



**LAUREA**

**Nursing Support To Families During  
Children ´s Palliative Care And  
After Bereavement Of The Child**



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**NURSING SUPPORT TO FAMILIES DURING CHILDREN´S PALLIATIVE  
CARE AND AFTER BEREAVEMENT OF THE CHILD  
(A SYSTEMATIC LITERATURE REVIEW)**

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Nursing Support to Families in Children's Palliative Care and After Bereavement of the Child:  
A systematic literature review.

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The purpose of this review is to throw some light on how current literature describes nursing support that is provided to families in children's palliative care and after bereavement of the child. The research question of this study is; what kind of nursing support is provided to families during children's palliative care and after bereavement of the child?

The purpose of carrying out this study was to contribute in creating awareness on the importance of nursing support to families in children's palliative care and also after the child has passed away. The methodology applied in collecting data in this review was a systematic literature review and was based on previous published studies such as journals and web searches. The articles used in this study were chosen based on the fact that its content answered the research question and were analyzed using an inductive analysis method. The total of articles used in this review are N=6.

The results of this study adopted from the chosen articles describe the type of care nurses do provide to families of children undergoing palliative care and it also describes the continuity of care after bereavement of the child. The findings were grouped into four categories, Family centered care, Communication as an important tool, Involving families in the caring team, and encouraging families in dealing with bereavement of the child. All four categories have sub-categories that is well described from pages 16-23 of this study and all four categories and their sub categories were titled; the process of continues nursing support to families.

The findings reported that Families need nursing support to be able to cope with the palliative care process, the changes it brings to their lives and how to deal with bereavement of the child. Every department in the nursing field needs continues development through innovations and children's palliative care and the support that nurses provide to families during this period is no exception. Nurses need to get involved in research work so as to contribute in developing the phenomenon.

Key words: Nursing support, Palliative care, Bereavement, The dying child

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## 1. Introduction

Death is an inevitable call that marks the end of life. Parents do not expect to outlive their children; tragically it is not often the case. The loss of a child causes great stress on families, temporarily impairing concentration, decision making and work performance. Caring for a dying child impacts the family's quality of life emotionally, psychologically and socially during palliative care and after the death of the child. In spite of the family's emotional state during a child's palliative phase, they still play a very important role in managing the child's quality of life thus requires nurses' support (Egan & Arnold 2003, 42).

Nursing is defined as the protection, promotion and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations (ANA 2011). Nurses are key to providing care support; they should be equipped to offer the practical, psychosocial and spiritual support that is central to the ethos of palliative, where aim is symptom management rather than curative treatment (Eyre 2010). Palliative care nursing is comprised of a team of health care professionals providing on-going information about the disease and various measures needed in making life easier and comfortable for the dying patient and their families. Support for the family is key and the nursing staff will strive to provide the support required (Terminal care.net).

After the death of the child, the family is placed in a bereaved state, which can be even more traumatising, as it denotes the emotions and behaviour of a person who has suffered the loss of another. Bereavement is said to be the time it takes to grieve the loss and adjust to life without the other, thus it's specific to survivors (Egan et al 2003). Previous researchers emphasized on the fact that family members who are care givers are very crucial to health care system, giving the fact that they provide majority of the physical and emotional care to love ones undergoing palliative care especially at home setting (Funk, Stajduhar, Toye, Aoun & Todd 2010).

According to Sepulveda, Marlin, Yoshida & Ulrich (2002), WHO defines children palliative care as the active total care of the child's body, mind and spirit, and also involving giving support to the family. The aim of palliative care is not to provide cure but to treat symptoms caused by the disease and providing comfort and death with dignity. The need for developing children's palliative care has been well documented by researchers based on the fact that very little search has been done on this subject as compared to adult palliative care or palliative care to cancer patients ( Lewis 2004). During the search, it was realised that very few articles described nursing support to families during a children's palliative care, which further more support previous researcher's concern on the topic in question. This thesis falls

under the triangle hospital project, which works in collaboration with Laurea University of applied sciences. The goal is to bring all the different units of health care into one building. The hospital is located in the Helsinki region; and it was opened for use in November 2010, made up of different branches such as the modern day hospital, policlinic, and Inpatient ward processes (HUS 2011).

## 2. Purpose of the study

The purpose of this study is to describe the kind of nursing support provided to families during children's palliative care and after bereavement of the child

Research question:

What kind of nursing support is provided to families during children's palliative care and after bereavement of the child?

### 3. Systematic literature review as a method

Systematic literature review is a disciplined method used in acquiring researched based or evidence based literature, which has already been published by previous researchers. The book states that the development and utilization of nursing knowledge is essential for continued improvement in patient care. A systematic review is focused on inquiries that help us answer questions or solve problems. The main goal of research is to develop, refine, and expand already acquired knowledge ( Polit, Beck & Hungler 2001, 4-17).

An understanding of systematic reviews and how to implement them in practice is becoming mandatory for all professionals involved in the delivery of health care. Health care information is being updated daily and nurses are also responsible in providing the consumers of nursing research with updating relevant findings that may affect their practice ( Polit et al 2003, 4-17). There are five main stages when conducting a systematic literature review. Stage one is choosing a topic. Stage two is to identify studies that are relevant to the purpose of the study from electronic databases, web searches, and books. Stage three is scrutinizing selected data that is relevant to the research question by applying the inclusion and exclusion criteria in order to obtain primary articles. Stage four is reapplying the inclusion and exclusion criteria in order to assess the studies for quality and stage five is using the quality criteria for qualitative studies (Khan, Kunz, Kleijnen & Antes 2002, 1-109)

### 3.1 Data search

It is the search for evidence based published literature relevant to the topic in question such as articles, journals and books. The second step after choosing the topic was to conduct an electronic search for articles and journals in order to identify previous literatures that are relevant to the purpose of the study. The search was conducted by running three search words on four different academic search engines and the criteria for the search engines were based on articles of medical and scientific journals.

Table 1. The electronic engine search

ELECTRONIC SEARCH ENGINES	Potential sources	Non potential sources	Sources with easily identified articles	sources with purchase articles
ELSEVIER	x			x
OVID(laurea journals)	x		x	
EBSCO(Cinahl)		x		
EBSCO(Academic search elite)	x			

In the above article, X is used to mark the results of the search. It also shows the potential sources, which are beneficial to the study; most of the articles from these search engines had available text, the ranking of some articles were partially green and some were fully green. Full green ranking means the articles matched the search words that were applied, partial raking articles did not necessarily match search words. The non-potential sources had good titles with key words that matched the search words but the articles did not have available text. OVID (laurea journals) was the most potential source because the articles were available; the titles of the articles that were potential to the study had the applied search

words highlighted with green, yellow and red colours for easy identification, and EBSCO(Cinahl) is rated non-potential because many of its articles did not have full text.

The search words were generated from the topic and purpose of the study. During the search, words were combined with “and” & “or” in order to get better results. Inverted comma’s were also used to recognise separate combined search words as one word. The search sites were Nelly portal and Books were loaned from the school library and University of Helsinki library. Articles were saved in Pdf format on memory a stick, NELLY, and email inbox. Out of the four search engines that were used, all four were accessible with the school computers while only three were accessible on other computers out of the school environment which was the OVID (laurea journals).

Search words:

Children’s palliative care and nursing support

Children’s palliative care and bereavement

Nursing support and family and bereavement

Nursing support and dying child or children’s palliative care

Dying child and bereavement and support to families

Table 2. The search results

SEARCH WORDS	ELSEVIER	OVID(Laurea´s journals)	EBSCO(cinahl)	EBSCO(academic search elite)	RESULTS
“Children palliative care” and “nursing support”	0	0	0	2	2
“Children palliative care” and bereavement	6	6	1	7	20
“Nursing support” and family and bereavement	39	13	2	42	96
“Nursing support” and “dying child” or “children palliative care”	17	11	2	11	41
“dying child” and bereavement and “support to families”	5	5	0	12	22

The figures presenting the search results in table 2 gives a total of 181 articles from all 4 search engines used in this review.

Table 2 shows the search results as in the amount of articles that each search engine provided when the various search words were applied. Only four search engines were used to conduct the search because the relevant articles to the studies found from other search engines such as SAGE, PUBMED, and OVID(Medline) were the same articles from search engines in the above table.

When “and” & “and”, or “and” & “or” were used to link three different search words, search engines gave less but most relevant results for example, search words “nursing support” and family gave 570 hits, the search word was refined by adding bereavement, the final results from ELSIVIER were 39 hits. EBSCO (Cinahl) 72 hits, the search was refined by adding and bereavement, the final results was 2 hits. With same search words, EBSCO (academic search elite) gave 446 hits, after the search was refined by adding bereavement, the final results was reduced to 42 hits. With OVID (Laurea’s journals), there was no need to refine search because the search engine had the possibility to run all three search words same time, giving it’s result just once. All four search engines gave a total of 181 articles.

### 3.2 Data screening

It is step three of systematic review which is the process of identifying what is relevant to the purpose of the study based on the inclusion and exclusion criteria (Khan K et.al 2002).The searched article were carefully assessed and placed in two categories, those that met the inclusion criteria and those that did not.

Table 3. The inclusion and exclusion criteria

INCLUSION	EXCLUSION
Previous studies in written English language	Previous studies not written in English language
Studies done between the year 2000-2011	Studies done before the year 2000
Studies that support the purpose of the study and answers research question	Studies that does not support the purpose of the study and research question
Scientific published articles	Non scientific published articles

After conducting the electronic search on Nelly portal, a total of 181 potential articles were found based on their titles and abstract. During screening, some articles were scrapped out based on the fact that the findings of the articles did not carry enough relevant information to support this study; as a result, the articles were reduced to 28 articles. A second screening

was conducted and the articles were narrowed down to 16 based on the realization that some of the articles were not journals, some articles did not made mention of research method applied in the study nor did they carry the year of publication. A third and final screening was conducted based on the inclusion criteria of this study and the number of articles was reduced to 6 articles, which were found to be highly potential to the intended study.

### 3.3 Data extraction

The aim for data extraction is to describe the general view of the study and to extract results from the retrieved articles in a consistent manner so as to allow later synthesis. It is also to extract information to enable quality appraisal so that the findings can be interpreted. Descriptive categories included in a review because of its relevance to the studies can be described, summarized and recorded as key words called key wording. Identifying certain aspects of their contents includes the topic, design, method, population of interest and so on. Data extraction must be conducted on full texts from retrieved articles based on inclusion criteria.

Quality appraisal is important in data extraction because it considers the validity, reliability and generality of each study's findings, examining the methodology that was applied in the study. Data extraction in systematic review should include a description of the final report in a table form, which briefly describes each study included in this study. The extraction process for all studies should be reported transparently in the review report, and the described table should be included in the main body of the study or in the appendices (Rutter, Francis, Coren, & Fisher 2010, 24, 47).

Data extraction was based on the purpose of the study, research question and screening criteria of the study, which guided the consistent extraction of data. The retrieved articles were carefully assessed by first reading the abstract to gain an insight to the content of the article. In some articles, the table of content helped facilitate thorough assessment of retrieving relevant material to the study in question from the findings of the article. Data was extracted from the abstract, findings and discussion of the chosen articles. The selected relevant articles were listed alphabetically and described in details in the appendix, listed on pages 29-31 of this study. The description included the author and year of publication, title, type of publication, purpose of the study, Method of data collection, and findings relevant to this study.

#### 4. *Data analysis*

Data analysis is stage five of systematic review (Klan et al 2002), where data and findings from different studies are brought together to answer the research questions (Rutter et al 2010, 58). An inductive approach is applied during data analysis of this study and according to Thomas (2003), there are three purposes of using an inductive approach, which are: to condense extensive and varied raw text data into a brief summary format; to establish clear links between the research objectives and the summary findings derived from the raw data; and to develop a model or theory about the underlying structure of experiences or processes, which are evident in the raw data.

The analysis process includes sorting, which means the researcher needs to decide on what is more important and less important in the data relevant to the purpose and research question of the study. The process also include inductive coding, which according to Thomas (2003), it begins with close reading of the text and consideration of multiple meanings that are inherent in the text. The researcher then identifies text segments and creates a label for a new category.

The second step was picking similar content and grouping them together, forming the first category. These grouped categories were named with titles that best describes them. For example, the articles described what it takes to know the child's family, how nurses act as advocates not only to the child, but to the child's family as well, and how to strengthen the relationship that exist between the patient, family and the nurse during palliative care. All three sub-categories were grouped together to form the first main category "family centered care".

The most important task in analyzing data is to be fully knowledgeable with the raw data that is to be analyzed. The best way in doing so is by reading the raw data several times in order to develop various categories from the data into a model of framework so as to identify key themes (Thomas 2003). The chosen six articles used in this study were systematically read repeatedly in order to establish its relevance to the research task. Important concepts were color coded while going through the articles for easy identification during categorization such as providing care with comfort, providing timely information, planning for anticipated needs, prepare families before difficult discussion, help make memories, referrals, help in negotiating needs, understanding, accepting and respecting grief, bereavement support services, families and so on.

The second group focused on the kind of communication skills needed when providing support to families, the effectiveness of information flow, and how guidance is executed through communication. After grouping together, these sub-categories were named "communication

as an important tool”. The next group was sub-grouped as comforting the families, families as part of the palliative care team, and family empowerment, giving the third main category “involving families in the caring team”. Furthermore, the fourth group was categorized as emotional support to families, maintaining bonding between child and family, and practical planning of care, all together categorized as “encouraging families in dealing with bereavement of the child”. All four categories were then linked to one category that relates to them and is also in line with the purpose statement and the research question of this study.

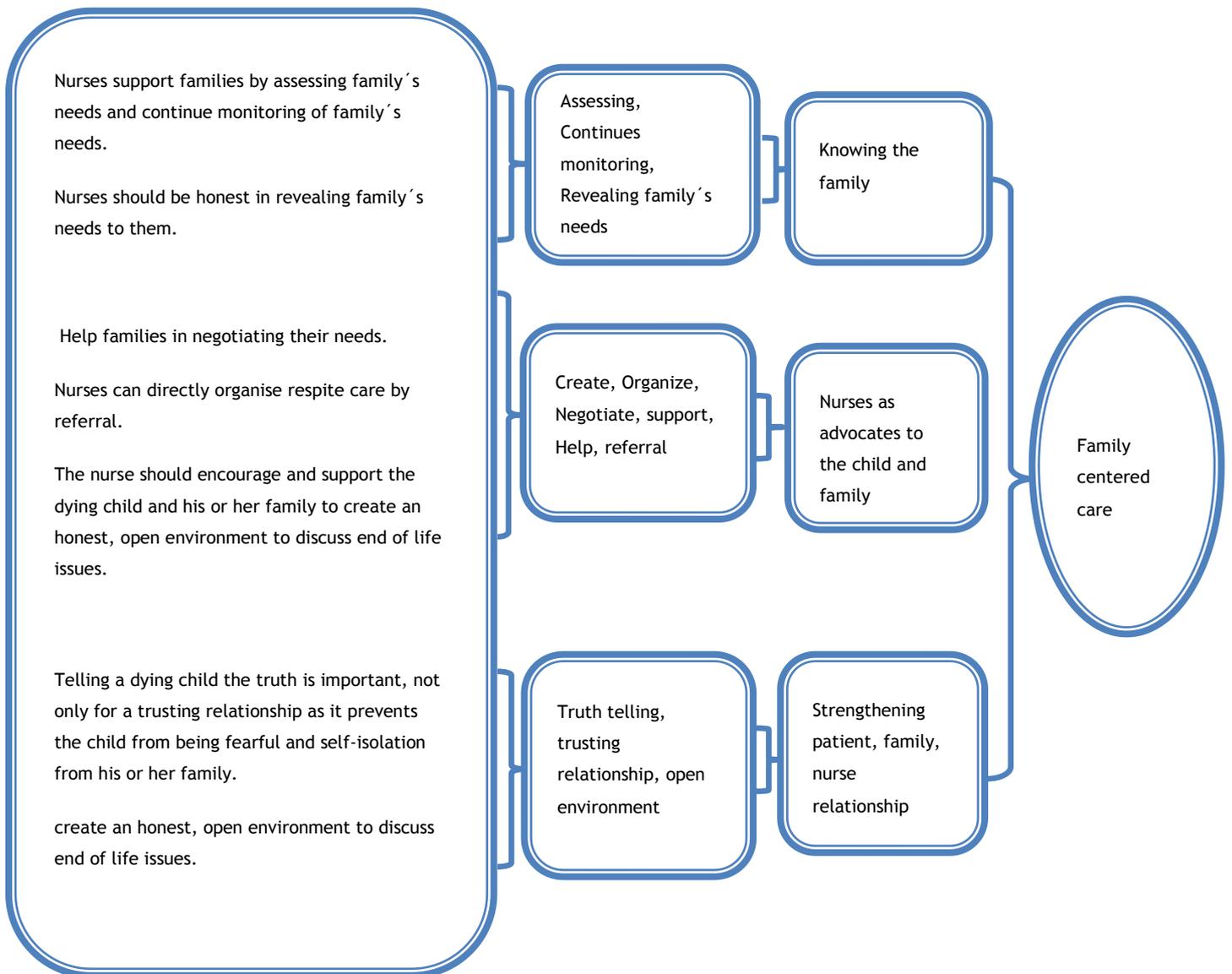


Figure 1. An analysis illustration of support to families during children’s palliative care

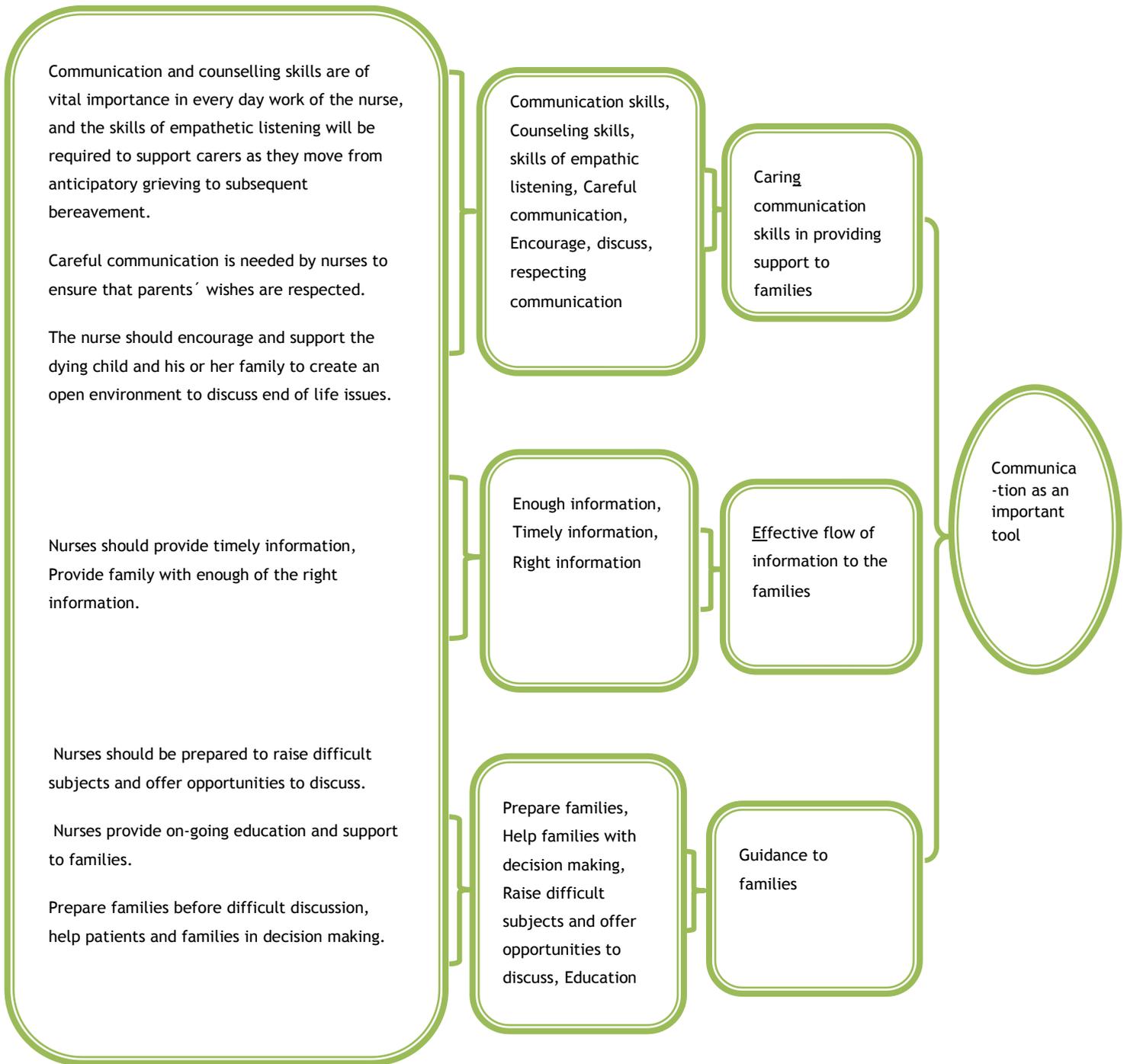


Figure 2. An analysis illustration of support to families during children's palliative care.

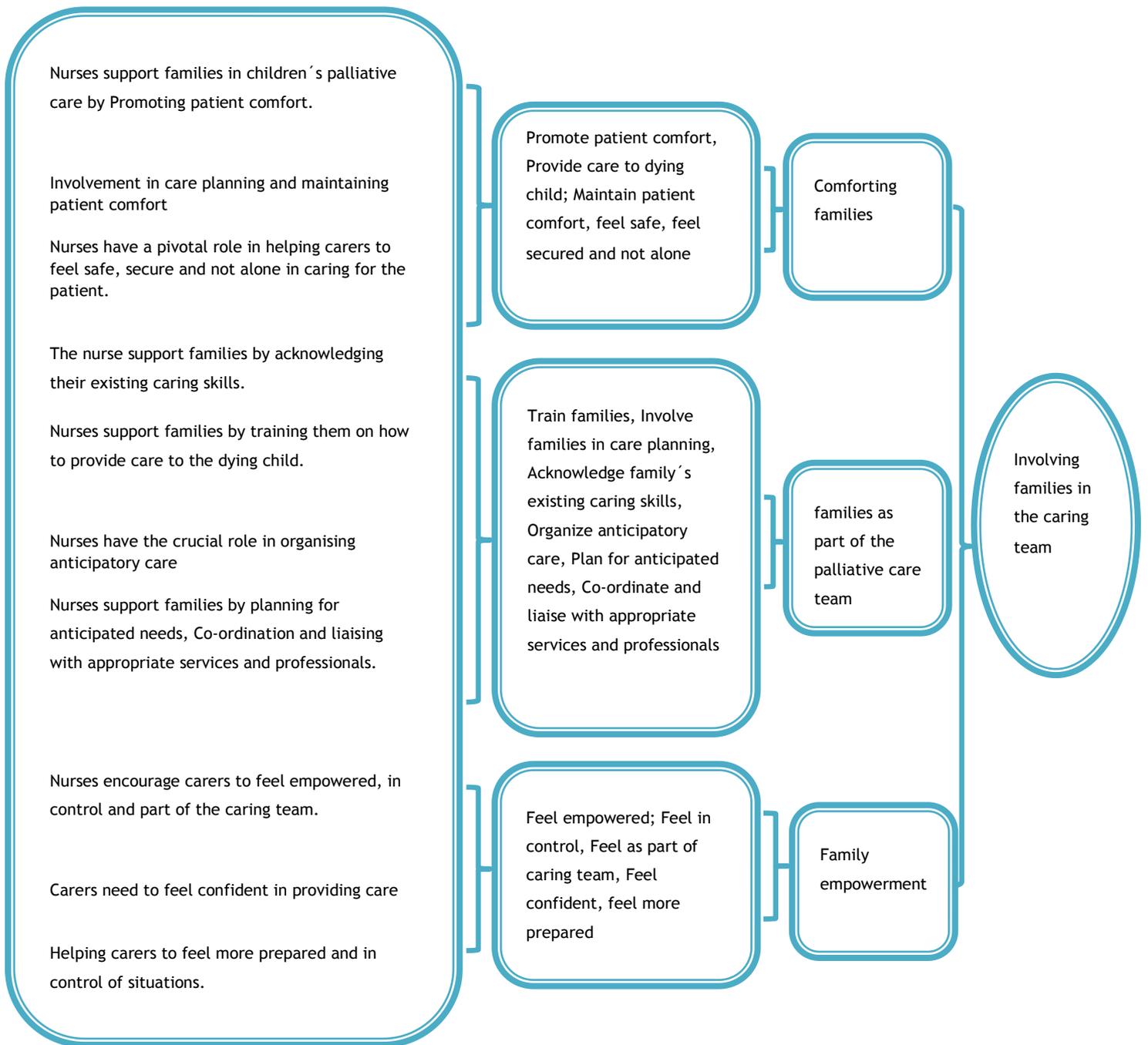


Figure 3. An analysis illustration of support to families during children's palliative care

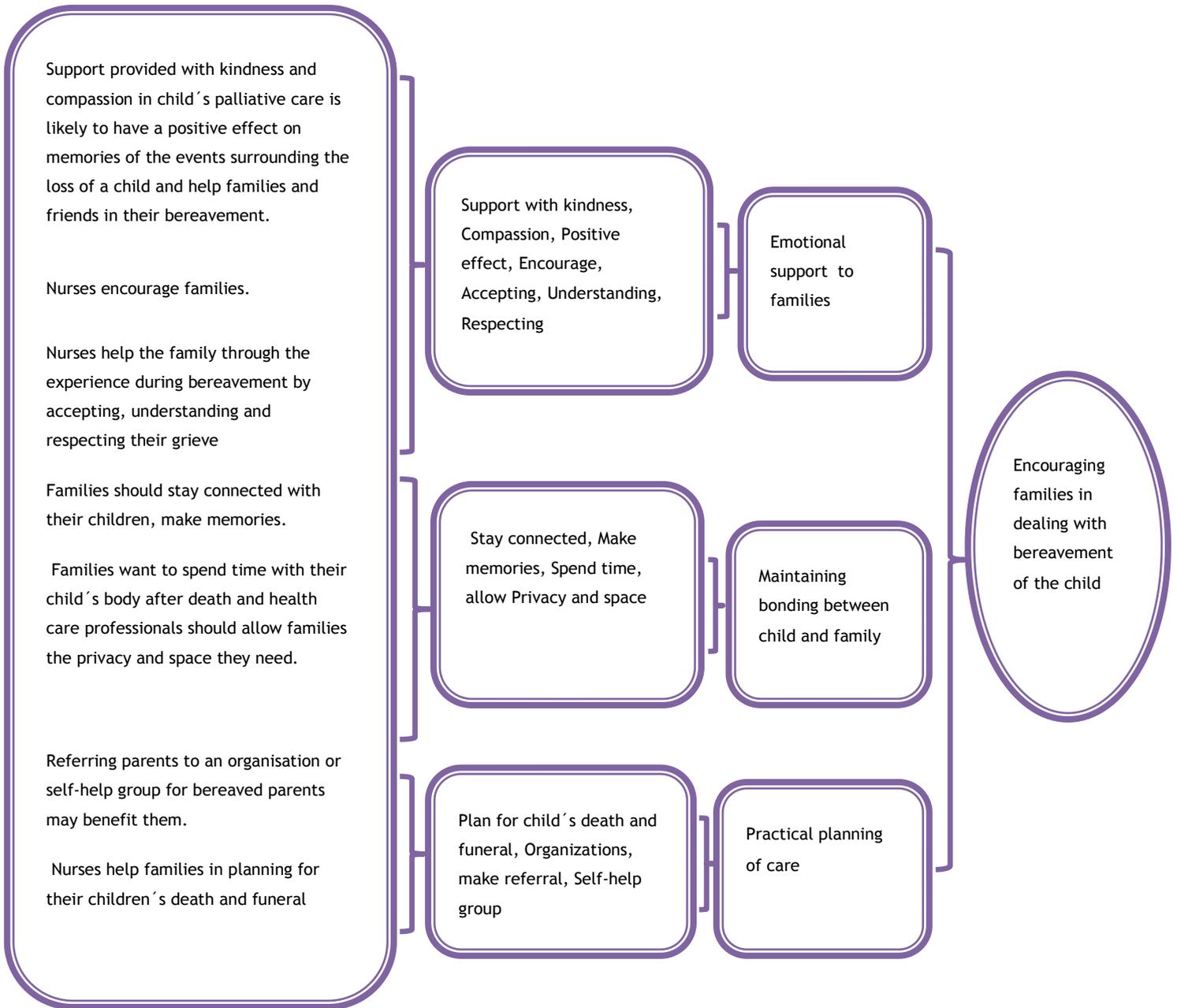


Figure 4. An analysis illustration of nursing support to families after bereavement of the child.

5. Findings

After the analysis process was completed, the final result emerged from the data was examined to make sure it corresponds with the purpose and also if it does answer the research question of this study. At the end of the analysis, four themes were identified; Family centered care, Communication as an important tool, Involving family in the caring team and Encouraging families in dealing with bereavement of the child.

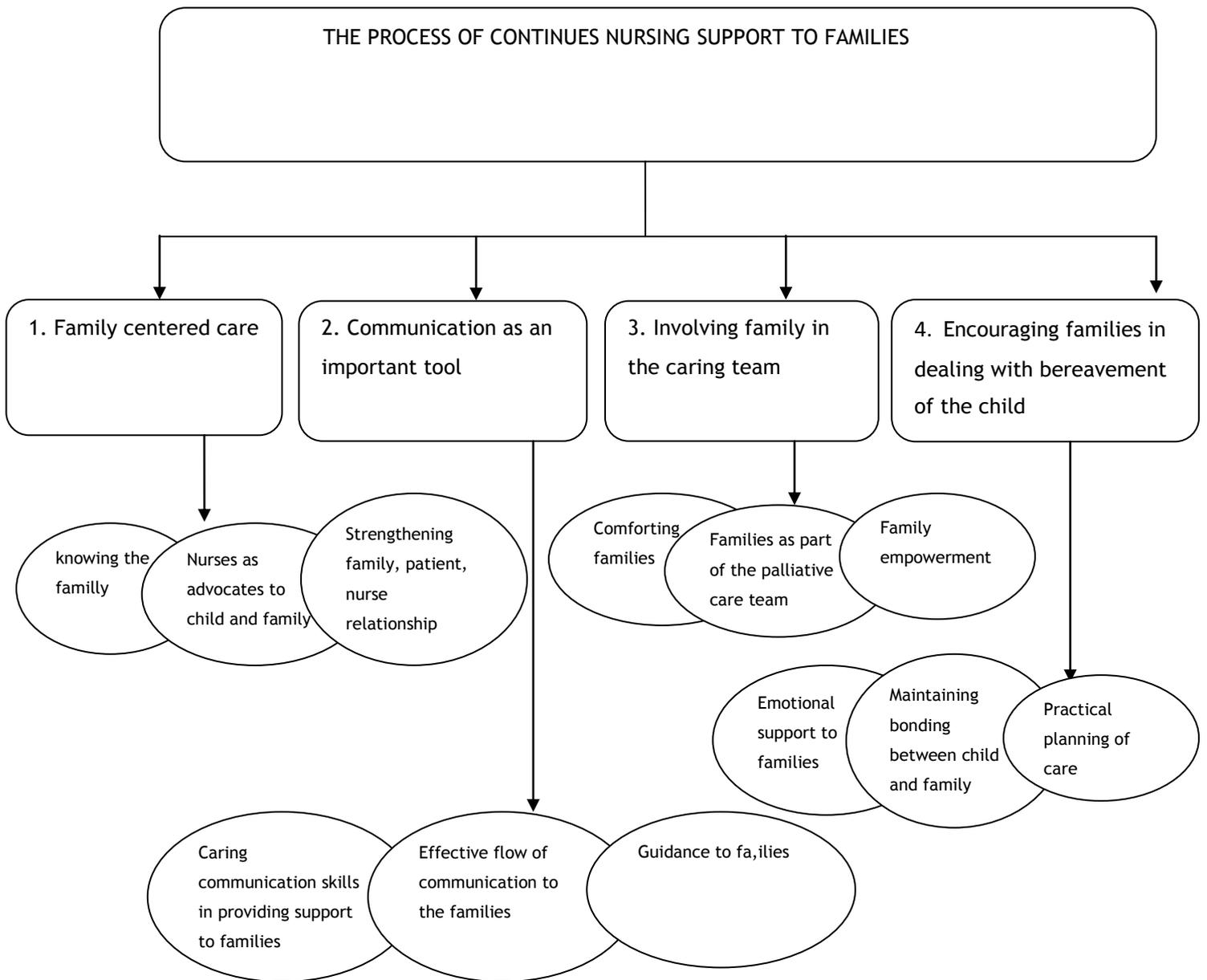


Figure 5. An illustration of main categories and subtitles

## 5.1 The process of continues nursing support to families

The process of palliative care begins when the doctor confirms the diagnosis of a child to be incurable and make the decision with the family to place the child under palliative care. The process includes providing nursing support to families of the dying child from the beginning of palliative care, which then continues till after bereavement of the child.

### 5.1.1 Family centered care

Family centered care means providing care not only to the dying child but also to the child's family as well. When a child is diagnosed of an incurable disease, palliative care is the best care to provide to the child because of its holistic approach to care. Relieving and preventing suffering is the goal of palliative care. A holistic approach in palliative care includes supporting children and families by helping them in achieving their physical, psychological, social and spiritual goals while maintaining sensitivity towards their personal, cultural, spiritual, religious values, believes, and practices.

### 5.1.2 Knowing the family

Providing family centered care includes knowing the family and their needs. Losing a child places a tremendous burden and stress on the family and families need support in dealing with the condition of their child all through palliative care and even after the death of the child. Nurses provide nursing support, thereby playing a vital role in providing family's needs as they are the core of support to the child and family giving the fact that nurses spend more time with the family and are the link between families and other multi-professional team members.

When nurses have a good understanding of the family's needs, it also expands nurse's tools on providing better care to the family including managing family's distress, which requires constant assessment and monitoring of the patient and family. In the course of providing patient care, nurses need to also assess family's physical and psychological symptoms such as; changes in behaviour, fatigue, exhaustion, loss of appetite, weight loss, disturbed sleep, confusion, anger, anxiety, worries, depression, guilt, loneliness, emotional strain, helplessness and grief.

Dying children suffer a great deal of discomfort as a result of pain and other physical and emotional symptoms that arises during the process of dying. Nurses need to be vigilant so as

to recognise symptoms such as nausea, anxiety and shortness of breath in order to act upon, there by easing the family's distress of watching their child in discomfort. After monitoring and assessing family's needs, nurses reveal these needs to the families, paying particular attention to the sensitivity and the appropriate use of language, as not all needs can be viewed by the family positively.

#### 5.1.3 Nurses as advocates to the child and family

Nurses advocate to child and family by creating an environment in which families can feel free in discussing their needs and issues that otherwise families will feel uncomfortable in discussing with the nurses. Nurses support families in helping them negotiate and organise their needs and make referral to other professionals who can provide support to families. Planning of care includes planning of area of care and such decision cannot be made by nurses or families alone. It takes a liaising effort from the nurses, other professional care team members and families to conclude such decision. Care planning also includes nurses bringing in support from other health professionals to deal with situations that are not part of their specialty or issues that nurses are not fully knowledgeable of. A good example is spiritual support, which can be provided by the hospital priest. Nurses can make referral for respite support to families that care for their dying child at home. Nurses should be honest with patient's families concerning their needs. All subjects being positive or negative needs to be brushed so as to support families in making appropriate decision on child's care, as well as negotiating family's needs.

#### 5.1.4 Strengthening patient, family, nurse relationship

The relationship between the child, family and nurses has a great impact on the quality of care provided to the child and his or her family. As mentioned earlier, nurses should be honest in providing care. In children's palliative care, families like to hear the truth about their child's condition and what to expect as the child's health deteriorate. Being honest with the family creates openness and trust making it easier for the family to discuss their personal feelings and needs with the nurses and in return can get support from the nurses. Nurses most often under estimates children's understanding of death and so nurses avoid being honest with them. Not telling a dying child the truth of what they might know will make it difficult for them to discuss their fears to nurses and their families. A dying child will act on the lack of trust by isolating and withdrawing themselves from his or her family there by placing the family under distress.

## 5.2 Communication as an important tool

Generally, communication is very vital in our daily lives, but in children's palliative care, nurses need to have special communication skills, mostly because emotions are involved. Families want to participate fully in providing care to their dying child, so they need to be well informed at every stage and that can only be achieved through communication. It is expected of nurses to take appropriate courses or studies in order to improve on their communication and counselling skills.

### 5.2.1 Caring communication skills in providing support to families

As the child's health deteriorates, so will the family's demand for information on how to deal with anticipatory symptoms increase. Giving the fact that families have the responsibility as the primary care provider, being well informed of the changes reduces their stress levels and anxiety. Nurses should ensure that the information they convey to the family should be done in clear language. The use of jargons and non-lay man language can lead to misunderstanding and confusion of the intended meaning. Caring communication means information provided should be understood and there should be trust between the parties involved. In this case the nurse, patient, family should establish a trusting and honest relationship.

Families undergo emotional trauma in children's palliative care and they cannot function well as child's primary care giver without counselling from the nurses. Nurses in children's palliative care are also required to have good counselling skills, which involves good communication skills, good listening skills including patience. Every family has a story to narrate regarding the long struggle of child's illness up till the palliative phase and they have the need to be heard as it might give them closure of their suffering, and even find healing. Failure of good communication with nurses and other health care professionals involved in caring for the child in general is considered one of the main reasons of family's negative experience of caring.

### 5.2.2 Effective flow of information to the families

In order to achieve quality nursing care and support to patients and families, a good communication flow needs to be established. Timing, environment and the manner of giving information to families are very important things nurses should pay attention to when providing information, as it has a great effect on how the content of the information can be interpreted by families. Nurses are known as the gate keeper to information, and so they must apply honesty and sensitivity in providing information, balance reality with hope, and separate sympathy from empathy.

Timely information is information that can help a situation provided beforehand, for example, when planning anticipatory care, nurses provide families with enough of right information on what to expect and how to deal with situations when they arise. For a nurse to have good communication skills does not mean that he or she has all the answers to the family's problems. It is the nurse's responsibility to be knowledgeable of other care services that families can seek for further information and support.

### 5.2.3 Guidance to families

Nurses support families by providing guidance to them as they undergo the palliative process with their dying child. As mentioned earlier, it is important for nurses to create an open, honest environment for families to feel free in discussing their needs. In doing so, nurses gain an insight into what families need and try to guide them in achieving these needs. Nurses should bring up difficult subjects that families are not able to initiate by themselves. Before raising such questions, it is very important for families to be prepared to discuss difficult subjects and it is the nurse's responsibility to ensure that preparedness in families.

As children are not old enough to make decisions regarding their care, their parents or legal guardians are in the position to do so but they need support from nurses in making these decisions. Families also need to make decisions regarding the kind of support they need in dealing with the problems they face due to the ill health of their child. Providing guidance to families requires on-going education which is established via communication and also requires good nursing communication skills to be able to convey information that can be understood.

### 5.3 Involving families in the caring team

As mentioned earlier, families usually want to be the primary care giver of the dying child, reasons being love and responsibility. Families are well aware that they lack the knowledge, experience and competence to assume a care giving role but they are very willing to learn in spite the emotional roller coaster and physical stress they will endure in the process. Nurses have the full responsibility to support families in assuming the role of a primary care giver, in doing so; great consideration should be given to family's culture, religion and believes as well as goals and wishes.

Nurses should carefully assess the level of family's wishes to be a part of the caring team to make sure that they don't feel forced to take on the caring role. It should be voluntarily because not every family can handle the task. Some families don't ask difficult questions such as child's prognosis, or the palliative care process but that does not mean they are not interested in being a part of the care team. Sometimes the nurse needs to initiate the idea and then assess the family's level of interest rather than assume they are not interested. Nurses should also assess the family's ability to care for the patient no matter how badly the family wants to assume the responsibility, as it has a paramount impact on the success of nursing interventions.

#### 5.3.1 Comforting families

Comforting the family is a very important aspect of support that nurses needs to pay attention to in children's palliative care. Providing quality care to the dying child by promoting their comfort impacts families' wellbeing. Poor care influences families' perception of care thus increase families distress. Families obtain comfort in watching or knowing that their child is being cared for with kindness and compassion.

Palliative care to the dying child in a hospital environment allows the families to be able to gain access to help round the clock, providing the families with some sense of security in knowing that there are nurses around to interfere if any unexpected changes arise in their child's health. For families that care for dying children in a home environment, they might feel in secured and alone in the caring process. It is important for the nurses to provide the families with enough information on where to get help if needed at any time of the day.

### 5.3.2 Families as part of the palliative care team

As part of the palliative care team, family members take on the role of providing all the basic care that the child needs such as comforting the child, showering, mouth care, dressing, feeding, moving, changing positions and transporting if needed, also in some cases administer pain medication according to prescription. When families are provided with concrete information on how to care for the child, they feel in control which contributes to the good quality care they can provide to the child.

Nurses should collaborate with families of dying children to create a nursing care plan, which will be executed through meeting sessions whereby patient care will be discussed and using appropriate paperwork. The purpose is for dying child and family's needs be anticipated better and assistance to be arranged ahead of need there by encouraging the family in assuming the caring role. During planning, the nurse should play the lead role in co-ordinating care. Nurses should learn to acknowledge carers existing skills, giving the fact that they know the child better than the nurses and the family has an inside as to how the child prefers to be cared for.

Nurses are responsible for planning and co-ordinating care in the process of training the family on how to care for the child. Nurses also need to recognize when the child's last hours are approaching so as to inform the general practitioner and family for them to start preparing for child's death. The caring team including child's family and other services needs to collaborate to implement already anticipated needs during the last moments of child's life on earth.

### 5.3.3 Family empowerment

Empowerment means increasing the strength of individuals or a group of people, being morally, physically, spiritually, emotionally and so on. Involving families to the palliative care team is a very important aspect of children's palliative care, basically because as mentioned earlier, families most often wants to be the ones to care for their dying child. In doing so, families are provided with the opportunity to spend more time with the child for as long as the child still lives. Training families on how to provide care and providing them with all the necessary tools needed in caring for their child is simply empowering the families. Nurses empower families by encouraging them in assuming the responsibilities of caring for the child; help them feel prepared by providing them with all the necessary tools that will allow them to feel in control such as educating them, training them, assisting them, which will in effect boost their confidence in providing care to their dying child.

#### 5.4 Encouraging families in dealing with bereavement of the child

Losing a child is a very painful experience for the family because it goes out of the normal rhythm of life where by children should live to bury their parents and not the other way round. Families need a great deal of encouragement from nurses and other support services in dealing with the loss of their child because it is a trying time for most families and most especially parents. Nurses need to use their professional skills in assessing the kind of support that families could need from them during bereavement. During this phase, families develop the tendency to lash out at nurses out of grief, frustrations and anger, and nurses need to act as a bouncing board and derive a coping strategy and give the family the support they need as professionals.

##### 5.4.1 Emotional support

Families start to grieve the loss of their child even before the death of the child, because they feel helpless, disappointment, and they already begin to picture life without the child, especially during the last days and hours of child's life. Nurses are in the best position to offer emotional support to families especially following immediate death of the child, giving the fact that a relationship had already been established making it easier for the nurses to reach out to the family during bereavement.

Emotional support provided to both dying children and families during palliative care has an impact on how families will relate to the nurses and how support will be received from nurses after bereavement of the child. Care provided with kindness and compassion when the dying child was still in palliative care has a positive effect on the family's healing process of the loss of their child. Nurses need to understand and accept the fact that different families have different cultures and beliefs. In doing so, they show respect to the families' values which in effect, affects the healing process of bereavement as well. There are several factors influencing the emotional impact of grief during bereavement such as individual's personality, social support, life experiences and spiritual beliefs.

#### 5.4.2 Maintaining bonding

It is very important for families to maintain a close relationship with their dying child during palliative care as it is also one of the factors that help recovery after bereavement of the child. Families caring for their dying child during palliative care helps foster this bonding that will last until after bereavement of the child. Nurses encourage families to make memories during this time such as taking pictures, videos, finger prints or foot prints of the child, lock of the child's hair and taking part in fun activities together. When the child passes away, nurses should provide support to the families by providing them with space and time to pay their last respect to the child and to say their goodbye. A good example of providing space and time is to leave the family alone with the child in the room, avoid immediate discussion of the next step such as funeral arrangements and so on.

#### 5.4.3 Practical planning of care

After seeing and spending time with the child's corps, families need to start planning the funeral. Nurses need to encourage families by making necessary referrals and provide families with information of the different services that they themselves can contact if the nurse cannot do it for them. Every family experience's grief differently, some come out of it and some never do. Nurses make referral to appropriate support services after thorough assessment of the family's needs. Some families need marital support and they can decide to attend counselling individually or as couples. Gender plays a role in grieving, fathers are notable for not expressing their grieve mean while it gradually eats them up and in effect affects grieving process and subsequently healing, so fathers are in high need of marital support or other support groups.

## 6. Ethical consideration and Trustworthiness

Fitz (2008) defines ethical consideration as Ethical principles guiding public health research built on a foundation of medical ethics, developed in the first instance to regulate the conduct of clinical research. This study is based on a systematic literature review, meaning no interviews needed to be conducted nor financial support was needed. Therefore, there wasn't any need for observation and questionnaires as part of the methodology due to the fact that no participants were involved. Privacy and confidentiality of names, identity, conflict and harm were not taken into consideration neither was the protection of raw data.

Ethical consideration was taken into consideration during data collection, screening and analysis based on systematic literature review as a method and laurea's thesis guide lines. Direct quotations were applied and credited for by accurately referencing them according to the laurea's thesis guidelines. There are no references in the findings based on the fact that the findings are an interpretation of the raw data.

The findings of this study will benefit not only the nurses in children's palliative care but nurses in general because in nurses daily professional lives, they will at one point encounter the death of a child or an adult, and the nursing support to families described in the findings of this study is also applicable in a non-palliative care situation. Nurses need to be aware of the kind of support they need to provide to the patient's family if they ever encounter such tragedy.

The aim of trustworthiness in a qualitative analysis is to support the argument that the research findings are "worth paying attention to" (Fenton & Mazulewicz 2008). In this study, the articles that were reviewed provided good descriptive support that nurses provide to families during children's palliative care, thereby supporting the purpose and answering the research question of the study. The trustworthiness and validity of the findings and discussion is based on the fact that the articles used in this study have been reviewed and published in medical journals. The process of a systematic literature review includes, data used in the review must have been published in a trusted site such as academic databases. The articles used in this study can be trusted because they were downloaded from Laurea University of Applied sciences data base known as Nelly portal. All articles carried titles relating to the topic of this study, names of publisher/publishers, dates of publication, the volume, number, pages, abstract and the methodology of the articles, qualifying them as journals.

## 7. Discussion of thesis findings and Recommendation

According to Pearson (2010), parents do not expect to outlive their children, and to face the death of a child is most parent's worst fear. When a child is placed in palliative care, it puts a tremendous stress on families and this review is focused on the type of support nurses provide to the families throughout their journey from diagnosis to post-bereavement and after the death of the child. Caring for a dying child is one of the most challenging tasks nurses have to encounter in their career, considering the fact that care is not only provided to the dying child, but to the dying child's family as well (Pearson 2010). Children requiring palliative care are a very diverse population, less than half have malignancies, and the remainder has a range of often rare conditions, including congenital abnormalities, chromosomal disorders and neurodegenerative disorders (Rallison 2004).

Statistics of children's death that undergo palliative care is based on cancer only and the rest is general statistics including those that died of curable disease due to lack of proper care or resources to care for them. According to WHO (2005) statistics, 160,000 children are diagnosed with cancer per year, and about 90,000 are said to eventually die of cancer. For children under the age of five, 7, 6 million died in 2010 caused by infectious diseases with pneumonia as the majority cause.

There are several approaches in providing care and support to dying children and their families, and it takes a multi professional team to provide adequate care and support. The findings support the fact that nursing support is one of the main sources of support in caring for dying children and their families because they are the patient's advocates (Pearson 2010). During children's palliative care, families usually want to be the ones to care for their dying child, but total care of the child cannot be achieved without the support of nurses and so, it is the nurse's responsibility to involve the family to the care team (Eyre 2010).

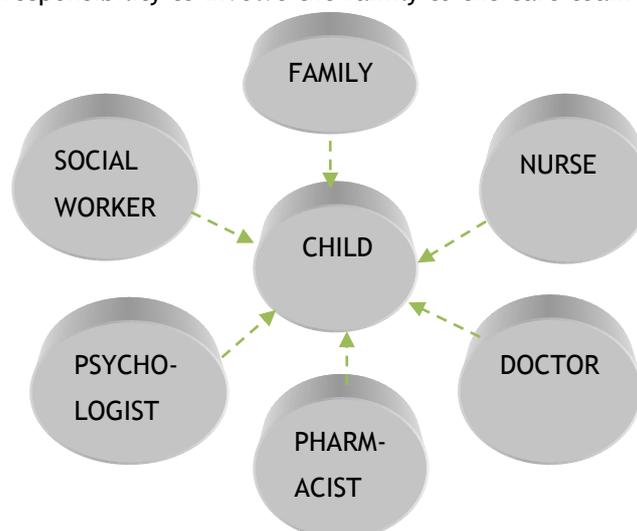


Figure 6. A chart illustrating the palliative care team

The findings also support the fact that nurses should recognize their limitations and know when to involve other health care professionals that can also help in providing the families' needs such as, support groups, social workers and respite care. Respite care is provided mainly to families that care for the dying child at home, so that families can take a break from care and attend to their social life (Eyre 2010). In order for nurses to successfully ensure total care to families, care needs to be provided from a holistic approach, nurses need to understand the fact that different families have different values, beliefs, religion and cultures. All four concepts influence how the patients and their families perceive the care that is being provided to them, so as a nurse, it is very important to take the patients and family's personal values, beliefs and culture into consideration while providing care (Pearson 2010).

Lack of nursing support from nurses could have a profound effect on family's health, quality of life and subsequently to the quality of care provided by families to the dying child, thereby not achieving the goals of palliative care, and also bereavement outcome. The impact of lack of nursing support to families includes physical burnout from continuously doing all the physical demands without taking a break, social, psychological, and emotional stress. Families also need bereavement support to be able to deal with their loss. According to the findings, women deal with loss better than men because they have the tendency to be open and discuss their losses with friends while men will carry on with their daily lives pretending everything is normal meanwhile it is gradually eating them up inside. So, marital support is very important to spouses especially the men or fathers during bereavement of the child. Group support is very important as well as bereaved families come together every now and then to share their experiences thereby gaining closure (Pearson 2010).

During the search for articles, it was very difficult to find articles that have a good description of nursing support to families in children's palliative care. Researchers emphasized on the point that children's palliative care services to families are underdeveloped and most research has been focused more on adult palliative care to cancer patients than palliative care of children (Rallison 2004). Death has no exceptions nor age limit, and other studies agree on the fact that families of children in palliative care need a lot of nursing support and so, it is highly recommended that in the future, health researchers should pay more attention on children's palliative care in general and especially nursing support to families. Another recommendation is, nurses should be more involved in research so as to help develop nursing support provided to families in children's palliative care. This is due to the fact that they are the ones who spend more time with the families, making it easier for them to recognize the families' needs and are in the position to best describe what kind of support has been offered in the past and how nurses can improve on it. This thesis is going to benefit the nurses of the triangle hospital in general, by improving their knowledge on the kind of nursing support they can provide to families of dying patients, especially nurses in terminal wards.

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## Appendix

Author and the year of publication	Title	Type of Publication	Purpose of the study	Method of data collection	findings relevant to this study
Eyre. S. (2010)	Supporting informal carers of dying patients:the district nurse's role.	Journal of art & science end of life care.	This article explores the role of the district nurse in supporting family and friends who act as informal carers for patients who wish to die at home.	A literature review	The findings describe the kind of support district nurses offer to the families of dying patients.
Horsburgh. M, Trenholme. A, & Huckle. T. ( 2002	Paediatric respite care: a literature review from New Zealand.	Journal of palliative medicine	The purpose of the study is to review relevant international and New Zealand literature, policy documents and reports on respite provision for children who are dying and their families.	A literature review	The necessity of respite care for children and their families. The interaction amongst the multidisciplinary team in the health care system, the impact of flexibility of services on families including appropriate medical and nursing support.

Author and the year of publication	Title	Type of Publication	Purpose of the study	Method of data collection	findings relevant to this study
Jennings. P. (2005)	Providing Pediatric Palliative Care through a Pediatric Supportive Care Team	Journal on pediatric nursing	The purpose of the study is to describe the types of palliative care support to children and families offered by St. John's hospital pediatric supportive care team.	A hospital was used as an environment for conducting a survey and a case study was applied to the research.	The findings describe nursing support to dying children and families in hospital and home environment. The responsibilities of the general care team including nurses. The goals of palliative care.
Knapp C.A, Contro N (2009)	Family Support Services in Pediatric Palliative Care	Sage publications	The purpose of the study is to describe what is known, and more importantly what is unknown, about research on pediatric palliative care support services	Literature review	The findings describes medical staff's support especially nurses' support to families on different levels of child's care including support and support services to families after bereavement of the child.

Author and the year of publication	Title	Type of Publication	Purpose of the study	Method of data collection	findings relevant to this study
Pearson.H (2010).	Managing the emotional aspect of end of life care for children and young people	A journal on pediatric nursing.	This article aims to explore the emotional aspects involved when caring for children and young people at the end of life stage.	A literature review	The findings describes important roles by nurses throughout the family's journey from diagnosis to post-bereavement
Rallison.L, & Moules.N (2004).	The Unspeakable Nature of Pediatric Palliative Care: Unveiling Many Cloaks	Sage publications  Journal of family nursing.	The purpose is to address the topic of palliative care and the unspeakable nature of the very practice of caring for children that are dying and their families.	A literature review.	The findings describe care provided by nurses to dying children and their families. Caring for dying children and families is an area of practice where nurses can make a difference, and this difference is built on relationship with children, families, and their care givers.