidence-based practise in the healthcare field and technological advancements. To scrupulously answer the research question, “What are nurses’ experiences of paediatric palliative care?” literature review methodology was preferred. A literature review had an upper hand in comparison to other methods in the sense that it allows a researcher to identify what has been researched already and what has not. Additionally, a researcher could develop new ideas from what already exists. (Aveyerd 2010, 1.)

Literature review is a research approach that includes searching and evaluating already existing literature related to a chosen subject (Aveyerd 2010, 1). The literature to be used could be in any form such as, books, scholarly articles, dissertations, conference proceedings or any other sources (Khan, Kunz, Kleinen & Antes 2003). The review was carried out in a rigorous manner comprising of several research stages. Sue and Comerasamy (2013, 48) summarised the stages of literature review into the following: identifying a research question, conducting a literature search and ascertaining the inclusion and exclusion criteria, gauging the completeness and genuineness of the obtained literature by conducting a critical appraisal and thereafter a risk assessment, data extraction and synthesis of the extracted data, and finally presenting the findings

### 6.1 Literature search and inclusion criteria

After identifying a research question, the next important part of this thesis was conducting a thorough systematic literature search. For a successful literature search, it was important to develop a strategy that will enable the writer to come up with the widest range of published materials (Aveyard 2010, 68). The literature review conducted was guided by Aveyard (2010). It is important to note that this thesis was not conducted with strict adherence to Cochrane-style systematic review which is the recommended protocol for nursing, however, it was conducted systematically as opposed to narratively. This was due to limited time and resources and the level of research which, in this case, is undergraduate.

The literature used for this thesis was obtained from two databases Laurea FINNA and EBSCOHost. Laurea Finna was preferred because it contained a collection of articles from most of the other databases which Laurea has access to (for example ProQuest, Ovid, SAGE etc., because it uses Primo Central Index) except, EBSCOHost. Laurea Finna provided an option for basic or advanced search. Advanced search was used for this study in order to cover a wider range of databases. Printed books, journals, e-books, Laurea theses, and library licensed databases could all be found on Laurea Finna. On the other hand, EBSCOHost was recommended on Laurea Finna for a more extensive search, it provided digital archives, databases, eBooks,

and online journals. The choice of only the two, therefore, helped to avoid repetition and it also simplified the data search without necessarily leaving out important articles. Laurea's electronic library was the most viable for this thesis due to ease of access, affordability, and credibility. Only online sources were pursued for this literature search due to practicality.

The keywords identified from the research question to be used for the literature search were nurses' experiences, pediatric (using paediatric yielded only one result hence pediatric was preferred), palliative care, oncology (search term used as it is mainly associated with cancer), caring and dying child. The synonyms used were, child and adolescent for pediatric, terminal care and hospice for palliative care, and life-limited child for dying child. The article search from the selected databases was executed using three combinations of the search terms. The Boolean operator "AND" was used in combining the terms. The search was then repeated by alternating the keywords with the synonyms for a more comprehensive and extensive search.

Having identified suitable databases and keywords for the literature search, a preliminary search was conducted. The minimum eligibility for the preliminary search (first screening) was set to be peer reviewed articles in order to have access to credible and high-quality data. The search was further limited to articles published between 2007-2017 to ensure that most recent and applicable data was obtained. Additionally, in order to get comprehensible, fully accessible and relevant data, only articles written in English and available in full text were considered. Search results with data meeting the minimum eligibility criteria resulted in N=710 hits for all databases and all the search term combinations. To further narrow down the results in order to get more relevant articles, the titles and abstracts of the articles were carefully read, and using the first inclusion and exclusion criteria as in figure 1, N=78 articles resulted. These articles were passed on to the second screening, where they were further reviewed using the second inclusion and exclusion criteria. N=12 articles were found suitable for answering the research question for this thesis. Table 2 shows search terms and database search results while figure 2 exhibits the step by step data extraction process.

Database Keywords	EBSCO-Host	Laurea Finna	Total number of articles	Discarded articles	Articles for further review
Nurses' experience AND Pediatric AND Palliative care	59	206	265	234	31
Nurses' experience AND Caring AND Dying child	19	181	200	178	22
Nurses' experience AND Pediatric oncology	16	229	245	220	25
<b>TOTAL</b>	<b>N=94</b>	<b>N=616</b>	<b>N=710</b>	<b>N=632</b>	<b>N=78</b>

Table 2: Search terms and database search results



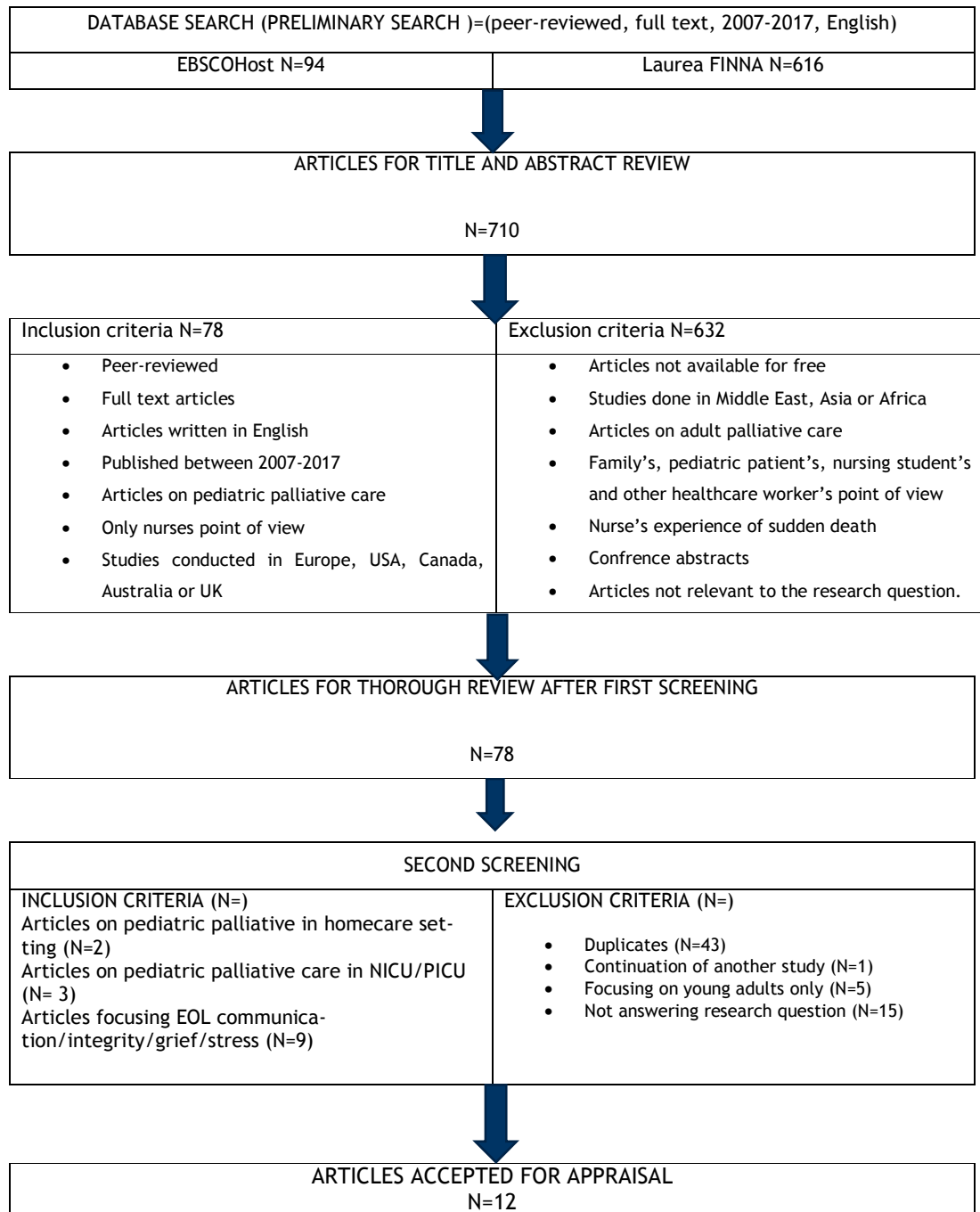


Figure 2: Data extraction process

## 6.2 Data appraisal

With the required literature obtained, it was important to determine the quality, that is the strength and weaknesses of the articles to be used together with their relevance in answering the research question, this process is referred to as data appraisal or critical appraisal (Aveyard 2010, 90). It could be said that papers published in reputable journals are not necessarily of great quality, hence the importance of critically scrutinizing every paper before deciding to use it. For an effective critical appraisal, the use of a critical appraisal tool is encouraged (Aveyard 2010, 90).

There is a vast number of research studies, each varying on the level, strength and quality of evidence (Dang & Dearholt 2017, 97). To determine the trustworthiness, quality and relevance of the 12 studies selected, John Hopkins Research Evidence Appraisal Tool was utilised for this thesis. This critical appraisal tool was the most preferred because it was specifically created for research in the healthcare field, it is highly reputable and at the same time simple to use and lastly it can be used to evaluate different types of research methodologies.

The John Hopkins Research Evidence Appraisal Tool contains two parts; the first part is for assessing the level of evidence of the study as shown in table 3 and the second part is for appraising the quality of the research. The evidence level is classified from Level I-III for the first part then Level IV & V for the second part. With level I representing strong evidence through to level III illustrating the weakest evidence. The type of evidence included in level IV and V could be obtained from respected authorities, experiential and non-research evidence, hence are considered weak. Table 3 shows the levels of evidence I-V.

Level 1	It includes experimental study, randomized controlled trials (RCT), systematic review of RCTs, with or without meta-analysis
Level 2	It is comprised of quasi-experimental study, systematic review of a combination of RCTs and quasi-experimental studies only, with or without meta-analysis
Level 3	Non-experimental study, systematic review of a combination of RCTs, quasi-experimental and non-experimental, or non-experimental studies only, with or without meta-analysis and qualitative study or systematic review, with or without meta-analysis
Level 4	Inclusive of opinion of respected, authorities and/or nationally recognized expert committees/consensus panels based on scientific evidence. Such as clinical practice guidelines and consensus panels
Level 5	Based on experiential and non-research evidence such as literature reviews, quality improvement, program or financial evaluation, case reports, or opinion of nationally recognized expert(s) based on experiential evidence

Table 3: John Hopkins Nursing EBP levels of evidence (Dearholt & Dang 2012)

The second part of the John Hopkins Research Evidence Appraisal Tool is graded from A through to C. Grade A indicating “high quality”, B indicating “good quality” and lastly grade C indicating “low quality or major flaws” as displayed in table 4 which shows the quality guide for evidence levels I to III. The quality guide for level IV and V will not be shown because it is not applicable to this thesis.

A High quality	Consistent generalizable results, sufficient sample size for the study design, adequate control, definitive conclusions, consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence
B Good quality	Reasonably consistent results, sufficient sample size for the study design, some control, fairly definitive conclusions, reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence
C Low quality or major flaws	Little evidence with inconsistent results, insufficient sample size for the study design, conclusions cannot be drawn

Table 4: Quality guide for level I-III evidence levels (Dearholt & Dang 2012)

From the results of the appraisal, the level of evidence for the data used in this thesis is weak but its quality is high. As shown in table 5, all the 12 articles were of level III evidence, 10 of them were of high quality (A) and 2 were of good quality (B). The research question of this thesis is, “What are nurses’ experiences of paediatric palliative care?” Due to the nature of this study question, all the 12 articles that were appraised were all qualitative studies. In the John Hopkins appraisal tool, randomised trials, experimental and quasi-experimental designs are more superior to qualitative studies, hence the low level of evidence for all the articles. Appraisals for each individual article are found in appendix 1.

Level of evidence	Number of Articles	Quality A (high quality)	Quality B (good quality)	Quality C (low quality)
Level I	0	0	0	0
Level II	0	0	0	0
Level III	12	10	2	0
Total	12	10	2	0

Table 5: Results from data appraisal

### 6.3 Data analysis

There are many approaches for analysing literature review in nursing, common ones being: meta-analysis, meta-ethnography, meta-study and content analysis. The method of analysis depends on the type of data whether qualitative or quantitative. Analysis of qualitative research needs a lot of detailed critique and rigor. (Aveyard 2010.)

With an aim of providing new insight and representation of facts, content analysis was deemed suitable for this study. It can be argued that it is a very flexible and content-sensitive research. Downe-Wambolt (1992), defines content analysis as “a research method that provides a systematic and objective means to make valid inferences from verbal, visual or written data in order to describe and quantify specific phenomena.” Inductive content analysis was the most preferred for this thesis.

Bengtsson (2016) divides the content analysis process into four distinct phases namely, the decontextualisation, the recontextualisation, the categorization, and the compilation. In decontextualisation, the 12 articles selected for this thesis were meticulously and repeatedly read to allow a better understanding of the article contents whilst at the same time highlighting relevant phrases and sentences and also making as many notes and headings on margins. The notes and headings illustrated all the possible aspects of the contents. The notes and headings emerging from each article were then transferred onto a different paper (code sheet) to form meaning units. The meaning units were then compared to the original content of the articles they were derived from, this ensured that everything answering the research question was incorporated (recontextualisation). (Bengtsson 2016; Elo & Kynga 2008.)

Following recontextualisation was categorization. To increase knowledge and understanding, the codes that were similar to each other in their context and content were grouped together to form sub-categories keeping in mind that, “codes are organized into a category when they are describing different aspects, similarities or differences, of the text’s content that belongs together” (Erlingsson & Brysiewicz 2017). The sub-categories were then organized into higher and broader categories to form themes/main categories (Bengtsson, 2016). The first findings did not seem to answer the research question due to wrongly labelled sub-categories. The analysis was then repeated again. Figure 2 reflects how the first theme which is emotional burden was arrived at from raw data and sub-categories, the other themes are displayed on appendix 2.



Figure 3: Data analysis for emotional burden

## 7 Findings

The purpose of this thesis is to describe nurses' experiences of paediatric palliative care. The research question being: What are the nurses' experiences of paediatric palliative care? To achieve this objective, 12 articles were carefully and thoroughly analysed through inductive content analysis. Five major themes emerged, emotional burden, coping with own emotions, a sense of meaning and purpose for work, learning at work and challenges in the provision of care. Figure 3 displays the relationship between the sub categories and the main categories.

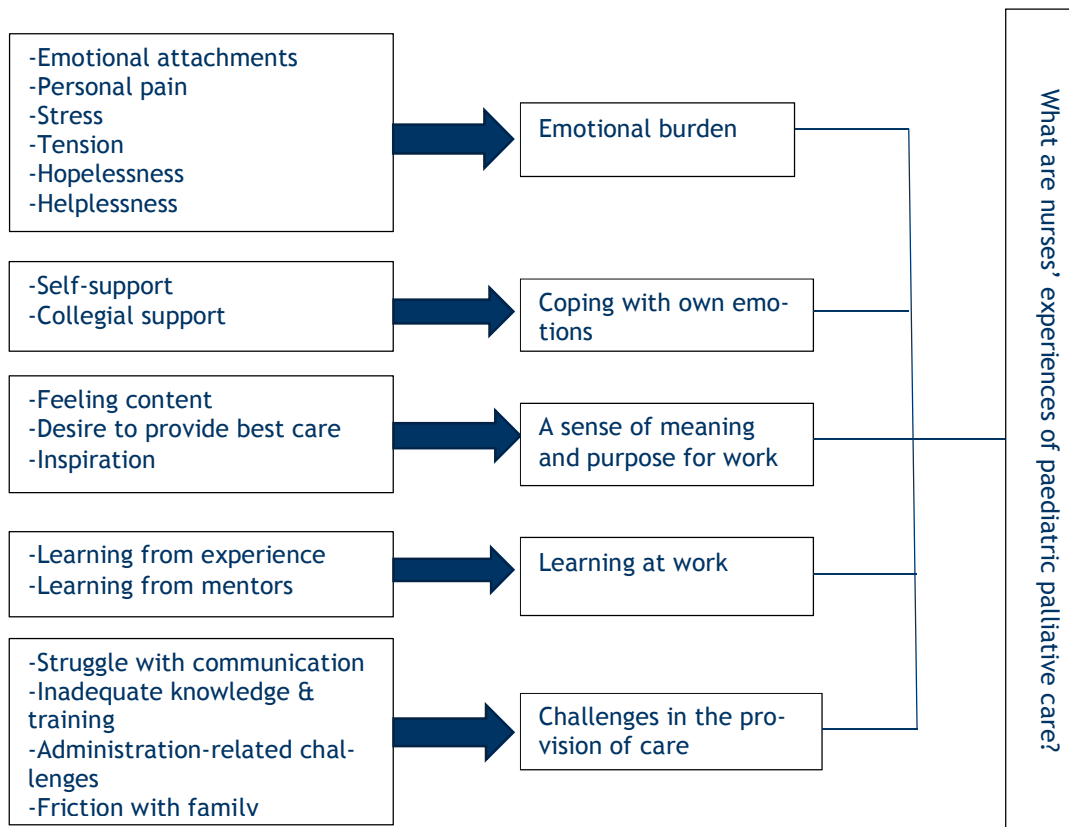


Figure 4: Summary of literature review findings

## 7.1 Emotional burden

It can be argued that any situation that involves loss of life is always accompanied by a lot of emotions, being humans, nurses are not immune to these feelings. Under this theme are emotional attachment, personal pain, stress, tension, hopelessness, and helplessness.

Frequent hospitalization and long stays in the hospitals or hospices facilitated bond formation between nurses and the patients together with their families. Nurses faced hardships because of the ease with which they loved their patients and felt attached to them. It was difficult to prevent the connection and to distinguish boundaries. Some nurses particularly admit to forming too much attachment during their first experience. Remembering patients' names and faces after they passed away and buying them gifts are some of the ways in which nurses' demonstrated their attachment. Some nurses report on having boundaries and maintaining professionalism in their nurse-patient interaction being of utmost importance to them, however, they admit that it was challenging. Others perceived exhibiting a lot of emotions in front of the families as being unprofessional. A sense of loss and grief were attributed to strong attachments with paediatric patients and parents. For homecare nurses, boundaries faded away with frequent visits to the paediatric patient and the family and they found themselves getting less professional. They also admit to visiting families when they were off duty, which generated issues. (Curcio 2017; Stayer & Lockhart 2016; Reid 2013a; McCloskey & Taggart 2010; Neilson, MacArthur & Greenfield 2010; Erickson & Davies 2017; Pearson 2013; Reid 2013b. )

While providing care for the dying children, nurses witnessed the suffering of their patients which caused them immense personal pain accompanied by feelings of guilt and regret, loneliness, sadness, and anxieties even after patient's death (Curcio 2017). Witnessing an actual death resulted in intense emotions that were felt over an extended period of time especially when it was their first death experience (Curcio 2017; Hendricks-Ferguson Sawin, Montgomery, Dupree, Philips-Salmi & Haase 2015 ). One nurse compared the emotions she felt to a black cloud over one's head, which she carried with her the whole day (Neilson et al 2010). Nurses felt sad whenever they thought of things that were left undone, and they felt that they should have done more (Hendricks-Ferguson et al, 2015). Nurses admitted the difficulty in dealing with death of a young person and the feeling of it being unfair that some children had to be in the hospital for a very long time struggling with recurring symptoms and dying without having lived a full life, terming it as upsetting, unfair and even faith (in God) testing (Hendricks-Ferguson et al 2015; Reid 2013b). Simultaneous deaths left nurses feeling like they failed the first family by not doing enough and that they lacked closure for themselves, this was so because they had to do things hastily and then proceed hurriedly to the second patient. Acknowledging their humanity and equally having emotions, nurses describe being

overwhelmed by the impact of death and that they sometimes lose their composure and cry with the family or cry at home and being inconsolable. Disconnecting from intrusive thoughts was not easy and taking up a lot of families' distresses was weary for the nurses. Nurses openly and legitimately grieved during funerals and that to a great extent they attained some level closure but sometimes they had to be professional and focus on the family and not on their sadness. On the other hand, some nurses felt that losing it in terms of sorrow was undesirable and that nurses should keep it together. (Curcio, 2017; Hendricks-Ferguson et al 2015; Stayer & Lockhart, 2016; Bloomer, O'Connor, Copnell & Endacott, 2015a; McCloskey & Taggart 2010; Reid 2013a; Reid 2013b.)

Nurses disclosed experiencing tension between them and the physicians, the patients and also the families. Sources of tension were in situations like, when the staff knew about the worsening situation of the child but they were unsure if the parents or the child knew about it and if they had accepted it or not, when the patient needed nurses, assistance to disseminate what the physicians had told them and when asked by parents the prognosis of their children (Hendricks-Ferguson et al, 2015; Stayer & Lockhart 2016). Additionally, physicians' hesitation in acknowledging that the patient's death was near created tension between them and nurses (Hendricks-Ferguson et al, 2015) and also in instances where nurses opinions were ignored by other members of the multi-professional team. Invitations to children's functions for example birthday parties, funerals and memorials often created tension when it jeopardized nurses' integrity in professionalism (Erickson & Davies 2017).

There were many instances in which nurses felt stressed and pressurised. Delivering care of less quality than intended and lack of relationship between nurses and patients or families stressed the nurses (McCloskey & Taggart 2010). Not being experts in children care caused a lot of pressure for nurses who are not trained for paediatric care, especially when they did not meet the care needs of their patients (Quin & Bailey 2011). The stress was strongly felt among the homecare nurses as a result of the unforeseeable nature of their workday, organizing, completing paperwork, fulfilling competing demands whilst working individually and also working within the same community they lived in (McCloskey & Taggart 2010). In addition, being on call at night was a stressor for community nurses because they might have done day shift as well (Neilson et al 2010). The caring process led to pressure mainly linked to lack of confidence and emotional unpreparedness which resulted in nurses feeling compassionless, isolated vulnerable, burnout and exhausted. These feelings resulted in nurses having thoughts of quitting their nursing career. (McCloskey & Taggart 2010; Quin & Bailey 2011.) Witnessing the death of their patients was also a stressor (Hendricks-Ferguson et al 2015).

Nurses expressed having to let go of their patients when keeping them longer only meant pain and suffering, at such times there was no hope for them to live and wishing them a good death was all they could do. In other situations, hopelessness was experienced more rapid



scenarios like when patient's recovery from coding takes longer than it usually does, nurses felt that they (patients) were not coming up quickly like they usually did. Whenever it was known in advance that there was no hope for survival, nurses were faced with the heavy and emotional task of helping patients prepare for their impending death. One nurse expressed feeling terrible for almost turning her back on the patient when nothing seemed to help. (Curcio, 2017; Stayer & Lockhart 2016; Bloomer 2015a. )

There are times when nurses did not know what to do, they felt in control and not in control, they notably felt helpless in situations such as, when supporting the family or when alleviating the child's symptoms (Pearson 2013). Nurses felt powerless and frustrated when their opinion was not considered by other members of the paediatric palliative care team. (Stayer & Lockhart 2016; McCloskey & Taggart 2010)

## 7.2 Coping with own emotions

It can be argued that due to the intensity of emotions involved in the provision of paediatric palliative care, developing coping mechanisms to help nurses continue working and functioning in a normal way is essential.

### 7.2.1 Personal support

Nurses tried to manage their emotions by being strong and taking every day at a time, this way they would be certain to return to work the following day. Having the ability to attach and detach was crucial to self-preservation which they achieved by ways like compartmentalizing emotions, choosing to forget and trying to keep it together for the sake of the patients and the families. Nurses disclosed that putting all emotions aside and focusing on work helped. However, some did bear the burden until they got home to talk to their loved ones about it. Other nurses managed by routinely changing their assignments when the emotional burden became too tiring. Learning to be at the peace with the situation and doing personal reflection were reported as being a good coping tactic. In addition, advocating for and focusing on themselves was beneficial. Bereavement support was deemed helpful to both nurses and the family by some nurses while others differed and termed it as emotionally draining. The need for psychological debriefing after the death of a patient was highlighted due stress and the complicated nature of paediatric palliative care through some nurses questioned its effectiveness. Clinical reflection sessions were provided in some instances, but they were poorly attended. (Curcio 2017; Stayer & Lockhart, 2016; Reid 2013a; McCloskey & Taggart 2010; Erickson & Davies 2017; Quin & Bailey 2011; Pearson 2013.)

### 7.2.2 Collegial support

Hendricks-Ferguson et al (2015) report that interacting with colleagues did boost trust and bonding amongst nurses, therefore, enhancing support which could be in form of a group or individual dialogues. Nurses describe feeling amazing and comforting because they were assured of support from their peers and the multidisciplinary team. Support entailed discussing emotions, addressing questions and cheering each other up. The knowledge that other colleagues had been through what was happening made it easier for the nurses to deal with the situation. Nurses in hospices received support from their managers and the organizations they worked for while those in homecare reported not feeling supported by their line managers. Community nurses delivering care disclosed having limited face-face support due to the huge geographical area, they however, supported each other via the phone. Other nurses confessed to not getting the support they needed and that they were reluctant and anxious about asking for help or asking questions as they were uncertain of what to expect from their peers. All in all, most nurses acknowledged that they would not have provided the care they did without the support of their colleagues who were really good. (Hendricks-Ferguson et al 2015; Stayer & Lockhart 2016; McCloskey & Taggart 2010; Reid 2013b; Quin & Bailey 2011.)

### 7.3 A sense of meaning and purpose for work

This theme covers experiences that motivated nurses during their provision of care and gave them a reason to continue working in the various settings of paediatric palliative care. These include feeling content, desire to provide the best care, and inspiration.

Nurses felt content in several situations. One nurse described feeling satisfied when one family thanked her for her honesty and kindness (Stayer & Lockhart, 2016). Nurses felt satisfied when they provided standard and quality care to the paediatric patient and the family and also when they established connections with them. Nurses expressed feeling privileged and being rewarding to provide care to the children at such a distressing time. They acknowledged the uniqueness of every child and feeling enriched having coped and managed with the situation terming it as a positive experience. (McCloskey & Taggart 2010; Bloomer et al 2015b; Reid 2015b.)

Desiring to provide the best possible care they could, nurses were determined to make the last moments between the families and their children very special, personal and peaceful. Over and above, of great significance to them was ensuring that the paediatric patient comfort needs were met. Providing effective pain management and symptom relief, respecting the child and recognising them as a person, advocating for the child, compassionate care of the body after death and leaving the family with a good physical memory of their child were key issues that were very valuable to the nurses. Owing to the fact that the experience would

remain with the family forever, nurses felt that it was the only opportunity they had to get things right for the family, therefore ensuring that everything went well. Nurses ensured that nothing was left undone, by counter-checking everything and were determined to provide optimum care. (Stayer & Lockhart 2016; Hendricks-Ferguson et al 2015; Bloomer et al 2015a; Pearson 2013; Bloomer et al 2015b; Reid 2015b; Quinn & Bailey 2011; Neilson et al 2010.)

Bearing witness to the strength possessed by paediatric patients, especially when they defied odds by recovering from the toughest of situations inspired nurses to be also strong and resilient. Nurses found inspiration from the religious and spiritual hacks they had deciphered from their paediatric patients. (Curcio 2010.)

#### 7.4 Learning at work

Working longer in the field of paediatric palliative was handy in gaining knowledge as nurses acknowledged having learned something new from every patient and that every time was a learning experience (Curcio 2017; Neilson et al 2010; Pearson 2013). Nurses acknowledged an improvement in their skills every time they got to provide care and that reading alone was insufficient (Pearson 2013). Erikson & Davies (2017) point out that nurses became better at defining and negotiating boundaries through experience. Pearson (2013) emphasises the input one's previous experience adds to the succeeding care experiences and nurses admit on not being satisfactorily ready until they experience the process of paediatric care.

Novice nurses appreciated their experiences of being mentored by more experienced nurses. Mentors were noted to have been more helpful in guiding novice nurses in the provision of holistic care for the dying children and their families and also their guidance during death and after death procedures. During mentorship, novice nurses played an observational role. (Hendricks-Ferguson et al 2015)

#### 7.5 Challenges in provision of care

The challenges mainly experienced by nurses were categorised into, struggling with communication, inadequate knowledge and training, administration related challenges and friction with family members.

##### 7.5.1 Struggle with communication

Hendricks-Ferguson et al (2015) & Pearson (2013) report nurses enhancing and simplifying communication between paediatric patients and their families, however there are situations whereby nurses found themselves struggling and anxious, for example, when parents asked directly about the situation of their child or when the patient was in need of assistance in dealing with what the physician communicated. Nurses felt uneasy and experienced some difficulty in responding to families and sometimes to the paediatric patients due to the unpredictability of symptoms. They sometimes found themselves being partially honest when

asked by parents what they (nurses) would have done if they were in the parent's shoes (Hendricks-Ferguson et al 2015; Stayer & Lockhart 2016; Reid 2013b; Quinn & Bailey 2011. ). In other situations, nurses were unsure of whether they should let the parents come to them for information or the other way around, especially when death was near (Hendricks-Ferguson et al 2015). Nurses reported being a bit uneasy when paediatric palliative care involved a lot of family members, who were all seeking answers (Reid 2013b). Nurses felt neglectful whenever their communication was not focused on the sick child and rather on the siblings or other family members, (Reid 2013b). On the positive side, nurses describe how seeking clarifications from the families and paediatric patients could make them open up further and share with nurses things they had not told anyone else (Bloomer et al 2015b).

Nurses expressed their experience of frustrations when physicians were not being very forthcoming with parents and patients about bad news, they kind off bet around the bush and nurses often felt that they were left alone to answer questions and be there for the family (Hendricks-Ferguson et al 2010; Stayer & Lockhart 2016). It was of paramount importance for the nurses that the paediatric patient is kept at the centre of all communications (Bloomer et al 2015b). Novice nurses admitted to having limited knowledge on effective communication and that there was an obligation to improve (Hendricks-Ferguson et al 2010).

#### 7.5.2 Inadequate knowledge and training

Nurses admitted the existence of knowledge gap (Reid 2013b; Bloomer 2015b). Novice nurses disclosed finding themselves in situations where they were uncertain of what to do and also unsure of the palliating symptoms, this made them feel less confident and inadequate in regards to paediatric palliative care (Hendricks-Ferguson et al 2015; Pearson 2013). Community-based nurses pointed out symptom control and its management as one of the areas where they evidently lacked sufficient knowledge on. They were also concerned by their infrequent exposure to rare symptoms, advanced pain management and use of equipment such as syringe drivers, in addition, some pharmacology presented challenges. Community-based nurses reported having better expertise and more self-confidence while caring for adults as opposed to children, they felt inadequate to provide guidance to the family. (Neilson et al 2010; Quinn & Bailey 2011; Pearson 2013.)

Novice nurses felt incompetent in post-death care procedures and reported on the need to expand their knowledge on these procedures as they are an indicator of compassion and respect towards the patient and the family (Hendricks-Ferguson et al 2015). There was frustration on the part of nurses due to unavailability of paediatric palliative care educational opportunities (Hendricks-Ferguson et al 2015; Reid 2015b; Bloomer 2015b) and where those opportunities were available, they did not entail practical skills hence nurses competencies could be misjudged (Neilson et al 2010; Pearson 2010). Registered children's nurses differed

from those who were not (who were only registered nurses) in reference to the level of confidence and professional expertise (Reid 2015b).

Nurses expressed the need for further training and enhancement of their practical skills in order to understand the various symptoms, in relation to that, nurses felt that on-site training would be more fruitful as opposed to attending short paediatric palliative care courses. In addition, having paediatric clinical nurse specialist in the community paediatric palliative care team was considered to be handy since they were specialised in dealing with children. (Quinn & Bailey 2011; Pearson 2013. )

### 7.5.3 Administration-related challenges

Reid (2013a), nurses grappled with instigating and keeping a-float care plans due to rapid turnover and endless disputes amongst budget holders over sourcing, financing and maintaining health equipment and health supplies. Nurses further struggled with poorly defined roles, lack of homogeneity in degree and quality of inter-professional collaboration and the availability of a few skilled nurses. The absence of formal 24hr care system and limited personnel in homecare meant that nurses provided 24hr services out of goodwill and the same also applied to weekend services. Insufficient infrastructure always meant that nurses were under pressure and overworked. (Reid 2013a; McCloskey & Taggart 2010; Neilson et al 2010, Reid 2013b; Quin & Bailey 2011. )

The homecare structure comprised of many, different agencies working together to provide efficient service delivery but, the complexity was very overwhelming for both nurses and families, especially when there were meetings, nurses were unsure of the benefits of inter-agency meetings (Reid 2013a). Comprehending the structure of service delivery was a challenge and nurses had difficulties in identifying their colleagues and instituting communication routes (Reid 2013b). The nature of homecare whereby, nurses have to meet with the client before initiating the actual care made nurses feel as if they were meddling and being intrusive (Neilson et al 2010). Nurses criticised not being introduced to the paediatric patients early enough when they could have been of more help and they also disclosed that relationships and trust take time to build, late introduction meant a rush in establishment of relationships (Reid 2013b).

Nurses had to work with poorly defined roles and they were confused about their duties, boundaries, and responsibilities supposedly so due to the contributions of specialist children's nurse and paediatricians (Reid 2013a; Reid 2013b; Quinn & Bailey 2011.). It was a concern for nurses whenever they had to work without clearly laid out plans in relation to relevant and applicable medical care and interventions (Pearson 2013).

#### 7.5.4 Friction with family

Nurses reported of situations where tension existed between them and the families. Disagreements amongst the family members and anger were sometimes directed towards the nurses, this created discomfort on the part of nurses. The anger was attributed to limited parental coping reserves or mental health issues. (Reid 2013a; McCloskey & Taggart 2010.)

Commonly, the division between nurses and family often arose when nurses had to protect the child's interest predominantly when it pertained to the continuation of care. At times parents were too protective of their children and they would not let their opinion be heard, causing a rift between them and nurses. (Reid 2013a; McCloskey & Taggart 2010.) Homecare nurses reported having been denied entry to access the sick child by the parents resulting in them not providing the child's care needs (Quinn & Bailey 2011)

Nurses reported struggling to isolate their beliefs whenever they had patients with different beliefs and cultural values from theirs, for example in Chinese culture it is not allowed to let a patient know they are going to die or their risks of death are high (Curcio 2013).

## 8 Discussion of the findings

The purpose of this thesis was to describe the nurses' experiences of paediatric palliative care, with the research question being "What are nurses' experiences of paediatric palliative care?" To answer this question, 12 articles were diligently analysed and 5 themes emerged, emotional burden, dealing with emotions, a sense of meaning and purpose to work, learning at work and challenges experienced in the provision of paediatric palliative care. These themes are partially interrelated and it is impossible to discuss one without involving the other. The claims on this section are based on the theoretical background and the findings of this thesis.

The findings of this thesis reveal the same findings as previous studies by Charlotte et al (2014) and Darla (2009) that, long periods of hospitalization of paediatric patients and frequent visits to their homes (for community nurses) lead to the formation of strong emotional attachments between nurses-paediatric patients and nurses-families. Connections formed by nurses leave them more susceptible to the same pain and suffering like that of the family (Darla 2009). On the other hand, it appears that, therapeutic relationships between nurse-patient, nurse-family and nurses not knowing their boundaries, threatened nurses' integrity and professionalism (Erikson & Davies 2017), for example, nurses reported buying gifts for their patients and visiting them when off duty. From the findings it seems that the pain and

sorrow is intensified owing to the fact that it was a young person's death which further led to feelings of guilt and regret. (Darla 2009.)

It can be argued that nurses are exposed to a lot of stress owing to the nature of paediatric palliative care. The findings assert that the major stressors for nurses are workload, absence of good relationship between nurses and the patients or the families, working within the same community, inadequate knowledge, emotional unpreparedness, low confidence, and administration related challenges. In concurrence with previous studies the findings assert that experiencing stress often exposed nurses to feeling compassionless, burnout and exhaustion, feelings of isolation and vulnerability and thoughts of leaving the nursing job. (Quin & Bailey 2011.)

From the findings of this thesis tension sometimes existed between nurses and the families, patients and physicians. It also appears that tension mostly was as a result of the worsening condition of the child. It can be argued that nurses, patients, families, and physicians were sometimes unsure on how to approach the subject of death, further on, nurses report that physicians were hesitant in acknowledging the inevitable death. (Hendricks-Ferguson et al, 2015; Stayer & Lockhart 2016.)

According to Bergstraesser (2012), the exact time of death for children living with life-limiting conditions is unpredictable. There are times when curative treatment only exposed the patients to more pain and nurses had to let them go and at other times there was no hope for survival or nothing seemed to work or help, therefore, rendering nurses hopeless as portrayed by the findings of this thesis. In addition, the uncertainty also created tension between nurses and other workers together with the patient and their families.

As per the findings, nurses experienced helplessness when they could not control symptoms and when their opinion was ignored by other health professionals. This is supported by Darla (2009) who points out that feeling helpless is part of providing paediatric palliative care.

Nurses seem to have various ways of coping in their role of providing care for dying children and their families because their ability to absorb emotions has certain limits. Self-protection is important to nurses' wellbeing because they are not helpful to anyone broken up (Neilson et al 2010). In line with Forster and Hafiz (2015) this thesis shows that nurses established a personal support by being strong and positive, compartmentalization(of emotions), talking to loved ones at home, changing assignments, personal reflections, attending debriefing sessions (which some nurses doubted its effectiveness), and by setting up boundaries. Support from colleagues and other healthcare professionals was deemed helpful in agreement with Pearson (2010a), however, due to anxiety and not knowing what to expect from others, some nurses

were reluctant to ask for support, on top of that, huge geographical area was a barrier to face-to-face peer support in rural community nursing.

It could be said that working on the edge between life and death gives nurses a desire to perform better at caring for the children and their families. There are circumstances that made nurses respond positively to care despite facing constant grief and bereavement at work. This thesis indicates that being appreciated by the patient's family and the satisfaction in the provision of good care was a source of motivation for the nurses. Nurses were motivated to provide the best care because the experience would remain with the family forever and they only had one chance to get the care right. In addition, nurses derived their inspiration from their patient's strength and the patient's spiritual experiences. It appears that little has been explored on the background studies about nurses' sense of meaning and purpose in the provision of paediatric palliative care, nevertheless, Darla (2009) admits that the provision of paediatric palliative care can be both demanding and rewarding.

The findings show that nurses felt that their professional skills and coping skills had improved over time through working with different patients and with the help from more experienced nurses. The finding concurs with Malloy et al (2015), however, despite their experience, nurses did feel unknowledgeable in some areas such as symptom and pain management, pharmacology, providing guidance and in the use of some equipment. There was a feeling amongst nurses that paediatric trained nurses were better at providing paediatric palliative care because they had been trained to work with children and families. According to Dochert et al (2012), few nurses have been trained to provide adequate palliative care and therefore most of them lack the vital knowledge needed in the provision of care for sick children and their families. Malloy et al (2006) point out that education geared towards the provision of paediatric palliative care would help nurses have more confidence during the care process hence making it easier for them to deal with the challenges they experience. Donnelly et al (2005) point out that good knowledge and understanding the needs of children living with-life limiting diseases enhances the delivery of better care.

As cited from previous research, nurses working in paediatric palliative care require good communication skills because both the parents and the children require clear information in order to make informed decisions on the direction of care. Previous studies also indicate the importance of good communication amongst healthcare professionals, however, there are some situations where good communication was a struggle for nurses. This thesis reveals that nurses experienced difficulties in communication, they struggled with honesty, when and how to initiate communication with the families, dealing with questions from a lot of family members and not putting the child at the centre of communication. To add to that, nurses felt that physicians should be more forthcoming when communicating about death. This thesis further reveals that their encounter of challenges in communicating resulted in them feeling



anxious, frustrated and neglectful of the child. On the good side, good communication with the family led the family to open up and nurses could learn more about them. Novice nurses admitted their need to enhance their communication skills.

The findings of this thesis show that nurses experienced struggles with administration-related issues. Lack of clear planning and high turnover rates appeared to be a common challenge across all healthcare settings whilst other issues were only experienced in the community settings. Going with the findings, provision of paediatric palliative care in the community is portrayed as being a complex structure involving many agencies resulting in confusion. Nurses experienced working with poorly defined roles and even providing some services out of good will (due to an absence of 24hr care system and lack of enough nurses). Nurses felt that late introduction to the family hindered the quality of care provided to the family. Working with limited infrastructure and disorganization resulted in nurses feeling pressurised and very concerned about the situation.

Background studies have articulated the involvement of family in paediatric palliative care and the role nurses play in supporting the family. Whilst nurses might experience good and satisfactory relationships with the family, the findings reveal that it may not always be the case. There are times when nurses experienced conflict with the patients' families which mainly arose due to differences in opinion, parents being overprotective, limited parental reserves or mental issues and cultural differences. The frictions and misunderstandings create discomfort for the nurses. (Reid 2013a.)

### 8.1 Ethical considerations

During the whole research process, the writer of this thesis upheld a high standard of ethical consideration, with strict adherence to the ethical principles of integrity, accountability, and transparency. The thesis guidelines for Laurea University of Applied Sciences (2015) were read in advance and strictly observed. Conflict of interest did not arise at any point. Transparency was achieved by revealing every stage of the research and explaining every step. Additionally, data was represented truthfully without any fabrication or misrepresentation. (Siu & Comerasamy 2013, 89.)

There was neither biasness nor any personal ambition throughout the whole process. The choice to use LaureaFINNA and EBSCOhost from Laurea's online library was based on their credibility. A clearly laid out predetermined inclusion and exclusion criteria was established to minimise bias during the data collection phase. The use of peer reviewed articles enhanced credibility of the data.

All the materials used for this thesis were accredited to their authors and researchers through in-text and end-text referencing as per the Laurea's guidelines for referencing (King 2013), therefore eliminating plagiarism. Initial elimination of duplicates ensured that copyrights were upheld.

## 8.2 Trustworthiness

Biases and personal opinions in interpretation of results are a concern in qualitative research, therefore to establish trustworthiness, the following principles are considered, credibility, transferability, confirmability and finally dependability (Lincoln & Guba 1985 cited in Pandey & Patnaik 2014).

Credibility pertains to the truth of the study and whether the research is applicable to reality. To achieve credibility, various techniques have been put in place namely, prolonged engagement, persistent observation, triangulation, peer debriefing, negative or deviant case analysis, referential adequacy, member checks, and thick description. Prolonged engagement requires that the writer has an adequate understanding of the phenomena to be studied (Lincoln & Guba 1985 and Merriam 1995, cited in Pandey & Patnaik 2014 .) This was achieved by pre-reading materials written about paediatric palliative care, nurses' experiences of paediatric palliative care and children living with life-limiting conditions. According to Pandey and Patnaik (2014), the aim of persistent observation is to obtain components most relevant to the research question. This was done by the selection of relevant articles using a previously established inclusion and exclusion criteria whereby 12 relevant articles were chosen for the study. Triangulation involves applying different methods to sufficiently elucidate facts or occurrences (Pandey and Patnaik 2014), more than one article was used for this research. In peer debriefing, the writer participated in different sessions where the thesis was critiqued by fellow students and the teacher. With the first findings, the names assigned to the subcategories were not answering the research question contrary to what the writer had assumed. The meaning units were then rearranged and the subcategories and themes renamed. In studying negative or deviant case analysis, there were subcategories that could not align with others this could be due to the different healthcare settings of the articles used. Referential adequacy involves having some part of the data set aside but not analysed then the researcher will return to analyse it after developing preliminary findings, in order to test the viability of the findings (Pandey and Patnaik 2014). Referential adequacy was not done for this paper. Another way to establish credibility is member checks whereby the researcher goes back to the participants of the research to verify that the interpretation did not lose the meaning they (participants) intended (Lincoln & Guba 1985, cited in Pandey and Patnaik 2014). This was not relevant to this thesis since the methodology used here was a literature review. Finally is the thick description which is achieved by providing enough details to the reader. The

writer tried to be descriptive and to give as many details as possible for every stage. (Pandey and Patnaik 2014.)

Transferability demands that the findings are applicable in other contexts. This had been achieved by thick description as stated above and it ascertains the external validity of the findings (Pandey and Patnaik 2014). The articles used were from Australia, USA, UK and Ireland, and the healthcare settings were different. The healthcare settings involved were hospitals, paediatric hospices, and community (homecare) environments. The results from the different countries seemed to be similar, whilst some of the results from the community environment were unique to that setting in comparison to the others.

Inquiry audit can be used to show that if the research was to be repeated in the same way and context, the same results would be obtained, that is dependability. The inquiry audit, in this case, was done by the teacher and colleagues. The limitation of dependability is the fact that different people interpret things differently. Lastly is the principle of conformability which ensures that the results are not biased and that they are objective, this is achieved by the use of audit trail which is, transparency in describing the research steps. The writer was not biased in any way and previous knowledge on nurses' experiences of paediatric palliative care did not affect the findings. (Pandey and Patnaik 2014. )

### 8.3 Limitations and recommendations

Despite the fact that this study answered the research question, it had several weaknesses. First and foremost this study was conducted by one novice author, this will have an impact on the results to some extent. Having two or more authors would have been advantageous due to the possibility of comparing opinions hence minimising bias in the overall review.

Secondly, use of the two databases LAUREA FINNA and EBSCOhost limited the number of article that could have been useful, in addition some relevant articles were not available in full text and they had to be paid for which was beyond the ability of the author. Thirdly, limiting the article search to articles written in English from only Europe, UK, USA and Australia might have resulted in missing out on important and relevant data, it also restricts internationality.

Lastly, in the John Hopkins appraisal tool, randomised trials, experimental and quasi-experimental designs are more superior to qualitative studies, hence the low level of evidence for all the 12 articles which were all qualitative studies. A better critical appraisal tool to be used would have been Critical Appraisal Skills Programme (CASP) because it has different checklists for each study design (CASP 2017).

Based on the findings of this literature review, it could be concluded that nurses do experience different kinds of emotions while providing palliative care to children. With the help of self and workplace established coping mechanisms, nurses can get through the stressful events they encounter and somewhat derive motivation and inspiration from them, hence fostering their ambition to provide quality care. Further on, nurses are satisfied with the knowledge they have acquired through experience and from mentors and colleagues, however, they feel that paediatric palliative care curriculum should be launched in schools and practical-based training organized at work. Anxiety and lack of confidence is a great hindrance to effective communication between, nurses and the patient, the family and other healthcare professions. Ineffective communication often resulted in a lot of tension between the parties involved. Working understaffed with poorly defined roles and limited resources remains a big challenge for the nurses, especially in the homecare environment.

It is highly recommended that more research is carried out to determine ways in which paediatric palliative care training and education can be improved. This will enable the nurses to be in a better position of handling the challenges they encounter and to further boost their confidence.

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Appendix 1: Data extraction table

Author & Publication Year	Title	Aim of study	Conclusions	Evidence Rating
Curcio, D.L. 2017. Journal of pediatric nursing 43(1).	The Lived Experiences of Nurses Caring For Dying Pediatric Patients	To explore, describe and understand the lived experiences of nurses caring for dying pediatric patients and to gather information that may help future nurses when caring for dying child.	Caring for dying pediatric patients involves not only the dying child, but the family and other healthcare providers. Preservation of the mental well-being of nurses concluded that when nurses are put in demanding experiences during the dying process, they use censoring to carry on.	Qualitative phenomenological Research  Level III Quality B
Hendricks-Ferguson, V.L., Sawin, K.J., Montgomery, K., Phillips-Salimi, C.R. & Haase, J.E. 2015 Journal of pediatric oncology nursing, 32(4), 240-252.	Novice nurses' experiences with palliative end-of-life communication	To explore palliative care/End of life communication of novice pediatric oncology nurses	Novice pediatric oncology nurses need substantial education, support and mentorship from experienced nurse mentors to acquire effective communication skills necessary to engage in caring and sensitive discussions with dying children and their families.	Qualitative, empirical phenomenology design  Level III Quality A
Pearson, H.N. 2013..	"You've only got one chance to get it right": Children's cancer nurses' experiences of providing palliative care in the acute hospital setting.	To explore the experience of novice children's nurses providing palliative care in acute hospital setting to evaluate current support, educational and pastoral preparation	Nurses working in the acute hospital setting have little exposure to caring for this patient group, therefore the limited studies within this area reflected this. Education impacted the participants' ability to deliver care due to limited experience.	Qualitative study  Level III Quality A

McCloskey, S. & Taggart, L. 2013.	How much compassion have I left? An exploration of occupational stress among children's palliative care nurses.	To explore the experience of stress in nurses providing children's palliative care in one region of UK	Maintaining and sustaining a skilled, compassionate, effective workforce is the responsibility of individuals, organizations and professions.	Qualitative study Level III Quality A
Neilson, S., Kai, J. MacArthur, C., Greenfield, S. 2010. Journal of pediatric nursing, 22(3).	Exploring the experiences of community-based children's nurses providing palliative care.	To explore the experiences of community children's nurses (CCNs) and children's palliative care nurses (CPCNs) who provide end-stage palliative care to children with cancer in the family home	Further funding is needed to develop teams of trained, experienced CCNs and CPCNs who can provide palliative care for children and young people 24 hours a day and 265 days a year.  The experience of providing palliative care is unique to each nurse	Qualitative study Level III Quality A
Quinn, C. & Bailey, M.E. 2011	Caring for children and families in the community: experiences of Irish palliative care clinical nurse specialists.	This study aimed to obtain a picture of the current nursing service that would help to determine whether the needs of these (children) patients are being met.	The provision of community children's palliative care emerged as a complex journey of often unknown duration.	Qualitative descriptive design Level III Quality A
Reid, F.C. 2013b. International journal of palliative nursing, 19(11).	Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas.	Aims to highlight some of the challenges perceived by rural adult community nurses when delivering palliative care to a child or a young person	It is evident that, regardless of their experience, the nurses were affected by the deaths of the children at both professional and personal levels, leaving a legacy of unforgettable memories.	Qualitative study Level III Quality A
Bloomer, M.J., O'Connor, M., Copnell, B. & Endacott, R. 2015b	Nursing care for the families of the dying child/infant in paediatric and neonatal ICU:	To explore how NICU/PICU nurses care for families before and after death; to explore nurses' perspectives	There is room for improvement in nurses' provision of anticipatory guidance, which	Mixed method study of focus groups and individual interview. Level III

Journal of Australian critical care, 28, 87-92.	Nurses' emotional talk and sources of discomfort. A mixed methods study.	tives on their preparedness/ability to provide family care; and to determine the emotional content of language used by nurses participants	encompasses effective and open communication focused on preparing families for the child's death.	Quality A
Erikson, A. & Davies, B. 2017. Journal of pediatric nursing 35, 42-92.	Maintaining integrity: How nurses navigate boundaries in pediatric palliative care.	To explore how nurses manage personal and professional boundaries in caring for seriously ill children and their families	Nurses working in PPC settings, both in and out of the hospital, can benefit from early recognition of the behavioral and emotional indicators of compromised integrity. Work environments can better address the challenges of navigating boundaries through offering resources and support for nurses' emotional responses to caring for seriously ill children.	A qualitative research design, specifically grounded theory  Level III Quality B
Bloomer, M.J, Endacott, R., Copnell, B. & O'Connor, M. 2015a.	'Something normal in a very, very abnormal environment'- Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia.	To explore how NICU and PICU nurses care for families when a child dies and how they perceived their ability and preparedness to provide family care.	Themes illustrated nurses' concerns for family members in preparing for death, how to present the child to their parents in the best way and the enabling of opportunities for family involvement including the creation of moments	Mixed method study of focus groups and individual interview  Level III Quality A
Stayer, D. & Lockhart. 2016. American Journal of critical care,	Living with the dying in the pediatric intensive care unit: A nursing perspective.	To describe and interpret the essence of the experiences of nurses in pediatric intensive care	Providing palliative care to children with life-threatening illness was complex for nurses.	Qualitative study  Level III Quality A

25(4), 350-356.		units who provide palliative care to children with life-threatening illness and the children's families	However nurses voiced professional satisfaction in providing palliative care and in support from colleagues.	
Reid, F. 2013a.  Nursing children and young people, 25(9), 31-36.	Grief and the experiences of nurses providing palliative care to children and young people at home.	To elicit the views of children's nurses with regard to the personal, contextual and interprofessional challenges faced when delivering palliative and end of life care to children and young people in the community.	Nurses experienced considerable internal and external pressures.	Qualitative study  Level III Quality B

Appendix 2: Complete data analysis

Raw data	Sub -category	Theme
<ul style="list-style-type: none"> <li>-Being strong , you cry about it later at home</li> <li>-It's almost easy to compartmentalize and forget</li> <li>-Putting all emotions aside</li> <li>-Frequently changing assignments</li> <li>-In order to do your job you have to draw boundaries</li> <li>-Being at peace and letting go</li> <li>-Pulling yourself for the kids and their families</li> <li>-Having to keep it together and keep things moving</li> <li>-There are many times I talk to my husband about a horrible case.</li> <li>-managing the nurses' own emotions when delivering palliative care</li> <li>-Clinical reflection sessions being beneficial but poorly attended</li> <li>-Comfort from sitting quietly and hearing other people speak</li> <li>-Trying to balance familiarity and emotional involvement</li> <li>-Demonstrating personal grief in funerals</li> <li>-Nurses engaged in self -care by advocating for, and focusing on themselves</li> <li>-Achieving closure at funerals</li> <li>-Need for psychological debriefing</li> <li>-Psychological debriefing not useful to everyone</li> <li>-Important to deal with emotions either through clinical reflection or debriefs within the multidisciplinary team</li> </ul>	<p>Self-preservation</p>	<p>Coping with emotions</p>
<ul style="list-style-type: none"> <li>-Discussing emotions and addressing questions with individual and group of other nurses</li> <li>-Peer interaction created trust and connectedness leading to support</li> <li>-Comfort knowing they could seek support from their peers as well as multidisciplinary members of the care</li> <li>-Amazing support from everyone (social workers, physicians, chaplains and pc teams)</li> <li>-Being supportive to each other during time of crisis</li> <li>Cheering each other up</li> <li>-Peer support and reflective practice were used as coping tactics</li> <li>-Positive support provided by immediate team, line manager and by the organization in hospices</li> <li>-Homecare nurses reflected on not feeling valued or included by their line managers</li> <li>-Restricted opportunities for face-to-face support</li> <li>-Roles poorly defined and a limited availability of resources</li> <li>-Felt amazing to have support from everyone</li> <li>-It was teamwork</li> <li>-Restricted opportunities for face-to-face support from others as a consequence of these rural issues and the geographical isolation</li> <li>-Participants acknowledged the support of their cns colleagues</li> <li>-Feeling unable to provide the care they did without the support of others</li> <li>-Feeling that everyone was good and that they offered help</li> <li>-Feeling like they did not have much support while caring for their patient</li> <li>-Anxious to ask for help as a result of not knowing what to expect</li> </ul>	<p>Collegial support</p>	<p>Coping with emotions</p>



