

# **Death and dying in children**

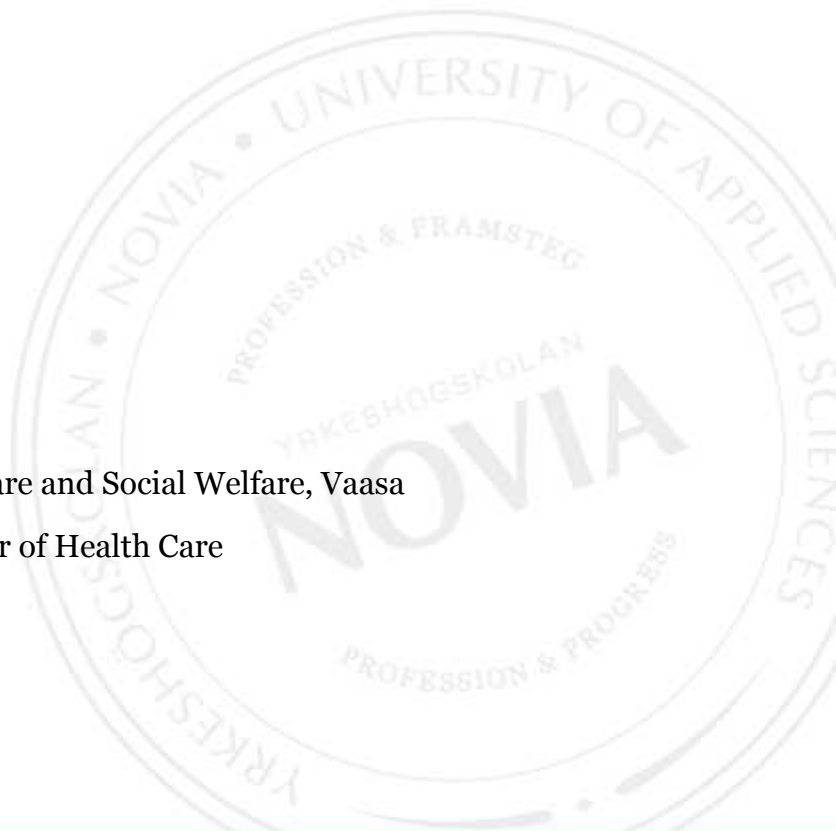
## **An empirical study about nursing activities during pediatric terminal and post mortem care**

Julia Kallinki

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Education: Nurse, Bachelor of Health Care

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## **BACHELOR'S THESIS**

Author: Julia Kallinki

Education and place: Nurse, Vaasa

Supervisors: Anita Ståhl-Levón & Ann-Helén Sandvik

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### **Summary**

The aim of this thesis is to disclose the current practices in pediatric terminal care and post mortem care for up to 12-year-old children in Finland. It also includes narration about how nursing professionals can support and care for the child and the family in culturally competent way in variety of different nursing environments. The goal is to discover similarities and differences between health care districts' ways to care for pediatric terminally ill patients, and to collect the best practices into a general recommendation for pediatric terminal and post mortem care.

This is a qualitative study made by content and constant comparative analysis with deductive approach. The theoretical framework chosen for this study is Kolcaba's *Theory of Comfort*. The data was collected from Finnish health care districts' pediatric units by a questionnaire. The participating units' answers illustrate the common practices for providing the pediatric terminal and post mortem care in Finland.

Results show that the pediatric terminal and post mortem care in practice is very similar to the recommendations published in literature, which indicates that pediatric terminal care in Finland is congruent and practical. Different health care districts provide pediatric care which varies in details, but focuses on the same nursing care actions. As planned, the study concludes in creation of recommendations for nursing care actions, narrating the compiled best practices in pediatric terminal and post mortem care.

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Language: English   Key words: pediatric nursing, caring, terminal care, post mortem care

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# OPINNÄYTETYÖ

Tekijä: Julia Kallinki

Koulutusala ja -paikka: Sairaanhoitaja AMK, Vaasa

Ohjaajat: Anita Ståhl-Levón & Ann-Helén Sandvik

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## Tiivistelmä

Tämän opinnäytetyön tavoitteena on kertoa pediatriksen terminaalihoidon sekä pediatriksen vainajan laitton nykyisistä hoitokäytännöistä alle 12-vuotiailla lapsille Suomessa. Lisäksi se sisältää selostuksen siitä, miten hoitotyön ammattilaiset voivat tukea ja hoitaa kyseistä lasta sekä hänen perhettään erilaisissa hoitoympäristöissä, kulttuurinen pätevyys huomioon ottaen. Tavoitteena on löytää samankaltaisuuksia sekä eroavaisuuksia eri sairaanhoitopiirien tavoissa tarjota terminaalihoidoa lapsille, ja koota parhaimmat käytännöt suositukseen pediatriksesta terminaalihoidosta sekä vainajan laitosta.

Tämä opinnäytetyö on laadullinen tutkimus käyttäen sisällönanalyysiä sekä jatkuvan vertailun analyysiä deduktiivisella tavalla. Tämän opinnäytetyön teoreettinen viitekehys on Kolcaban *Theory of Comfort*. Tutkimusmateriaali kerättiin Suomen sairaanhoitopiirien pediatriasilta yksiköiltä kyselylomakkeen avulla. Vastaukset kuvaavat yleisiä pediatriksen terminaalihoidon sekä pediatriksen vainajan laitton hoitokäytäntöjä Suomessa.

Tulokset osoittavat, että pediatriksen terminaalihoido sekä pediatriksen vainajan laitto ovat käytännössä hyvin samanlaisia kirjallisuudessa julkaistujen suositusten kanssa, mikä osoittaa, että pediatriksen terminaalihoido Suomessa on yhtenevää sekä käytännönläheistä. Eri sairaanhoitopiirit tarjoavat pediatrista hoitoa, joka eroaa yksityiskohdissa, mutta keskittyy samoihin hoitotyöhön toimiin. Opinnäytetyö päättyy suunnitellusti pediatriksen terminaalihoidon hoitotyön toimintojen suosituksen luomiseen, jossa kuvaillaan koottuja hyväksihavaittuja hoitokäytäntöjä pediatriksessa terminaalihoidossa sekä pediatriksen vainajan laitossa.

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Kieli: Englanti Avainsanat: pediatriksen hoitotyö, huolenpito, terminaalihoido, vainajan hoito

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# 1 Introduction

Death is a natural part of life, and care for a dying person is an essential part of nursing care actions (Eho, Hänninen, Kannel, Pahlman & Halila, 2003, 3; Saastamoinen, Hietanen, Juvonen & Monto, 2010, 218) even though people today tend to have forgotten the brutality of death as modern medicine succeeds to ameliorate illnesses and improve overall well-being in the world. It can be said that people do not die as often as in the past, and not due to the same causes, as nowadays many disease that was lethal in the past can be treated and cured with modern medical knowledge making the person live longer. Due to that significant improvement in life expectancy death of a young person is in these days often seen as a tragic event (Taipale, 1998, 231; Perkin, Swift & Raper, 2005, 133; Hänninen, 2006a, 19), being somehow wrong and gruesome even though before child's death was thought to be a natural part of life; sad but more or less common incident. (Korpi, 2010).

Yet again, no matter how often and in what age death occurs, it is still universal. According to Heikkinen, Kannel and Latvala (2004, 16) no matter how medicine evolves, people are still mortals. It should also be remembered that when there is no curative treatment available anymore, there is still much to do to make the person's life easier. Care for the patient still continues; the aim has just changed from curative treatments to best possible care to give and the best quality of life possible to have. (Pihkala, 2004, 351). Price and Gwin (2012, 420) announce that the person's final moments are just as important as the beginning of this person's life. This appreciation is shown by constant creation of new evidence-based guidelines for nursing care and continuous research about the end-of-life care during the past few years, i.e. recent guidelines made by Grönlund, Anttonen, Lehtomäki and Agge (2008), The Finnish Ministry of Social Affairs and Health (2011) and Käypä hoito (2012). Hovi and Sirkiä (2010, 3028) remind that the first guideline for pediatric palliative care in Finland was published already in 1985, and most of the thoughts presented in it correspond well with current guidelines. However, a good and easy death is nowadays defined by the dying person's own wishes and fears rather than by some general definition, as Hänninen comments. (2006b, 9). The guidelines are only meant to be the starting point for the individualized care plans.

As Price and Gwin resemble, the families will never forget the care for their dying child (2012, 415). Therefore end-of-life care should, beside of the medical focus, also focus on psychological, social, ideological and spiritual problems the dying person might encounter. (Iivanainen & Syväoja, 2012, 154). Even though palliative care and end-of-life care have

been researched a lot lately, I have not found much literature or studies focusing only in the final days of life, when the death is expected to happen soon, as usually the studies concerned a longer time phase, like the whole palliative care process which can last for months. In Finnish this nursing care phase during the person's final moments of life is called *terminaalihoito* (Hänninen, 2006a, 19) which could be translated into English as *terminal care*, as it describes the terminality and shortness of the time phase well. This phase should be differentiated from *saattohoito*, in English *end-of-life care*, as the words vary in their meanings, the first one being shorter and the other being longer. In English a term *comfort care* is also often used, but as it can mean both palliative and the terminal care phases (The World Federation of Right to Die Societies, 2015) it does not suit my purposes in this thesis as good as *terminal care* does. I will therefore from now on use the term terminal care, meaning the last days and moments in a person's life.

Death has been respected by humans throughout the time, and the corpse has also been taken care of even after the death. Still today we continue performing these traditions and show respect to humanity and mortality with similar post mortem care procedures. In what comes to post mortem care nowadays in Finland, there are some hospital-specific guidelines instructing what to do after the patient has died (for example Etelä-Pohjanmaan sairaanhoitopiiri, 2012), but I have not found any general nursing guidelines available in Finland which are focusing only on children's deaths. Moreover, Bowden and Greenberg (2011, 585) have published a post mortem care procedure guideline for child patients, like Lähteenoja and Laine (2004, 459-460) as well as Robbins and Mascrop (1995, 95-97). Since there is information available, it should not be too difficult to use it for general good. With no doubt nursing professionals in Finland would approve and use new, common and detailed instructions and scientific research about terminal and post mortem care in pediatrics if they only were available. Both of those nursing actions are important caring situations that should not be underestimated. Single pediatric units may have their own guidelines, but there is a need for specific, general guideline for child patients in terminal care, which could be used in all Finnish pediatric departments, instead of every ward having their own recommendations.

## 2 Aim and problem definition

The aim of this study is to disclose the current practices in pediatric terminal care and post mortem care for up to 12-year-old children in Finland; including narration about how nursing professionals can support and care for the child and the family in culturally competent way in variety of different nursing environments. The intention is to clarify what nurses need to think, ask and observe when caring for a child in terminal care. Focus is also on determining how nurses can take into account different cultures and religions while giving this care, because beliefs will with no question affect the child and the family. The study will examine how literature describes the general practice guidelines that should be used in children's terminal and post mortem care and how the pediatric units really take care of these children in real life situations. The goal is to create comprehensive and public recommendations for nursing care actions in pediatric terminal care and post mortem care to be used in Finnish pediatric care units, because there seems to be no profound general guidelines available about the topic.

The research questions for this thesis are:

1. What nursing actions are included in pediatric terminal care and why?
2. How do nurses in pediatric terminal care support the dying child and his/her family?
3. What do nurses need to acknowledge when giving culturally competent care in pediatric terminal care?

## 3 Theoretical framework

The theoretical framework chosen for this study is Kolcaba's Theory of Comfort. Comfort care describes what kind of actions nurses should establish to ensure patient's comfort in all levels and aspects of comfort. Theory of Comfort is a mid-range theory in nursing sciences. Kolcaba (1994, 1179) described that comfort exists in three different forms; *relief*, *ease*, and *transcendence*, meaning that comfort is actually a holistic outcome. In addition, according to Kolcaba and DiMarco (2005, 188), comfort is thought to be more than just absence of discomfort.



The Comfort Theory is built on three assumptions; that humans have holistic responses to different external stimuli, that comfort is a wanted outcome especially in area of nursing and that humans strive to meet basic needs, including comfort. (Kolcaba, 1994, 1178). The theory consists of two dimensions, first one defining the three states mentioned earlier and the second dimension narrating the contexts in which comfort occurs; physical, psycho-spiritual, social and environmental. For example, when a patient's comfort need, such as distress due to lack of oxygen, is met by giving extra oxygen with oxygen mask, we are comforting the patient in *the relief* sense of comfort. Comfort is an immediate and desirable outcome of nursing actions (Kolcaba, 1994, 1183), although requiring constant assessment of the patient's comfort levels and evaluation about the nursing care plans' effectiveness (Kolcaba & DiMarco, 2005, 187). Overall, the Comfort Theory is very usable for pediatric care as it is easy for professionals to understand and implement. Kolcaba and DiMarco (2005, 193) see comfort as an important part of peaceful death, which is the main reason why this particular theory is used in this study; in terminal care all dimensions and aspects of comfort have to be assessed.

Comfort care has been derived from Kolcaba's Comfort Theory, aiming to be a creative, effective and holistic model for individualized terminal care. (Kolcaba, 1995, 287). Comfort care means the comforting actions performed by a nurse to a patient, rising from the understanding that patients need comfort when in stressful health care situations. As known from Comfort Theory, some needs are met and comfort is gained, and some needs remain unmet, the desirable outcome being health seeking behavior or a peaceful death. (Kolcaba, 1995, 288).

Kolcaba (1995, 288) states that the person's comfort needs should always be estimated in the context of patient's experiences, including all physical, psycho-spiritual, social, and environmental dimensions. The nursing actions are implemented to meet the person's needs, leading to comfort care strengthening the patients, while their level of comfort is objectively assessed by the nurse (Kolcaba, 1995, 288), continuing with evaluation and moreover resulting in new care plans, including possible continuance of the same care, trying new caring methods and of course reassessing the comfort needs.

The aim of comfort care is to provide care that increases the patient's well-being above the earlier experience. When practicing comfort care by following those propositions, the nurse must remember that comfort care is holistic; meeting some of the patient's needs will have positive effect on the other unmet needs, creating an experience to the patient and

gaining comfort, even though not all of the needs were actually met. Giving comfort care can therefore be satisfying to the nurses, as meeting even one need will have an effect on the patient's well-being and ease the patient's suffering. However, without the desired outcome (*comfort*), the process of giving comfort is not ready and finished. Comfort increases the patient's performance, and it is also easy to measure at the bedside of the patient. In addition, comfort care is at the same time scientific and natural, efficient, easy to design, realistic, patient-centered, nurse-sensitive and transcultural. (Kolcaba, 1995, 288-289). All in all, comfort care is beneficial to be used in terminal care, since meeting even one need makes a huge difference to the patient's well-being. Kolcaba's theory is easy to remember and understand, and can be used by professionals but also by the family and close ones. The significance in both terminal care and Kolcaba's Comfort Theory is that by trying to meet the suffering person's needs; one by one, little by little we make a difference to someone's life.

## **4 Theoretical background**

This chapter deals with the different dimensions of pediatric terminal care by presenting information and guidelines learned from the literature. The aim is to examine the nurses' responsibilities and possible recommendable actions according to the literature.

### **4.1 Pediatric terminal care**

Pediatric terminal care may seem to consist only of nursing care actions, but it actually focuses also on providing the best kind of care possible in many different layers. For this, the care plan always follows certain values, such as family-centered care or honoring cultural diversity. Much is to be considered beyond the actual nursing care actions. The child should be given opportunity to live as normal life as possible even in the final stages of life. (Eho et al., 2003, 13).

#### 4.1.1 Definition of concepts

End-of-life care, palliative care and terminal care as concepts are somehow overlapping each other however they are used to describe slightly different kinds of treatment periods. (Heikkinen et al., 2004, 16-17). In palliative care focus is no longer in the improving the child's chances to live but in giving the child the highest possible quality of life under the circumstances as well as to minimize pain and suffering. This period could last from several months to even years. (Kübler-Ross, 1976, 114; Eho et al., 2003, 5; Lindén, 2004, 34; Hänninen & Anttonen, 2008, 23; Hovi & Sirkiä, 2010, 3027-3028; Henter, 2011, 162). The National Health Service (NHS) in United Kingdom (2015) define end-of-life care as support for a person in the last months or years of life, aiming to help the patient to live as meaningful life as possible, and to die with dignity. Palliative care is included into end-of-life care, although palliative care is not used only for dying patients. (The National Health Service, 2015).

As stated earlier, the focus in this thesis is more on the terminal care period, which means care given to a person who is presumably dying soon or otherwise near-to-death, focusing on not more than a couple of weeks at most. (Eho et al., 2003, 6; Lindén, 2004, 34; Vainio et al., 2004, 19). Terminal care's nature is similar to the end-of-life care and palliative care periods, and it might be somehow old fashioned term to be used (Vainio et al., 2004, 19) but at the moment terminal care is the most accurate term to describe the length of time of the caring period wanted to be studied in this thesis, and therefore the use of this obsolescent concept should be condoned.

Terminal care is not a clearly defined area of end-of-life care, and neither a separate area of study, as Hänninen and Anttonen (2008, 32) notify. They define it as variety of caring actions towards a dying person and his/her family members in his/her last weeks and days of life. (Hänninen & Anttonen, 2008, 32). Price and Gwin (2010, 415) mention some ethical principles in children's terminal care, which should include respect for the child's autonomy, confidentiality and non-maleficence among other desirable values. Heikkinen et al. (2004, 21) emphasize every person's right to die with dignity in a safe environment, receiving love and being pain-free. Most importantly, as Perkin et al. (2005, 10) underline, the pediatric patients should be recognized primarily as children, and only secondary as terminally ill patient.

#### 4.1.2 Psychological development and perception of death

Even the very youngest children realize their coming death (Perkin et al., 2005, 46-47; Hänninen, 2006b, 12). Kübler-Ross (1987, 23) states that all children know, if not consciously but intuitively, how their disease is going to end. However, children do not normally fear death in the same way adults do. (Varimo, Kaartinen, Leppänen, Warttinen & Määttä, 2004, 156). Children, like adults, approach death in very individual way (Price & Gwin, 2012, 417), although the child's developmental stage affects how much the child can understand about the actual concept of death. (Kübler-Ross, 1976, 117; Vilén et al., 2006, 452-453; Storvik-Sydänmaa, Talvensaari, Kaisvuo & Uotila, 2012, 294). The individual works with the perception of death for long, as death is not clarified or resolved over lifetime as other problematic periods, such as puberty or aging. (Taipale, 1998, 231). That being said, the terminally ill child's understanding about death can however differ from the average in that age group as the terminally ill children seem to mature faster than others in the same age. (Perkin et al., 2005, 46-47; Grönlund & Huhtinen, 2011, 83).

Newborns feel holistically; they do not differentiate emotions or crave anyone. A good basic care and closeness are usually enough to ease the baby. (Ivanoff, Kitinoja, Rahko, Risku & Vuori, 2001, 299). Children under 3-years-old have still hardly any understanding about the concept of death, even though they might feel it is coming; they do sense sadness and anxiety around them, and they can notice if a person important to them is missing. They feel pain and discomfort. Children in this age also absorb feelings, both positive and negative, and can react to negative emotions with irritability and eating problems. Abandonment and separation are the worst fears of a child in this age, although they do not have the fear of actual death. The child can best be helped by supporting the parents to face the child's death calmly, passing the calmness to the child. (Kantero, Levo & Österlund, 1996, 157; Lähteenoja & Laine, 2004, 453; Henter, 2011, 163).

From the age of 3 years the child understands death as altered state, but understands it as reversible, as if the person just went somewhere and is coming back or that broken things, even humans, can be replaced with new ones. Seeing the death as a place where they can come back is helping them to handle the fear of death. Abstract concepts are still difficult to understand. From 3 to 6 years of age this understanding is developing, as understanding of own body. Pain remains to be one of the worst fears, included with bodily mutilation. (Kantero et al., 1996, 157-158; Henter, 2011, 163). When the child reaches the age of four, the fear to be abandoned becomes greater than the fear to be hurt. To ease the fears parents

should be allowed to visit children whenever they want to. (Kübler-Ross, 1987, 98). The children can also be impatient when the illness is limiting their playing and free movement. (Kantero et al., 1996, 157-158; Henter, 2011, 163).

Under six-year-olds think the deceased can come back to life. (Ivanoff et al., 2001, 298). In about 5-6 years of age children start to understand that every living thing will die, that it is irreversible and in ages of 8-9 they will understand that they self will also die eventually. 12-year-olds have the same understanding about death as adults do, and they understand that death is eternal. (Perkin et al., 2005, 49; Henter, 2011, 163). This allows them to make more knowledgeable decisions, but greater understanding might lead to greater fears. (Price & Gwin, 2012, 418). However, a healthy school-aged child does not think of their own death; in their opinion death is for old people. When that child is ill, they naturally resist the idea of dying. If the parents react to death naturally and support the child, it helps him/her to deal with the issue better. (Kantero et al., 1996, 158; Grönlund & Leino, 2008, 42).

Children should be allowed to be involved in a conversation and information process according to their level of development. (Kübler-Ross, 1976, 117; Dominica, 1989, 120; Perkin et al., 2005, 51-52; Hovi & Sirkiä, 2010, 3027; Henter, 2011, 157). Over 12-year-old has to be heard when discussing about one's treatment. (Hildén, 2006, 70). Being informed also includes the family and siblings. (Grönlund & Huhtinen, 2011, 84). Adults still have the main responsibility over the situation and right for decision-making (Kübler-Ross, 1976, 115; Perkin et al., 2005, 8; Hannikainen, 2008, 11-18) when the child is under 12-years old. (Hildén, 2006, 54, 70; Mannerheimin Lastensuojeluliitto, 2015). Professionals' task is to consider the child's best interests, if the parents' point of view is in serious conflict with the medical point of view.

Denying the inevitable death as well as omnipotence are normal reactions in children. (Grönlund & Huhtinen, 2011, 87). It is important that the child has as much control over him-/herself as possible. However, offering a choice, when there is none, is not recommended. The child should be taken into the decision making as also children have the right for self-determination. In that way, children also gain some control over the situation, as usually ill children feel like they have lost all control of themselves to the disease or to adults. (Sinkkonen, 2004, 284). Discussing about the illness and prognosis gives an opportunity to see the child's honest reactions and decreases the risks for distrust between the child and parents. Honesty is absolutely necessary as children always need to

be able to trust their parents and the caring team (Kübler-Ross, 1976, 117; Kübler-Ross, 1987, 24; Sinkkonen, 2004, 284; Price & Gwin, 2012, 417-418), and they will notice if parents are trying to hide important information. (Kübler-Ross, 1976, 117; Henter, 2011, 157).

The child's level of understanding about death shows in spoken words, during playing and in drawings. For example, the child can draw birds, cars and other leaving-associated things, or play funerals. (Lähteenoja & Laine, 2004, 453). Playing is an action where the child can feel being in charge of his/her own life, and it also promotes joy, pleasure and can ease adjusting to the hospital and treatments. Playing is a way for a child to express and deal with thoughts, emotions and feelings. (Varimo et al., 2004, 154-155). Time and space must be given to expressions of fear and sadness. (Eho et al., 2003, 13).

Since small child cannot tell about his/her experiences, so the anxiety is showing in his/her actions. It should also be remembered that children react holistically to situations; they can even regress or develop somatic symptoms. (Sinkkonen, 2004, 278-279). Important is that if the child wants to talk about death, the staff should be able to talk about it, but the communication with the child should go on the child's terms. It is also recommended to write the child's words down so that they can be discussed about with the parents later on. (Lähteenoja & Laine, 2004, 455). Adults might see the child's thoughts as incongruous and macabre, but being part of the understanding process they should be allowed to be expressed. (Taipale, 1998, 232).

Adults often try to protect the child from pain and distress by avoiding to give the child as much information as the child would like to get. This leads to that the child feels being excluded from own care. (Robbins & Mascrop, 1995, 209). However, children are not small adults, and should be treated like they are; children. (Robbins & Mascrop, 1995, 132). Robbins and Mascrop (1995, 135) question the child's actual need to know about own upcoming death, though still honoring the child's a right to know about own prognosis. Interesting enough, terminally ill children tend to grow up mentally a lot faster than other children in their age as mentioned earlier. This is sometimes narrated to be a compensatory mechanism for their short life by developing inner wisdom and intuitive skills that adults have already in childhood. (Kübler-Ross, 1987, 23-24). All this makes it difficult for adults to balance between the child's right for both ignorance and knowledge.

### 4.1.3 Family-centered care

Families play a vital role in health and well-being of children (Perkin et al., 2005, 22), and therefore family centered care should be in focus in pediatric terminal care, not leaving out the possible siblings either. (Robbins & Mascrop, 1995, 132; Grönlund & Leino, 2008, 47-58; Hovi & Sirkiä, 2010, 3027-3031). Family-centered care results in better health outcomes and greater satisfaction. (Perkin et al., 2005, 22). Therefore, when taking care of a child patient the professionals are actually taking care of the whole family. Also, an ill child also needs his/her parents' presence more than s/he normally would. (Vilén et al., 2006, 338). Nurses should encourage the family members to participate in the caring actions and teach them how to perform the care, alone or with help from professionals, creating a supportive partnership between the caregivers. (Kübler-Ross, 1987, 24-26; Perkin et al., 2005, 22). Even the younger siblings can participate by braiding hair, reading a book out loud, help with feeding and play or listen to music together with the ill child. The older siblings can also be taught how to use suction or give nitrous oxide, if those are used in the ill child's care. (Kübler-Ross, 1987, 24-26).

As a part of family-centered care, nurses should encourage the parents to leave the bedside and support them to take time for themselves without feeling guilt; they, too, do need sleep, relaxation time and food, not to mention obligations to the siblings or even to work. (Kübler-Ross, 1987, 24; Robbins & Mascrop, 1995, 142). Iivanainen & Syväoja (2012, 155) agree, that supporting the dying person's relatives include ensuring that they remember to eat, drink and sleep, encouraging them to take part of the child's care and together going through the dying child's life and spend the final moments together as a family. Still, having a social life is not punishable. (Kübler-Ross, 1987, 24).

The siblings' reactions to the illness and eventually to death vary widely; they might feel guilt, anger, loneliness or withdrawal. Problems with school, eating and sleeping or somatic symptoms such as headache and nausea are common. (Sirkiä, 2006, 73-74). Moreover, the sibling's age, developmental stage, the relationship between siblings, parents' reactions and earlier preparation to death all affect to the sibling's reactions. (Sirkiä, 2006, 73-74). The siblings may also feel themselves attacked, especially if the palliative and terminal care periods last for long and if the parents seem to focus only on the ill child. The situation becomes worse when the dying child is in center of attention, and it may lead to jealousy of siblings as well as to feelings of neglect or reject, and sometimes even make the healthy siblings worry about their own health. (Sirkiä, 2006, 73).

Older siblings may feel ashamed about these feelings and need of attention and try to hide their true emotions. If these feelings are not recognized or managed properly, they may lead to behavioral problems such as enuresis, school phobia and depression. (Robbins & Mascrop, 1995, 137). The siblings should be given adequate amount of information about their ill sibling's status, as insufficient information leads to them being puzzled and not understanding what is going on, Sirkiä states (2006, 73), that the information of course should be given according to the siblings' developmental stages.

#### **4.1.4 Health care professionals and pediatric terminal care**

Families are expecting three main things from the pediatric terminal care; to see the staff members care about their loved one, to be at present when death occurs and to gain emotional support from the professionals. (Hänninen, 2006a, 20). However, nurses represent only one type of professionals participating in the care for a dying person (Grönlund et al., 2008, 3) as pediatric terminal care should be provided by multi-professionals teams (Lindén, 2004, 34; Perkin et al., 2005, 17; Price & Gwin, 2012, 416) consisting of nurses, physicians, psychologists, physiotherapists, priests, teachers, social workers and so on. (Hovi & Sirkiä, 2010, 3027-3031). The nurse's responsibility is to provide nursing care for the dying child, as well as offer guidance and support both for the patient and the mourning family. (Saastamoinen et al., 2010, 218). Naturally, the family can be best helped by supportive and emphatic nurses with good know-how and skills, and who are constantly educating themselves about their area of specialty. (Sirkiä, 2004, 292).

Being a health care professional providing terminal care is not an easy career, as the care of a dying person is very emotional and requires interpersonal skills, especially in pediatrics. (Iivanainen & Syväoja, 2012, 160). It demands flexibility and use of imagination (Dominica, 1989, 129), but on the down side working with own personality makes the nurse vulnerable. (Snellman, 2008, 102). Nurses should clarify their own thoughts about death and afterlife (Lähteenoja & Laine, 2004, 452) as self-exploration is perhaps the most important nursing action, because attitudes about death will affect the care provided. (Robbins & Mascrop, 1995, 4; Iivanainen & Syväoja, 2012, 160; Price & Gwin, 2012, 415).



Death does not affect only to the ill person and the family members, but also caregivers. Many health care professionals have identified their difficulty to face a dying person, and felt inadequate in front of him/her. Lack of words and skills leads easily to avoidance and urge to flee from the situation, preserving the taboo nature of death. Giving care that respects the individual values of the dying person is thought to be demanding and energy consuming. (Molander & Karisto, 1998; Perkin et al., 2005, 249-250). Death can bring up variety of emotions from the professionals, sometimes thought to be not acceptable for competent and skilled nurses. Recognizing own feelings help to keep control and remain as a professional even in the hardest situations, including the time of death, as the bodily changes occurring then may cause fear, disgust and anxiety. (Iivanainen & Syväoja, 2012, 160). Death also reminds of own mortality, which can be a devastating feeling to constantly work with. As the dying person usually needs closeness and warmth from the caregivers, they become attached to the patient. (Kübler-Ross, 1976, 122-123; Robbins & Mascrop, 1995, 4; Molander & Karisto, 1998).

Own anxiety can discharge as anger and hostile behavior towards others, and they may rise from feelings of inadequacy and failure as well as guilt, even though there would be no reason for such feelings. Blames coming from the parents are of course not helping the nurse's guilt. The pain will be even stronger if the nurse has own children in the same age or other similar situations going on in her live. (Kantero et al., 1996, 161-162). Having an open and respectful working environment, supporting active attempts of taking care of oneself and having conversations and feedback situations for the staff cannot be emphasized too much; the nurses need to get opportunities to actively work with the emotions and thought rising from the patient cases to maintain their ability to be professionals. (Kantero et al., 1996, 162-163). A good debriefing can ease the feelings and help to work with them after the patient has died. In a long run, no one is capable of caring for only dying patients. (Molander & Karisto, 1998; Keituri & Laine, 2012). No one can ever get used to a child's death. (Vilén et al., 2006, 452).

#### **4.1.5 Environment for pediatric terminal care**

Pediatric terminal care can be provided in different settings; at home, in hospital or in both of them, with shorter or longer visiting periods. Every family with a terminally ill child should have a possibility to choose their environment for the child's last weeks, and feel

that no matter what option they choose, they still receive the same care and support as they should. They also have the right to change the environment if the situation changes. (Heikkinen et al., 2004, 102; Sirkiä, 2004, 286; Perkin et al., 2005, 23; Hovi & Sirkiä, 2010, 3027). No one should have to live in facilities if seen unnecessary. (Perkin et al., 2005, 3).

Home care might be the happiest solution for the child, and even the shortest opportunities for home care should be used (Dominica, 1989, 113; Lindén, 2004, 34), as it is the most natural environment for a child to be, ill or not. (Kübler-Ross, 1976, 115; Perkin et al., 2005, 27; Vilén et al., 2006, 338). At home the parents become the child's main caregivers. (Sirkiä, 2006, 71). However, in home-care situation the parents still require much support from the professionals, and they should not be left alone. (Kübler-Ross, 1976, 115). For that parents will need adequate education as well as home visits by a nurse and maybe some borrowed equipment from the hospital. The parents have an opportunity to make a phone call and get guidance and support around the clock if the situation needs it. (Vilén et al., 2006, 338; Hovi & Sirkiä, 2010, 3027). Privacy has to be honored when doing home visits, and they are always agreed about with the parents. (Lähteenoja & Laine, 2004, 457-458). The hospital has the responsibility for the situation all the time once the child is admitted to a hospital, and home visits do not change that fact. (Dominica, 1989, 113; Lindén, 2004, 34). However, parents do still have the general responsibility for their child as the child is still theirs, not the hospital's, no matter what the caring environment is. (Varimo et al., 2004, 156-157).

Home care is justified when the death is approaching; the person's sense of security is increased when the surroundings are familiar, loved ones are close and when s/he knows that s/he can stay in the same place for the rest of his/her life without sudden changes. (Iivanainen & Syväoja, 2012, 154). At home the child's nutritional status might improve as daily preferences with food can be taken more into account. The attention from the professionals can be maybe more individual than what it could be in the hospital, where patients tend to be seen as a more homogenous group than in the home environment. (Robbins & Mascrop, 1995, 208). The ill child should not however be lifted into a pedestal, but be treated in the same way as the siblings. (Kübler-Ross, 1987, 24-25). The child still needs a recognized structure for daily life, even when there might be a temptation to overlook the child's negative behavior or to carry him/her overwhelming amounts of gifts, this often leads to child's increased bewilderment, as s/he needs physical and emotional love and strength more than material gifts, just as any child does. (Dominica, 1989, 126-127).

However, every family and their home are different, and sometimes the home is not the best place for terminal care, not only because of the distance to the hospital. (Kübler-Ross, 1976, 116; Sirkiä, 2004, 286-287). Also, the worst thing to do for the terminally ill child is to turn the home into a morgue even though the child still lives. Home care does not suit all, and also hospital can create a sense of safety for the family. A hospital is still always a facility, not an actual home. (Sirkiä, 2004, 286-287).

If the terminal care is taking place in the hospital, the aim is to give the child a familiar room in a familiar ward. The parents are supported to stay with the child as much as possible, and provide care for him/her with help from the professionals. There are no special visiting hours for a terminally ill child's family. If desired, the parents can also stay overnight and sleep in the room, which means that the room should be rather big and of course calm. All unnecessary bureaucracy is tried to be avoided and the situation is tried to be made as easy for the parents as possible. All caring situations are made as calm as possible, and the professional's unnecessary presence is avoided. Going to the room should not be feared, but personnel should not go there too often or without a reason. Some families want the presence of a nurse when the child dies, and some families want to be alone in the moment, and both of the wishes are equally acceptable. (Lähteenoja & Laine, 2004, 459; Pihkala, 2004, 351-352; Varimo et al., 2004, 151; Hovi & Sirkiä, 2010, 3027-3031; Soukka & Lehtonen, 2011, 60; Keituri & Laine, 2012).

There are also four hospices specialized into end-of-life care in Finland (Heikkinen et al., 2004, 19). However, according to the head nurses of Terhokoti, Koivikko-koti, Karinakoti and Pirkanmaan hoitokoti (personal communication, 9.6.2015) none of these hospices take care of pediatric patients.

#### **4.1.6 Nursing care actions in pediatric terminal care**

As being said, the care for the child does not end even when the active medical treatments are no longer being used. (Taipale, 1998, 233). Holistic pediatric terminal care includes taking care of the child's nutritional status, cleanliness of skin, secretions, pain and spiritual needs (Storvik-Sydänmaa et al., 2012, 295), but also fulfilling the family's different physical, emotional and spiritual needs and preparing the family members for the upcoming death. (Pihkala, 2004, 351). During the final days no unnecessary care should be done, as caring situations should not be a burden to the child. (Heikkinen et al., 2004, 116-

117). When the death is inevitable, the care plan focuses on good basic care. (Robbins & Mascrop, 1995, 88; Eho et al., 2003, 5; Price & Gwin, 2012, 417). Usually one (or several) personal nurse is named to the child. (Ivanoff et al., 2001, 300). The nurse is responsible for the basic care, but the family can participate in it. (Iivanainen & Syväoja, 2012, 155). Also the family's needs should be assessed by the nurse. (Dominica, 1989, 125-126).

A child with a terminal disease has actually a lot of caring needs; not only for physical care, but also emotional and spiritual needs with equal importance. (Dominica, 1989, 125-126; Hovi & Sirkiä, 2010, 3027-3031). A dying child has also often many symptoms which can increase with time. (Perkin et al., 2005, 128). World Health Organization (WHO, 2013) lists the symptoms which palliative care should be focusing on the terminal phase of life. Those symptoms are anorexia, anxiety, constipation, delirium, depression, diarrhea, dyspnea, fatigue, nausea and vomiting, pain and respiratory tract secretions. (Hovi & Sirkiä, 2010, 3027-3031; WHO, 2013). Physical needs of a dying child are pain management, management for symptoms and comfort measures. Psychological needs are anxiety, stress, guilt, anger, depression, fear of dying and grief. Small children can find it difficult to differentiate anxiety and pain from each other. (Perkin et al., 2005, 176). Social needs, often more on the parents' point of view, are financial and insurance concerns, but also role and relationship changes and social isolation. Spiritual needs include meaning, religiosity and sense of despair. (Price & Gwin, 2012, 417).

If the child is too tired or cannot talk, another way to communicate is tried to be found. Simple and effective ways to communicate are nodding, closing and opening the eyes and squeezing hands. (Iivanainen & Syväoja, 2012, 159). Nurses also need to evaluate the child's psychological level of understanding according to the child's individual age and experiences, examining if the child is able to talk about death and dying in a meaningful way. Nurses need to be able to identify the child's physical and psychological needs with help from the child's parents, as they know their child the best. (Robbins & Mascrop, 1995, 132). Additionally, in pediatrics the nurse's task is to listen rather than to inform the child, and to avoid lying. Letting the child direct the pace of the conversation, and admitting uncertainty is better than trying to answer unanswerable questions, as the child seeks for someone to share his/her feelings with rather than hearing complicated answers about unknown afterlife. (Robbins & Mascrop, 1995, 135). In addition, the smaller the child is the more significance touching has to the child's well-being, as physical intimacy makes the child feel safe. Holding the child in arms is therefore very important and encouraged. (Varimo et al., 2004, 153).

Good basic care includes taking care of breathing, nutritional status and fluid intake, secretion, cleanliness and appearances and analgesia until the very end. (Price & Gwin, 2012, 420). The nurse should make every effort to find the cause and cure for discomfort, even though it might be a sign of impending death. These problems might be a full bladder, dry mouth, constipation, or even uncomfortable position in bed. (Robbins & Mascrop, 1995, 89).

Shortness of breath can be a frightening symptom reminding of the coming death; the patient should never be left alone in that situation. Dyspnea is often caused by anemia, pneumonia, heart failure or simply by worsening of the disease process. (Price & Gwin, 2012, 420). Noisy chest sounds called death rattle occur due to building up of secretions. (Price & Gwin, 2012, 420). Helping the child into a better position, giving supplemental oxygen, opening the windows and ensuring adequate level of analgesia helps the situation to sooth down. (Sirkiä, 2004, 289; Iivanainen & Syväoja, 2012, 158; Price & Gwin, 2012, 420-421). However, the patient can also be unconscious at that time; then removing death rattle is done to ease the family. (Perkin et al., 2005, 199). Coughing is another symptom easily causing distress; the ill child may be disturbed by it, but mostly it annoys the family. The optimal care for cough is to treat the underlining cause. (Perkin et al., 2005, 194).

Poor appetite is often more of a problem to adults than to the child itself. Child should not be forced to eat, and artificially feeding the child is no longer of interest in terminal care. (Perkin et al., 2005, 193-194). Poor nutritional status might be caused by nausea or vomiting, overall decrease in appetite, dehydration, constipation or dysphagia. These can be either related to the progress of the disease, the slowing down of metabolism, or being side effects for medication. (Perkin et al., 2005, 182-183; Price & Gwin, 2012, 421). Terminal dehydration is a clinical status where the patient cannot drink adequate amounts of liquid anymore, which leads to dry mouth, fatigue and weakness, nausea and vomiting, confusion and muscle cramps. (Hildén, 2006, 56). However, slight dehydration in dying patient can be comfortable, as it leads to decreased urine output and fewer respiratory secretions. (Robbins & Mascrop, 1995, 88-89; Price & Gwin, 2012, 421).

Intravenous hydration or nutrition is usually not justified in the terminal care phase. (Sirkiä, 2006, 71; Vilén et al., 2006, 453). Proper mouth hygiene should not still be neglected. (Robbins & Mascrop, 1995, 88-89; Price & Gwin, 2012, 421). To tempt the child to eat some ice chips, popsicles and soft fruit sweets can be given to the child to suck, but only if the child wants them. Tiny pieces of pineapple can also be offered, the general

rule being that the food should be easy to swallow, sweet if the child prefers that way and cold, as it usually eases the discomfort the child has. (Robbins & Mascrop, 1995, 88). Plan a resting period before and after a meal, and encourage to different activities. Allow the child to spend time outside the room and be as active as possible, with help of wheelchair or bed as decrease in activity leads to weakness and constipation. (Perkin et al., 2005, 182-183; Price & Gwin, 2012, 421). Constipation should also be actively prevented and treated, as it causes unnecessary discomfort for the child. (Vilén et al., 2006, 453).

Skin care is also important. (Robbins & Mascrop, 1995, 88; Price & Gwin, 2012, 421). Decrease in activity and incontinence of urine and feces makes the problem worse. The child's dignity can be maintained by keeping the bed clean with new linens. Wound healing is difficult due to decreased circulation in peripheries; therefore preventing any skin breakdown is important. Manual handling of the patient, including positioning and turning the patient to reduce pressure is essential part of skin care. (Price & Gwin, 2012, 421) Possible wounds should be taken care of to prevent odors. (Robbins & Mascrop, 1995, 88). In addition to skin care, the eyes should be kept moist to prevent irritation and the nostrils should be kept as open as possible without irritating the mucous membranes too much by suction. Good dental hygiene is also important to prevent disgusting odors and flavors as well as encouraging the child to eat, as mentioned earlier. Lip salve can also comfort and ease talking and general well-being. (Robbins & Mascrop, 1995, 88; Sirkiä, 2006, 71).

Even though no curative medication is available, the use of palliative medications is possible. However, during terminal care no unnecessary injections are given, no blood samples taken or other examinations are performed. Any underlining chronic disease is taken care of in a way that it causes minimal harm to the child. (Vilén et al., 2006, 453). Blood products are given as long as the child's condition allows normal daily activities such as playing. (Sirkiä, 2006, 71). In some cases, cancer patients could benefit from palliative radiation and chemotherapy. (Käypä hoito, 2012). Withdrawing all unnecessary medications is done to minimize the risk for combined effects. Note that antibiotics may not give the person more time, but may alleviate the symptoms. (Iivanainen & Syväoja, 2012, 154-155). The intramuscular or the rectal route are seen offensive and causing unnecessary discomfort in what comes to administering medication, according to Price and Gwin (2012, 418), and those routes of administration should therefore be avoided, whereas oral route is desirable at all times. (Perkin et al., 2005, 139; Hovi & Sirkiä, 2010, 3027-3031).

Palliative care is all about alleviating symptoms, so medication should not be completely overlooked. Medications can be used to control nausea and vomiting, to keep eyes moist with artificial eye drops and to suppress cough reflex with morphine. Morphine also diminishes the feelings of air hunger, which is the sensation caused by dyspnea. Other medications can also be ordered to breathing problems, such as bronchodilators and even anxiolytics, Price and Gwin guide. (2012, 420-421). Also delirium, occurring for example in fever, should be prevented and treated (Vilén et al., 2006, 453) not to mention pain control. (Perkin et al., 2005, 147).

Analgesia for children is aiming for the child to be pain-free (Ivanoff et al., 2001, 299; Hovi & Sirkiä, 2010, 3027-3031). The challenge is that pain is always felt subjectively, and that also newborns do feel pain although they might not be able to communicate verbally. (Perkin et al., 2005, 135, 151). Accurate pain assessment is truly fundamental in pediatric nursing care and it should be performed at regular intervals. (Perkin et al., 2005, 151-152). Adequate amounts of pain medication are given, and the route is chosen so that giving the medication does not cause pain or discomfort. Since pain is an individual experience, the right medicine and dosage to alleviate the pain is not always immediately found. Information about the child's pain status should be constantly asked from the child him-/herself and from parents. Observing the child's body language, facial expressions, ability to move, sleeping pattern (intermittent, shallow, crying), and the characteristics of the pain (continuous/intermittent/when moving/differs by time of day) tell us much if the child cannot talk. Different scales can be used in addition to these observations. (Lähteenoja & Laine, 2004, 456; Iivanainen & Syväoja, 2012, 159). When the child is having pain, any unnecessary moving of the child is avoided. (Ivanoff et al., 2001, 299).

At first pain medication is given orally (for example paracetamol, ibuprofen or ketoprofen). When their effect is not enough anymore, stronger analgesia is given, often opioid derivate analgesics such as tramadol, methadone, fentanyl and morphine. Fentanyl patches are good for children's terminal phase pain as they release the analgesic efficiently and can be administered topically. It is the most suitable for situations where the child cannot swallow anymore but injecting is too painful. For cancer breakthrough pain, fentanyl can be administered to oral mucous membranes with special sticks covered with fentanyl, which is then smoothed to the surface. This is also a fast and effective way to administer analgesia, as the medicine is absorbed quickly from the mucous membranes in mouth and offers a fast relief to pain. (Lähteenoja & Laine, 2004, 455; Perkin et al., 2005, 135; Iivanainen & Syväoja, 2012, 154-155).

If other ways fail to relieve the child's pain, primary medication for strong pain is to give morphine intravenously. The dosage is always individual, and it is raised slowly to the level where the child is somehow pain-free. The dosage is also raised in long-term care where tolerance is developed. Continuous infusion by patient controlled analgesia infusion pump sets the base level for the analgesia; additional doses can be administered by the child or the adults when necessary. Bolus can be given also beforehand, for example before washing. Other pain medication should be used alongside. (Lähteenoja & Laine, 2004, 455; Hovi & Sirkiä, 2010, 3027-3031). It also has to be noted that addiction to pain medication is a behavioral and therefore a psychological problem, not a physical one. This kind of behavior is rare in children, not to mention being irrelevant in terminal care phase. (Perkin et al., 2005, 141).

Alongside with pain medication, complementary methods can be efficient in what comes to alleviating pain. (Perkin et al., 2005, 173-175). Relaxation techniques can be taught to the child to tense and relax different muscle groups. Also learning different breathing techniques can help. Distraction is used to draw attention away from unpleasant experience. Price and Gwin (2012, 418) suggest blowing bubbles with the child, as an example of distraction. However, the best and one of the most natural complementary methods is guided imagery, putting the child's inner ability imagine and play in good use. An example of guided imagery could be asking the child to imagine a vacation spot and to ask the child to describe how it is like in there. (Price & Gwin, 2012, 418). Lähteenoja and Laine (2004, 456) emphasize the power of simply talking about frightening things. Most importantly; being present in the room, playing and chatting with the child and comforting him/her makes a big difference in pain relief. (Lähteenoja & Laine, 2004, 456).

#### **4.1.7 Psychological support for the family**

Both the ill child and the family need psychological support during the terminal care period (Henter, 2011, 162) as the child's inevitable death is almost unbearable to comprehend. (Varimo et al., 2004, 146; Perkin et al., 2005, 228). Awareness of the impending death is affecting every family member's life in many ways, not least by the strong emotions that death brings up. However, those feelings and emotions have to be met and dealt with, with or without assistance from a nurse (Grönlund & Leino, 2008, 47-58), as we know that death of an own child could very likely to be the hardest possible thing that a person can



encounter in their adulthood, and that a person can never truly recover from it. (Sinkkonen, 2004, 283; Hovi & Sirkiä, 2010, 3030-3031).

Normally fear of dying is thought to contain many different fears; the fear of dying in pain, the fear of losing all bodily control, fear of losing dignity and fear of dying alone, as well as the fear for the actual process of death and the unknown. (Robbins & Mascrop, 1995, 84; Price & Gwin, 2012, 416). However a small child does not usually fear the death as much as abandonment, or the upcoming symptoms. (Sirkiä, 2006, 72; Price & Gwin, 2012, 417). Discussing about death with the child decreases tendency to depression and isolation. Adults should use the opportunity if the child shows willingness for a discussion about death or other topics. (Hänninen, 2006b, 12; Sirkiä, 2006, 72). Sometimes adults aim to protect the child from negative feelings and sensations that death brings up, but often end up isolating and leaving the child alone with own imaginations. A child senses rapidly that something serious has happened in the family, even though s/he might not be able to put it in words. Children's ways to express sorrow can seem odd to grown-ups, but are nonetheless as permissible and right as adults'. Trying to hide death from a child and protect him/her from sorrow may seem to be a good idea in adult's mind, however letting the child realize what is going to happen does not hurt the child but may help him/her to deal with the future. (Grönlund & Leino, 2008, 42).

Stress can lead to problems between the family members. The nurse should give time to handle the hard emotions and support the family members to show them and deal with them. (Robbins & Mascrop, 1995, 142). Most of the parents will face variety of feelings when their child is about to die. They might feel inadequate as parents, confusion about all that has happened, including anger, hopelessness and fear. They might feel guilty about their child's status and be still in shock about it and feel stupid or having lost control. (Dominica, 1989, 126; Robbins & Mascrop, 1995, 136; Perkin et al., 2005, 228-229). Guilt can arise from failure to recognize child's symptoms earlier, if the disease is hereditary or if the parents believe their actions have caused the child's distress. It should be noted, that these negative feelings can imprudently be projected on the nurse who still needs to remain calm, supportive and sympathetic. The nurse's aim is also to help the parents to rediscover their roles after the child's death. Nurse should also be alert to expressions of guilt or self-blame and help them to forgive themselves. (Robbins & Mascrop, 1995, 136-137). What parents actually need in that situation is to have someone who is able to function and be an adult beside them, supporting them when they are struggling. The best way to help is to ask

directly what kind of support and help the family wishes and needs. (Vilén et al., 2006, 452).

The nurse should remember that also the grandparents need support, as it is of course hard to see their grandchild dying, but also because they feel helpless when seeing their own child's huge sorrow. They can blame themselves for living a longer life than their grandchild. Although hospital staff usually takes care of only the core family, it does not demand much to guide the grandparents to get some kind of help also, if they are visiting the child in the hospital anyway. (Ivanoff et al., 2001, 301).

## **4.2 The Farewells**

Robbins and Mascrop (1995, 85-86, 94) listed some of the symptoms which often occur in the person's last moments. These include gradual loss of interest what is happening around, increasing restlessness, discomfort, agitation, plucking at the bed clothes, anxiety and fear, general weakness and signs of pain. Changes in skin color or vital signs come eventually, the eyes may be staring or glazed and the child may suffer from incontinence, feel coldness or have cold sweats and so on. Also the facial expressions can vary from fear to calmness. Price and Gwin (2012, 421) have listed similar signs of impending death, where the caregivers and the family members can anticipate the future.

The nurse should assure the child that crying, sadness, other emotions and also complete silence are all acceptable, no matter how confusing it might sound. If a child chooses to express feelings, an adult listener should be available. (Price & Gwin, 2012, 416). It should be remembered that children are aware of their pain status and sleepless nights, so do not depreciate their symptoms or try to hide them. (Kübler-Ross, 1987, 24). The child's fear of death can be devastating, but it can be alleviated by leisured presence and listening. However, the child might also need some time alone and that should be respected.

The last moment the child has should be allowed to be spent with the family alone, with siblings if possible. (Keituri & Laine, 2012). They could sing the child's favorite song, hold hands and enjoy the last moments together as a whole family. (Kübler-Ross, 1987, 26). Every dying person needs to know they made a difference in this world. Also children love to hear stories how they made an impact to their family and that they will be remembered. (Ivanoff et al., 2001, 300; Price & Gwin, 2012, 419). The nurse can

encourage the family to spend as much time together as they can. Even unconscious patients need presence of their loved ones, and hearing familiar voices may bring sense of safety. (Iivanainen & Syväoja, 2012, 159; Price & Gwin, 2012, 419). Though, no one can be forced to be with the child in the time of death. (Storvik-Sydänmaa et al., 2012, 295). If relatives are not with the child, a nurse should be there with the child or at least visit frequently, if it is not in any way possible to be there all the time. (Robbins & Mascrop, 1995, 94). A child needs to have a feeling that someone is close and that s/he is not left alone. (Ivanoff et al., 2001, 299; Sirkiä, 2004, 289).

Knowing that death is usually peaceful can give some comfort to the parents. The child does not have to suffer from pain, as analgesia is given in dosages that keep the pain away. (Vilén et al., 2006, 454). The child's condition weakens slowly, consciousness is blurred and his/her breathing becomes intermittent, leading finally into cessation of respiration and heartbeat. (Robbins & Mascrop, 1995, 94).

When the child has died, the nurse should straighten his/her legs and close the eyes to make the child look peaceful. The nurse also leaves the bed and surroundings clean and tidy and offers his/her presence if wanted. (Robbins & Mascrop, 1995, 95). The family is not left alone, if they have not particularly wished to be left in private. (Keituri & Laine, 2012). Parents and siblings are given time to stay with the deceased. It is important to allow the siblings to say farewells to their sister or brother, to let them see that s/he is pain free and does not suffer anymore, nor that his/her body or appearance has changed. A vital moment to begin the mourning process and adjustment is to state the death. The parents are allowed and encouraged to hold the child in their arms if that is what they wish. There is no hurry anymore. (Lähteenoja & Laine, 2004, 459; Sirkiä, 2006, 71-72; Keituri & Laine, 2012).

### **4.3 Continuance of care after the child's death**

Terminal care does not end in death; it includes the valuable post mortem care and support of the parents and the family in their sorrow. (Kübler-Ross, 1976, 122; Ivanoff et al., 2001, 298). In this chapter routines after the child's death are taken into examination.

### 4.3.1 Routines after the child's death

After the child's death the corpse is held in the ward for about two hours, so that the family has a possibility to say farewells. The family can stay in the room for as long as they want. Lighting a candle in the room is a beautiful way to honor the deceased, if the family's cultural and spiritual beliefs allow it. (Heikkinen et al., 2004, 118; Grönlund & Huhtinen, 2011, 170).

A common courtesy is that the doctor passes the news about the child's death to the parents if they were not present at the time. Also the person who was the last one to take care of the child should talk with the parents. (Saastamoinen et al., 2010; Keituri & Laine, 2012). Both parents should receive the information about the child's death at the same time, if possible. (Keituri & Laine, 2012). The parent's and the family's need for professional support should be assessed immediately and then continue by helping them with concrete things; do they have anyone to talk to, any place to stay for the coming night, would they like to get something to drink and could the professionals help them in any way. Making sure that the family gets something to eat and they have some kind of plan what to do next is also part of the care for the family. Everything that is said out loud to the parents should be short and clear, with compassion. Nurse's task therefore is to be the safe adult with logical thinking and comfort in the difficult moment. (Lähteenoja & Laine, 2004, 453). Only experience educates to act better and better in these situations. (Ivanoff et al., 2001, 307).

Parents are asked to give permission to an ordinary autopsy if it is considered to be a necessary examination. The parents are given the child's death certificate and information about the possible autopsy. Other written material can also be given. If the mum was breastfeeding the ill child, medicine is given to gain cessation of lactation. (Soukka & Lehtonen, 2011, 60). Naturally, this is not done if the mother is still breastfeeding for example the dead child's twin. Both of the parents are recommended to ask for sick leave, so that they could be together and support each other. The need for calming medication should also be assessed. (Keituri & Laine, 2012).

### 4.3.2 Pediatric post mortem care

Performing the last offices, meaning post mortem care, is an old tradition. Post mortem care is the last service for the deceased, and it should be performed with the respect it deserves (Grönlund & Huhtinen, 2011, 169); there should be no hurry, and the service is done in a suitable, calm place. Enough time should be given to the relatives to say farewells. (Saastamoinen et al., 2010, 219; Iivanainen & Syväoja, 2012, 163). It is vital that the parents can be involved to the post mortem care if wanted; to wash and dress their beloved child for the last time. Rituals performed to the deceased child are important means of expressing sorrow and mourning. (Kantero et al., 1996, 161; Saastamoinen et al., 2010, 219). A silent moment is always spent, even though no relatives would be around. (Iivanainen & Syväoja, 2012, 158). The dead child is taken care of as well and beautifully as a living child would be; called by his/her name, and his/her hair and skin can be smoothed softly. (Ivanoff et al., 2001, 302).

Two nurses or a nurse and a family member are needed in the last offices. All the equipment is gathered before starting the care. If possible, single-use equipment should be used for the corpse. The nurse wears personal protective equipment (apron and clean gloves), which are recommended for the family member also. Aseptic technique should be used. The corpse is placed in supine position, the bed is put flat and all extra pillows etc. are removed from the bed. Arms and legs are placed in natural position to the side. Arms can also be crossed on the chest. (Grönlund & Huhtinen, 2011, 170; Iivanainen & Syväoja, 2012, 156-157). The care after death consists of washing the body, putting a diaper on to the corpse and a clean bed linen and a lifting sheet are placed under the corpse to ease lifting from bed. A special gown or child's own clothes are put on. The legs are tied together. An identification band with the child's name, time of birth and death, social security number, ward and hospital's name and special information about foreign objects etc. is put on ankle or wrist according to local protocols. (Storvik-Sydänmaa et al., 2012, 295-296).

The child's hair is brushed, possible dentures are cleaned and put to mouth and some lip balm is put on. The eyes are closed carefully by pressing softly the eye lids or putting some wet compresses on them. The mouth is closed with support of bandages or special pillow under the jaw. The aim is to make the position to be as natural as possible. (Heikkinen et al., 2004, 118; Grönlund & Huhtinen, 2011, 170; Iivanainen & Syväoja, 2012, 157-158). Babies can also be swaddled. (Storvik-Sydänmaa et al., 2012, 296).

Finally a clean white sheet is put on the corpse. A cross or a flower can be put over the sheet, depending on the child's religion. If the child had some transmittable disease, use of a special body bag has to be considered. (Heikkinen et al., 2004, 118; Grönlund & Huhtinen, 2011, 170; Iivanainen & Syväoja, 2012, 157-158). Ivanoff et al. (2001, 302) add that the child's favorite toy can be put with him/her. Most importantly, the living should respect the body until the very end. (Molander, 1999, 49).

### **4.3.3 Mourning**

No other feelings are as characterful and individualized as love and sorrow. (Ivanoff et al., 2001, 301). Mourning is a healthy, natural and necessary reaction (Schmitt, 2008, 61) and sorrow is a positive feeling for a mourning person (Lähteenoja & Laine, 2004, 460). Sorrow cannot be healed, but it can be shared. (Ivanoff et al., 2001, 301). Every person grieves in his/her own time and way, making it often impossible for spouses to support each other (Price & Gwin, 2012, 419) because then maybe the most therapeutic support, the spouse, is not always available. (Perkin et al., 2005, 232-233; Sirkiä, 2006, 73). The parents may feel like they have lost part of themselves when their child dies, that they have failed in their task to take care of the child. It is said that a parent's grieve is more powerful, multiform and long-term than any other sorrow, and parents are known to form somatic and psychological symptoms after their child's death. (Sirkiä, 2006, 73).

If family members mourn differently, conflicts happen; parents might doubt that siblings mourn at all, as children get over sad events faster than adults, and children feel it tough to handle the parent's sorrow in the house. Especially older children tend to try to hide the sorrow from the parents. Unsocial behavior occurs when the children try to deal with the stress and sadness, and the fact that usually only positive things are remembered from the deceased sibling is not helpful, as it is tough to compete with a dead person. Siblings can also feel guilt for being alive, leading to them isolating themselves. It is also noticed that fear of death usually decreases in parents, but increases in the siblings. (Lähteenoja & Laine, 2004, 462; Sirkiä, 2004, 290).

Support for this family can be shown with compassion, friendliness, comforting words and warm handshakes, among many ways. (Iivanainen & Syväoja, 2012, 155). When there are no words left to say, we can still listen. (Kübler-Ross, 1976, 122). Professionals should remember that a family may adjust to their loss, but they never get fully over it. (Dominica,

1989, 128; Perkin et al., 2005, 231; Hovi & Sirkiä, 2010, 3030-3031). Most importantly, Sirkiä (2006, 75) underlines, the family needs to have a feeling that professionals are interested in their well-being also after the child's death.

Supporting the siblings is just as important as supporting the parents. (Perkin et al., 2005, 238). Like adults, children also need to complete steps of mourning before moving on with their lives. Adults should use concrete language using the word death when explaining the situation to a bereaved child and maybe even show with pulse or breathing that the person is no longer alive. (Robbins & Mascrop, 1995, 275). This helps the child to understand the concept of death and prevents mixing death up to sleeping, which otherwise could cause problems at bed time. At home, family routines should remain as same as possible to help the siblings feel secure in their home environment. (Robbins & Mascrop, 1995, 137; Perkin et al., 2005, 238-239). It should always be assured that the death was not the sibling's fault, answer to possible questions and offer comfort and support. (Perkin et al., 2005, 238-239).

Memories are important to the grieving parents and other family members. Photos, videos and other material are encouraged to take, as well as foot and hand prints and hair tresses. (Perkin et al., 2005, 241; Soukka & Lehtonen, 2011, 60; Keituri & Laine, 2012). At first the child is idealized by parents: they remember only the good and positive sides of the child. Eventually they will create a diverse and realistic image of their child with memories of disappointments and other negative things the child had done. (Kantero et al., 1996, 161). Anniversaries become important in the family for years. Although the family has recovered from the grief, the anniversary brings back memories and sadness. In addition, it is important to tell about the dead child to the children who are born afterwards and not try to avoid that phase in the family's history. (Lähteenoja & Laine, 2004, 462-463). According to Varimo et al. (2004, 160) the death of a child creates an empty space inside the family, causing a feeling that someone is always missing.

#### **4.3.4 Moving forward after the loss**

The death of a child breaks the common illusion in many families that nothing bad could ever happen to them. Due to fear of something as traumatic happening again the boundaries of the family are tightened, but overprotecting the siblings prolong their independence. (Lähteenoja & Laine, 2004, 462). It is important to let and encourage children, especially siblings, to participate in funerals and wakes, but not against their own

will. Adults should talk about it as a self-evident thing, just as eating and sleeping and not try to forbid the sibling from going to the funerals. (Kübler-Ross, 1987, 28, 96).

Reactions to bereavement in children are similar to adults', although the feelings might be manifested a bit differently. Regression, anger towards others, educational difficulties and sadness can be signs of denial and anger and the child needs to be told that all feelings are accepted and not out of the common after loss of a loved one. Sometimes a child shows acceptance of loss with very direct statements, "now when he is dead; can I have his/her bicycle?" which might seem harsh and non-grieving, but it helps sorting out the situation in the child's head and should not cause worry in parents. (Robbins & Mascrop, 1995, 276).

Two months after the child's death the attending physician and the child's personal nurse have a meeting with the child's parents. The answer from possible autopsy is given, the family's well-being is investigated and emotions and thoughts about the past few months can be shared. The need for support is assessed again. Another meeting can be arranged after several months. (Kübler-Ross, 1976, 122; Taipale, 1998, 234; Perkin et al., 2005, 231; Sirkiä, 2006, 74; Soukka & Lehtonen, 2011, 60). It is however essential that the communication with the family is only temporary and within the limits of professionalism. (Varimo et al., 2004, 159).

#### **4.4 Cultural competence in pediatric terminal care**

Culture means all the things that community members have been learning to do, appreciate or believe and enjoy during their existence, which makes it a way of thinking, living and reacting for an individual. In a way, culture is the community's personality. When working with people from other cultures, collisions may happen if the perceptions about right values and ways of life differ, especially when every culture has its own perceptions about health and illness which explain why and how the disease occurs. Applying the family's own cultural traditions into the care may help the grieving process, but it requires that the care personnel understand and knows about the family's culture. (Kantero et al., 1996, 18).

When the family learns about the bad prognosis of the child's situation, all of a sudden the parents as well as the child's minds are full of deep questions about the life and death, afterlife and other phenomenon which are maybe not thought of in normal daily life. This is often the place where religions and cultures come into the picture. Fear of death can be



emerged from religious beliefs, as death is often seen as a passage from one form of life to another as Boyd and Bee (2012, 491) narrate. Sometimes it is hard to connect the rational medical activities and irrational beliefs, traditions and emotions that belong to normal life. Occasionally it is hard to motivate why the doctor's medical action would be better than the person's own religious action. (Hänninen, 2006a, 20-21).

In practically every culture, a funeral is an immediate response to death (Boyd & Bee, 2012, 502) as no culture understands death to be only a biological event. (Sutinen, 2004, 90). Traditions' and medical approaches' collision is clearly seen for example when performing post mortem care, Hänninen (2006a, 21) says, as it is the last opportunity for the family to honor their loved one with their cultural traditions. Sutinen (2004, 89) agree that the variety of cultural beliefs affect not only to spiritual care of a person, but actually to the clinical practices in general. No matter what, the person's own beliefs have to be respected. There are many different ways for professionals to take care of the mourning family after the patient's death, and those manners are always based on the culture they are developed in. (Sirkiä, 2004, 291). The main things in existential support around the world are discussions about the meaning of life as well as maintaining hope. If the patient or family members wish for praying or other religious activity, the professionals try to arrange someone to fulfill the wish. The dying person and the family have a right to get a visit from a priest at any time of day. (Iivanainen & Syväoja, 2012, 159). Other common nominator is meetings with the family right after the death and another later on in about a month. (Sirkiä, 2004, 291).

To be culturally competent, a nurse needs to know some basic collisions between cultures and medical opinions. Most of the religions in the world advise to arrange a private room for a dying person. Depending on the religion, religious items such as candles, icons, and crosses may or may not be accepted to be in the room. Some religions may not allow autopsy to be performed, and some allow it only if it is necessary due to the law. The person might have some dietary restrictions, allergies or personal preferences in what comes to nutrition. Some cultures and religions wish that the nursing professional caring for the dying person is the same sex as the person, and some allow all professionals to participate in the care. Sometimes it is prohibited to tell the person about the upcoming death. Some may refuse for medical treatments, such as blood products and antibiotics, and focus on their own remedies or prayers. Some sees music as a very important part of saying farewells. Some will definitely participate in post mortem care, some will not want to come and some want to perform it in their own way without nurses participating. As can

be seen, there are many things to be considered, and for example using the words *bless you* can be very offending. Nurses need to be aware how not to offend the dying child or the family, nor say any opinions about which care is better. Interventions are only done if they are somehow violating the child's rights or being harmful. (Laukkanen, 2001).

## 5 Methodology

This chapter contains a description of how this study was conducted and what strategies and methods were used. This is a qualitative study made by content and constant comparative analysis with deductive approach (Elo & Kyngäs, 2007, 111). Data was collected from Finnish health care districts' pediatric units by a questionnaire. Moreover, the data collection is using systematic review and is performed by nonrandomized hand-picking of the participating units and the literature, with careful observation for being biased and fallacious.

### 5.1 Data material

As the aim of this study is to learn more about how pediatric terminal and post mortem care is provided in Finland, the best but not maybe the most practicable thing to do would be contacting all the pediatric wards and units in Finland. This being too resource-consuming, a more manageable plan was to contact the places who most likely have some knowledge about pediatric terminal and post mortem care, as not every pediatric unit is taking care of them. The chosen representatives' answers illustrate the common practices for providing the pediatric terminal and post mortem care in Finland. The sample quality was ensured by contacting various pediatric units from different health care districts. Selection of the pediatric units who were offered the questionnaire was therefore performed with hand-picking strategy. (O'Leary, 2010, 170).

Finland is divided into health care districts, which are responsible for providing special health care, including also terminal care, within their areas. (The Finnish Ministry of Social Affairs and Health, 2013). Knowing this, approaching university hospitals and central hospitals together with smaller health care units seemed to be the best plan to reach for various pediatric units across the country within suitable time range. Since there are 21

health care districts and five university hospitals in Finland (The Finnish Ministry of Social Affairs and Health, 2013), approaching majority of the districts and the university hospitals ensured quality of data sample as the participating units represent different areas of Finland rather than just one health care district. Additionally, when contacting one health care district the answers came from different hospitals and pediatric units in the area, which ensured even more comprehensive sample.

## **5.2 Data collection methods**

Collecting scientific data for theoretical background of this study was performed by hand-searching literature and journals known to include relevant material performed by manually searching key words from tables of contents and databases and doing an author search of key researchers of the topic in bibliographical databases, as Polit and Beck recommend. (2012, 658). Data material to be analyzed was collected from previously determined participating units' by a questionnaire sent by an e-mail.

O'Leary (2010, 170) instructs to use handpicked sampling when needing particular information about a topic. Especially the information gained from websites was found by this method, although the chosen material was carefully screened to determine if it meets inclusion criteria. (O'Leary, 2010, 170; Polit & Beck, 2012, 658). For example, choosing the background theory for the study was a result of some friendly guidance from a teacher, whose reference articles were the starting point for searching new information on the topic. Although all this may be a questionable way to find literature, and not sounding that scientific, the data collection strategy was performed as it was planned; hand-picking with critical thinking and constant evaluation of the trustworthiness, aiming to use only reliable and well-known websites, books and articles. Search tools such as Google and Google Scholar were used to find specific information about certain topics, for example the amount of health care districts in Finland. Reference books were found mostly by hand-searching from the public libraries.

Data about current pediatric terminal care and post mortem care practices in the health care units is collected via a questionnaire sent by an e-mail to the units' head nurses, after granted permission to do so. Before contacting the personnel in the most likely places

where terminally ill children are taken care of (including the university hospitals' pediatric wards, home care units in central and university hospitals among other various places), permission for conducting the study was needed. Every health care district has own research permission forms, but also a general application for conducting a study (Appendix 1) was used alongside. The process for contacting the pediatric units started with finding the appropriate work units which probably take care of children in terminal care phase. A list of health care districts in Finland was searched from Google. The next step was to find the pediatric units in one health care district and search for their contact information. Also information about the health care district's thesis policies was searched, but was not always easily found. Guidance about the practicalities concerning theses was asked via e-mail from the unit's contact persons or the health care districts' nursing directors, who were usually the responsible persons for granting permissions for students' theses. Granting research permission for this study was more or less time consuming process depending on the health care districts' protocols.

After receiving an official permission the questionnaires were sent to the chosen units. The goal was to reach 5-15 pediatric units and learn about their ways of providing terminal and post mortem care for children by asking them kindly to answer in a questionnaire. The most convenient way to perform the questionnaire phase was sending the questions via email to the wards' and units' head nurses or other contact persons, and allowing them to answer by themselves or by asking opinions from their unit's nursing professionals. The questionnaire is attached as an appendix (Appendix 2). In total 20 health care districts were contacted, including hospitals and pediatric units across Finland. The Åland Islands were left out from this study due to language policy. The participating units answered in written form by email or letter, having at least a couple of weeks' time to answer. After a few weeks a reminder was sent to the contact persons, if no answers were given before that. Envelopes and stamps for returning the questionnaires were sent to the contact persons if requested. Majority chose to send the answers in the health care districts' own envelopes, if not sending the answers electronically. Moreover, participating to the study provided an opportunity to use the finished outcome of this thesis, the general guideline of best practices in pediatric terminal care and post mortem care, in the pediatric units after its publishing.

The questionnaire for this thesis used one close-ended question to determine the kind of work unit the participating units were representing, as Centers for Disease Control and Prevention (2008, 1-2) recommend, and five open-ended questions asking descriptions

about their ways to provide pediatric terminal and post mortem care (Attachment 2). The participating units' opinions about the need for more detailed guidelines and further schooling about pediatric terminal and post mortem care were also surveyed. The answers were allowed to be anonymous and were supposed to be representing the whole work unit. The participating units got an information letter attached to the questionnaire (Attachment 2), aiming to elucidate the purpose and value of the study. The pediatric unit's contact information was added in the questionnaire, if the participating unit allowed further contacting. A reminder was sent to the contact persons by e-mail few weeks before the deadline of the questionnaire to ensure numerous answers.

Informed consent (Attachment 3) was created to ensure the objectivity and neutral nature of the answers. The aim was to remind everybody to read the instructions first, before answering the questions, to secure the quality of the data. The participating unit was asked to sign the informed consent, or ask the ward's superior to sign it, as a mark of participation and understanding the instructions. The informed consent was not obligatory to send back; if not signed, the unit's superior had responsibility of data quality, as in the situations where the informed consent was signed but not sent back. In total, 13 out of 32 informed consents were sent back, ensuring the data quality by themselves, while the others gave the responsibility of data quality to their superiors.

Centers for Disease Control and Prevention (2008, 1-2) also encourage performing a pilot study before starting the real survey, but this was not officially done in this study due to difficulties in time management; the research permission processes took more time in other health care districts than in the others, so the questionnaires were sent at different times to each health care district. This long process allowed some editing to happen in the instructions given to the wards. Some health care districts wanted more clarifying instructions about the process, some ensured details in the practicalities or had other questions from returning of the answers to which kind of wards can answer to the study. The directions were then narrated again to them and possible questions were answered in e-mail conversations. This all means, that some kind of pilot study was performed as the last pediatric units to receive instructions were given better guiding in e-mail conversations than the units who answered in the early phase. The frequently asked questions were already explained in the e-mails sent to the final participating units when they received the questionnaires and information letter, just in case if they would have had the same

questions. The questionnaire and the information letter however were the same for all from the beginning.

All the participating units were health care professionals who have been taking care/ are taking care/ could in theory take care of pediatric terminal care patients. No actual patients or their families were contacted. The participating units gave anonymous answers, which represented the whole work unit and contained no individual opinions. The participating units were asked if they would like to answer additional questions arising from their answers, but agreeing to it was not compulsory and did not affect to the participating units' rights in any way. Additional questions would have only provided more specific and usable data to the study. No additional questions were however made to the participating units; those units, whose answers would have needed more clarification, usually did not give permission for further contact. Sometimes the units also had similar routines; comparing two answers from the same hospital provided the same clarification than a phone call to the pediatric unit would have provided. Nonetheless, the data material was collected without any major problems other than difficulties in finding the right forms for research permission in every health care district.

### **5.3 Data analyzing methods**

In this study, both content analysis and constant comparative analysis were used for analyzing the data material, with a deductive approach. Using these two analysis methods together helps to take into account all the aspects of the data. Deductive reasoning progresses from general to specific (Trochim, 2006); information found from the literature is examined and compared to the data gained by questionnaire, leading into collection of the best practices and most common themes within pediatric terminal and post mortem care and concluding with a general guideline about the recommended pediatric terminal and post mortem care.

The aim in the content analysis process was to examine different themes brought up both in the data material and in the theoretical background, summarizing the characteristics of pediatric terminal and post mortem care. After those themes were formed, their similarities and differences were compared to each other in the constant comparative analysis. This eventually led to common patterns (Polit & Beck, 2012, 498), but also to singular example

practicalities. Distinguishing between actions that apply for all the answerers and actions that are unique for particular kind of answerers is an important part of data analysis. (Polit & Beck, 2012, 562).

Once the themes were developed (with observation of recurrent topics in the data material and in reference literature's tables of contents), the data was read through again, coded and set under those themes. This strategy was used both when reading the literature and when examining the questionnaire answers. The themes were completed during the process, and the data was re-analyzed when new themes occurred. (Elo & Kyngäs, 2007, 109-111; Polit & Beck, 2012, 559). Grouping data lead to rearranging the themes into broader ones, as Elo and Kyngäs (2007, 111) guide. Abstraction of the themes by grouping is a relevant part of the process, continuing as far as reasonable. (Elo & Kyngäs, 2007, 109-111; Polit & Beck, 2012, 559). Data management in this study was performed manually.

After finding out common patterns, nursing care activities and protocols, some example citations were collected. These findings formed a base line for the general guideline about the recommended pediatric terminal and post mortem care, which aims to present the variety of different themes included into pediatric terminal and post mortem care. Figure 1 illustrates the data analysis process simplified.

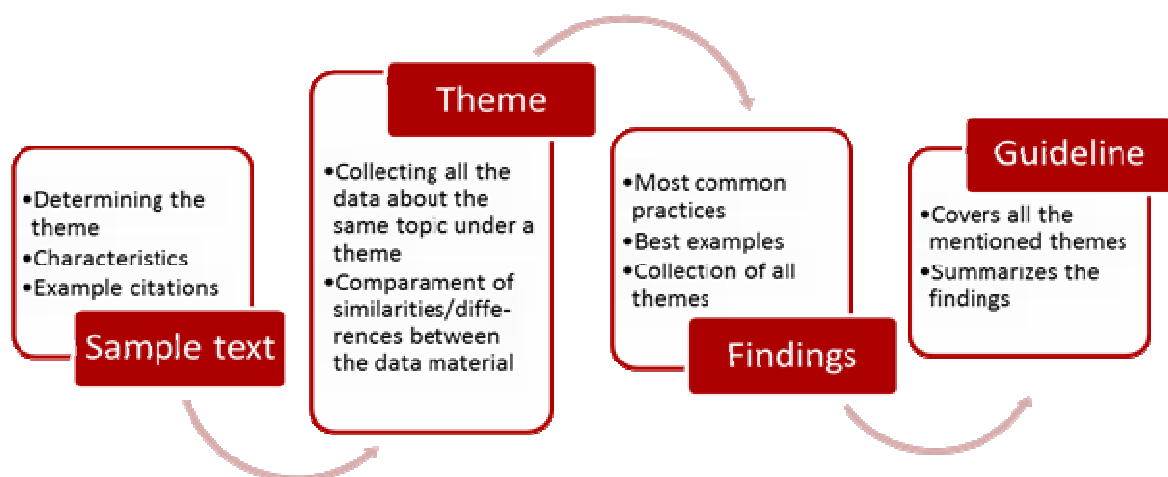


Figure 1. The data analysis process.

## **5.4 Ethical considerations**

Ethics in this study was maintained by contacting only social and health care professionals within working units, not individual patients, families or individual nurses. No stories about patients were told or used as an example, however patient cases have of course affected to the answers given. Professional nurses are presumably capable of discussing about all sides of nursing care, even about the most unpleasant issues. The researcher has still responsibility towards the participants' well-being. (O'Leary, 2010, 40).

No pediatric units were contacted before approved research permission. (O'Leary, 2010, 42). This study was purely professional and honoring participating units' rights in scientific research; to not participate into the study at all, to discontinue at any time without further notice or explanation, to use as much time for answering as wished for and to allow answering anonymously. (O'Leary, 2010, 41-42). Informed consent was attached to the questionnaire (Attachment 2), as recommended by O'Leary. (2010, 42). Every length for an answer was accepted, and unnecessary contacts with the participating units were tried to be avoided; the real participants were the nurses in the pediatric units, and any extra paperwork is taken out from the actual patient care, which is especially important for terminal care. Using more time to paper work than for caring for a real patient is ethically unacceptable. On the other hand, nursing as an area of science is constantly developing, and new studies need to be performed in order to develop the profession. Using the valuable time for answering a questionnaire and supporting developmental work pays off by getting a new guideline which will hopefully be useful in practice.

## **6 Presentation of findings**

All the participating units belonged to public health care; none were from private or nonprofit sector. The participating units came mostly from university hospitals and central hospitals; none came from regional hospitals, health care centers or hospices. The most common unit types were pediatric wards and different intensive care units, although many answers came also from other types of pediatric units.

Out of 20 health care districts contacted 15 gave permission to conducting the study, one rejected the research permission application due to that health care districts policies, two



politely refused from participation due to difficulties in timing and two health care districts did not respond to any contact attempts. Out of the 15 health care districts, 14 sent back answers from 31 different pediatric units. In total 99 pages of data from the questionnaire was analyzed, including the actual answers, but also currently used guidelines, protocols, example photos of equipment used in post mortem care and leaflets, sent together with the answers as attachments.

A majority of the pediatric units have 0-2 pediatric terminal care patients in a year, some even more seldom. However, few intensive care units in some university hospitals are exceptions that exceed the average; they talk about more than ten children in a year, or even more than that. The location of the pediatric unit has a huge role in this; Southern Finland's pediatric units had more terminally ill children to be taken care of than Northern Finland's pediatric units. This could be explained by the variation of the amount of population within different areas in Finland, which makes variation in patient cases understandable.

The participating units' answers reveal that the pediatric terminal care currently given in Finnish pediatric units follow the literature's recommendations. All the participating units followed, at least partially, Käypä hoito (2012) recommendations. The routines for pediatric terminal care were all similar to each other, but had some diverse aspects in what comes to details. The participating units focused to answer directly to the questions given in the questionnaire, which made the deductive approach in data analysis quite shorthand; the main themes were visible from the beginning. Therefore the data material was divided into four main themes; *nursing care actions*, *supportive caring actions*, *culturally competent care* and *characteristics of pediatric terminal care*, according to the topics established by the research questions and following the themes set in the questionnaire. Each theme was split up into major and minor sub-categories, eventually ending into examples and specific citations. Table 1 will present the main themes of the data material shortly. Moreover, there are many smaller sub-categories that are seen to be included in the minor sub-categories; Table 1 shows some of the smallest sub-categories as examples, however listing them all in a table would be impractical.

Table 1. Presentation of the main themes of the data material.

Themes	Major sub-categories	Minor sub-categories	Examples of the smallest sub-categories
<b>Nursing care actions</b>	Palliative care	Basic care  Symptom control	Nutrition/Hydration Skin care Positioning etc. Analgesia Giving supplemental oxygen etc.
	Post mortem care	-	-
<b>Supportive caring actions</b>	Psychological support	Support for the child Support for the family Professionalism	Use of touch Holding the child Debriefing etc.
	Social support	Paperwork Continuance of care after the child's death	Memories Sick leave Medications for the parents etc.
<b>Culturally competent care</b>	Special wishes	Diet Pastoral care Own room	Emergency baptism etc.
	Post mortem care	Environment Equipment Own clothes	Personal protective equipment <i>Exitus</i> -set etc.
<b>Characteristics of pediatric terminal care</b>	Ideologies	Holistic care Individualistic care Family-centered care	Personal nurse Own clothes etc.
	Practicalities	Caring environment Multi-professionalism Regular schooling	Home care Calm environment etc.

## 6.1 Nursing care actions

Palliative *nursing care actions* were comprehensively featured in the responses. This theme was divided according to different types of care (major sub-categories **palliative care** and **post mortem care**), which then consisted of minor sub-categories **basic care** and **symptom control**. It should be noted, that **post mortem care** is categorized under two main themes (*nursing care actions* and *culturally competent care*), but is reviewed under the latter theme since as a nursing care action it is considered to be a single procedure, when as a part of culturally competent care it can be divided into sections and be reviewed more efficiently.

Participating units comprised that nursing care actions in pediatric terminal care consist mainly of “*kivun lievittämisestä, perustarpeiden tyydyttämisestä, lapsen kuuntelemisesta ja sylissä pitämisestä*” [translation: alleviation of pain, meeting the basic needs, listening to and holding the child], as “*terminaalihoito tarkoittaa, että lapsen vointi on huono ja lääketiede ei kykene enää pelastamaan lasta, oireita täytyy tietysti helpottaa*” [translation: terminal care means that the child’s condition is bad and medical care cannot rescue the child anymore, the symptoms must of course be alleviated]. Others saw that the child’s rights include “*kivuttomuus, turvallisuus, riittävä ravitsemus/nesteytyminen, vatsan toiminta, puhtaus ja ihon hoito, asentojen säännöllinen vaihtuminen ja näissä perustoiminnoissa auttaminen*” [translation: analgesia, security, adequate nutrition/hydration, adequate bowel function, cleanliness and skin care, regular change of positioning and helping with these basic functions]. Overall, adequate pain management was seen as the most important aspect in pediatric terminal care, good basic care being mentioned almost as many times.

As narrated earlier, **palliative care** is divided into **basic care** and **symptom care** due to the nature and aims of the nursing actions. **Basic care** consists of adequate nutrition and hydration, skin care, recurrent positioning, ensuring bowel function and so on, and is the primary care type provided to every patient. **Symptom care**, on the other hand, focuses on alleviating the symptoms that the child is suffering from by giving supplemental oxygen, ensuring adequate hydration with intravenous fluids and giving palliative radiation therapy, among other ways.

The participating units brought up many important aspects in pediatric terminal nursing care actions. In adequate nutrition and hydration “*yleinen periaate - - on, että lapsi ottaa suun kautta sen, minkä pystyy ottamaan*” [translation: the general principle - - is that the child takes orally that which s/he is capable of taking]. Monitoring vital signs was seen unnecessary, but is left for a physician to decide. Besides, “*mittausarvojen sijaan kuolevalta potilaalta tulee arvioida säännöllisesti kipua, levottomuutta, hengitysteiden eritteitä, hengenahdistusta sekä oksentelua ja pahoinvointia*” [translation: instead of measurements the dying patient should constantly be assessed for pain, anxiety, secretions in respiratory tract, shortness of breath and also for vomiting and nausea]. Skin care and frequent patient positioning with supportive pillows is done with prevention in mind, as well as maintaining normal hygiene. All in all, “*toimenpiteiden sijaan hoitaminen muuttuu läsnäoloksi, keskusteluksi ja kuunteluksi*” [translation: instead of nursing care actions the care transforms into presence, conversation and listening].

## 6.2 Supportive caring actions

In *supportive caring actions* and support for the family, grief was named as the number one reason why support was needed from the nurses. Many felt like being responsible for the child's loved ones as a part of family-centered care. Nevertheless, it was seen vital "*välittää tieto siitä, että - - lasta hoidetaan parhaalla mahdollisella tavalla*" [translation: to convey information that - - the child is taken care of in the best possible way]. This theme is roughly divided into **psychological support** and **social support**.

The **psychological support** was the most prominent part of support mentioned, underlining "*aito läsnäolo ja välittäminen*" [translation: genuine presence and caring]. Listening to the child, holding the child in one's arms and use of touch are seen as natural actions when facing sorrow and trying to comfort the child. Use of touch and holding the child in one's arms are used when aiming to support the child in the dying process. Other ways to **support for the child** also exist: one pediatric unit has a list of topic-related books available at the municipality's central library; they can be borrowed to help discussing about the situation with the child or siblings, or to provide the parents more information. "*Lapsen oma käsitys kuolemasta riippuu lapsen iästä*" [translation: The child's understanding about death depends on the child's age] and "*lapsi saa itse valita puhuuko kuolemasta*" [translation: the child can him-/herself choose if to talk about death or not]. "*Vuorovaikutus- ja hoitosuhde antavat lapselle mahdollisuuden käsitellä tunteitaan*" [translation: Interaction and caring relationship provide the child an opportunity to deal with feelings]. Enough room should be given to the arising emotions. The participating units also reminded that nurses need to be available if the child wants to talk about death or other distressing things.

However, grief was not seen only in the family members; also nursing staff admitted having sorrow. **Debriefing** and discussions with colleagues are seen to be vital parts of handling nurses' mental well-being, belonging into the **psychological support**. Nurses were encouraged to show own feelings, but reminded them to maintain **professionalism** when at presence of the family. According to the participating units, emotions are allowed to be shown, but the nurse needs to be able to support the family, and not the other way around.

The participating units also showed their worry when sending the family back to home after the child's death; can they survive there? As a part of **social support**, many units have a routine of writing sick leave to both of the parents immediately after the child's death. Also medication helping the parents to fall asleep is prescribed in some health care districts; some even provide few tablets from the unit's dispensary. What is more, one pediatric unit allows the parents to take the child's corpse home; "*kuolleen lapsen saa viedä kotiin, pakko vain haudata*" [translation: the dead child can be taken home, compulsory is only to bury]. Nurses consider that reminding the parents about the possible **paperwork** is part of their job, although actual helping is social workers' and other professionals' job.

Many reminded to collect memories for the family including photos, foot and hand prints, hair ringlet and so on; even though the parents might not want them now, they might change their minds after time passes. Collecting the child's personal things is also seen as part of the post mortem care process, but also "*tarpeen surutyön kannalta*" [translation: necessary for mourning process]. One hospital has pretty gift bags for this purpose; collecting them into regular trash bags is seen offending and disrespecting for the deceased and the family.

Some pediatric units confirm to have a routine of **continuance of care after the child's death** also after the child's death; some even participate in the child's funerals if being invited to. Many pediatric units call the parents the next day after the death and ask how the night went. Some units send a card with their condolences after few weeks of time. Usually the professionals meet the parents after 1-2 months from the child's death for summarizing discussions about the child's care. The aim is to find "*perheelle sopiva yhteydenpito kuoleman jälkeen*" [translation: a suitable way for contacting the family after the death]. All in all, "*on osoitettu olevan erittäin tärkeää, että vanhemmat käyvät tapaamassa hoitohenkilökuntaa, jotta saataisiin selvitettyä kaikki hoitoon liittyvät mieltä painavat asiat*" [translation: it has been shown to be important that the parents go and meet with the professionals, in order to clarify all the things about the care that are distressing the parents].

### 6.3 Culturally competent care

*Culturally competent care* was only shortly described in the responses. It can be grouped with both *nursing care actions* and *culturally competent care*, as narrated earlier in chapter 6.1, but under the latter theme it can be reviewed in more detail. After all, **post mortem care** is often a situation where one's cultural traditions and religious beliefs appear. Therefore the theme can be divided into **special wishes** and **post mortem care**.

Almost all of the participating units named listening to the family's **special wishes** as their primary way to take into account cultural beliefs and practices in what comes to pediatric terminal and post mortem care, not to mention listening to the child's wishes. Health care professionals listened and honored **special wishes** if they were not contradicting the law. Nurses also try to arrange reasonable requests, however acknowledging that "*usein toiveet ovat pieniä ja ne on helppo toteuttaa*" [translation: mostly the wishes are small and easily arranged]. Some wishes, like **own room**, are already included into the care plan, and do not require any additional effort from the nurses. The participating units underlined that "*uskonnollisten - - rituaalien tulisi olla lapsen tarpeita tukevia, eikä saisi aiheuttaa - - lapselle raskautta*" [translation: the religious - - rituals need to be supporting the child's needs, and may not cause - - discomfort for the child] nor the hospital or other patients. For example, one central hospital has a quiet room where anyone can go to calm down, no matter of the person's religion or culture. The room is open night and day.

Talking about the possible culture-related wishes in advance was mentioned to be vital; in emergency situations respecting cultural beliefs was only done if remembered, one intensive care unit admitted. Units gladly invite priests if the family wishes so; **pastoral care** is an important part of culturally competent care, however not usually being part of a nurses' job. Emergency baptism can however be performed by a nurse, if a priest is not available or not coming in time. Especially in intensive care units this is a rather common situation.

Respecting the family's routines, beliefs and cultural wishes is justified; the child feels safe when the daily routines stay the same also in the hospital environment. The easiest ways to honor **special wishes** might include following the child's bedtime routines; "*ennen nukkumaanmenoa luetaan iltasatu tai iltarukous*" [translation: a bedtime story or prayer is read before going to bed], or "*hoitaja voi ehdottaa esim. sairaalapastorin käyntiä ja laulujen tai virsien veisaamista*" [translation: the nurse can suggest e.g. meeting with the

hospital's pastor and singing songs or hymns]. The child can also wish for special meals or follow a special **diet**.

Many participating units felt that **post mortem care** starts by arranging and cleaning the environment making it as beautiful as possible. The deceased child is still handled like a living person; carefully and honorably. Some referred to the golden rule "one should treat others as one would like others to treat oneself". Otherwise the post mortem care procedure was described similarly to the literature; the nurse has personal protective equipment on and all recommended to ask parents to come and help with the ritual. Some used the existing adult's *exitus*-sets for older children, some used only parts of it and some had created own sets for children. Those who take care of babies use so called white boxes, which can be ordered to the hospital. The child corpse is taken care of like an adult corpse, but some units have special tricks for child corpses; for example, if the mouth does not stay closed, a pacifier can help to close it. The child's **own clothes** or the unit's clothes are being used.

Many mentioned flowers as decorations on top of the white linen. In one university hospital, a small bouquet can be picked up for free from the nearby florist when a child patient has died. Others buy them in a normal manner with the unit's funds. One pediatric unit has a crocheted cross for Christian patients to be put on top of the white linen and a crocheted rose for patients with other religions. Another unit uses children's bed linen with pretty patterns in it. Others use quiet music in the background when performing the post mortem care, and others light (rechargeable) candles. One unit has spotlights in one of their room's roof, imitating starry sky. "*Virsikirjan lopussa on ohje saattohetkeen sairaalan kappelissa*" [translation: In the end of hymnal there is a guideline for paying respects to the deceased when arranged in the hospital's chapel] as one pediatric unit reminded. The nurses should remember to enable "*myös muiden sukulaisten osallistuminen hyvästi jättöön*" [translation: also the other relatives' participation to the farewells].

Some pediatric units have own guidelines about pediatric terminal and post mortem care available either in the unit or in the health care district. Almost all of those pediatric units who have guidelines also have created an own post mortem care set for children. On the other hand, some acknowledged that they do not have any post mortem care sets for children, and one unit admitted that they do not have any guidelines available about the phenomenon. Participating units presume that this thesis will most likely be useful to them, but few pediatric units (belonging to the ones who already have their own guidelines and

pediatric post mortem care sets) doubted if this study will gain them more knowledge about the topic. Others were more or less doubtful about gaining new information, but eager to compare practicalities in different health care districts. Additionally, although one health care district refused from participation of the study, they announced to be waiting for the study's results with interest.

## 6.4 Characteristics of pediatric terminal care

*Characteristics of pediatric terminal care* are divided into **ideologies** and **practicalities**. Pediatric terminal care is described to have focus in **family-centered care**, **individualistic care** and **holistic care** in its ideological aspect. On the other hand, practicalities are often concentrating on **multi-professionalism**, **regular schooling** and choosing the most suitable **caring environment**. Overall, the aim of pediatric terminal care can be summarized in one sentence; "*Lapsella on oikeus olla elävä, kokeva ja tunteva lapsi loppuun asti*" [translation: The child has a right to be a living, experiencing and sensing child until the end].

The participating units see **family-centered** care as natural focus of the pediatric terminal care. However, **holistic care** for the whole family as part of ideal pediatric terminal care was not often mentioned separately from family-centered care. Majority of the pediatric units particularly mentioned the use of personal nurses for each child and family, since "*hoidon jatkuvuus luo perheelle turvallisuutta*" [translation: continuance of care provides sense of safety for the family]. No other patients should be on that nurse's responsibility, or at least it is strongly avoided. Any additional paperwork and such is left to wait until the crisis is over. Some units told that the whole unit is taking care of the family and not just one specific nurse, even though personal nurses are mainly used. Kindness and caring shows in many ways in the health care districts; in one university hospital's area some places are not belonging to the same municipalities' aid system as others are. If the family lives in those areas, where the municipality does not pay for the home aid, the university hospital pays the bill for the parents. Moreover, the child can wear own clothes, or use the hospital clothing if preferred. The child's life is aimed to continue as normally as possible, one unit reminds, but in terminal care phase the child is usually already so tired that the difference to the previous, more active life period is shown.



In practice, some characteristics make the pediatric terminal care so special. Many mentioned **multi-professionalism** and cooperation with for example pharmacists and physiotherapists (even though not mentioning **multi-professionalism**) as one of the key aspects in pediatrics. The participating units also underlined the need for peaceful and calm environment for pediatric terminal care and the family's participation to the care, emphasizing home care. Visits are regularly made to the family's home if necessary, and in one unit the family could have contacted the personnel at any time of the day, even though normally they would not have answered their phone during night time.

The child and the family usually get an own room, where "*perheen ympärivuorokautinen läsnäolo*" [translation: the family's round-the-clock presence] is possible. This was the aim in almost all participating units. However, there are some units who cannot accommodate parents in their small premises. Many offer mattresses for the parents to sleep on the floor, because no extra beds are available. No matter what, a calm environment is aimed to provide for the family to be in; "*tärkeätä tuolloin on muistaa, ettei enää ole kiire mihinkään*" [translation: at that point it is important to remember, that there is no hurry anymore].

The knowledge and skills in pediatric terminal care are seen to be passed forward as tacit knowledge. **Regular schooling** about subject was seen beneficial, especially about cultural competence within pediatric terminal and post mortem care. Usually only few people have access to these schoolings from the pediatric units, and are then supposed to share their knowledge to the others. This is an area of expertise which is thought to be mastered only with time, after years of work experience. However, some feel that practical exercises with a doll could help to feel more secure when performing post mortem care to a deceased baby.

## 7 Interpretation of findings

As discussed above, comfort care is practicable approach for pediatric terminal and post mortem care, endeavoring for peaceful death. Comfort is supposed to be estimated in a holistic manner, including physical, psycho-spiritual, social and environmental dimensions. (Kolcaba, 1995, 288). In practice, the participating units demonstrated their understanding of the importance of holistic and individualistic care in pediatrics by planning the care in

the child's terms, not the hospital's. Participating units also thrived to give the child an opportunity to live as normal life as possible even in the hospital settings, like Eho et al. (2003, 13) recommended. Pediatric patients are seen primarily as children, not terminally ill patients, as Perkin et al. (2005, 10) underlined, not forgetting the child's need for structured daily life.

Kolcaba (1994, 1183) sees comfort as a desirable outcome of nursing care actions. So did the participating units; no unnecessary care is done, but alleviating the child's suffering is seen worth effort. Heikkinen et al. (2004, 21) emphasized the child's right to die with dignity in a safe environment, with adequate analgesia and with presence of the family. Participating units agreed that the best caregivers for children are the parents, and the best environment for the care is almost always the child's home, especially in terminal care period. Family-centered care is in the center of focus, not forgetting the siblings. Pediatric terminal care is provided by multi-professional teams including variety of professions, depending on the child's needs and the health care district's resources. Beside from encouraging to home care, the pediatric units concentrated on making the hospital environment more home-like, for example by simply following the same routines that the child has at home. The family is allowed to choose the caring environment, and health care districts explore different ways to support for these families.

Nurses acknowledged that the child understands death only according to the developmental stage s/he is in, and that reaction to it can be very individual. Literature reminded, that children need to be included in their own care, but should be given information according to their age. (Kübler-Ross, 1976, 117). The participating units respected the parents' wishes as supposed to, but also honored the children's rights. Balancing between these two aspects was not apparently seen problematic, because no participating unit brought that up in questionnaires. Maybe the focus is more on the adults' point of view in this case, when the child's opinions are taken into account in other types of situations, for example when discussing about nutrition.

It seems that pediatric terminal care in practice is very similar to that is described in literature. It might be because of the earliest pediatric palliative care guidelines; the best type of care has been announced and available to Finnish nurses since 1985. (Hovi & Sirkiä, 2010, 3028). Presumably all nurses working nowadays have therefore been taught some aspects of pediatric terminal care, and those common routines and protocols are therefore self-evident and maybe not considered to be somehow special characteristics for

pediatric care. For example, is encouraging the child to play or take a nap during the day seen obvious parts of child's life or parts of nursing care plan? The difference is sometimes imperceptible. The same goes with overall nursing care actions; when there is not much left to do to help the terminally ill patient, the focus automatically goes into alleviating suffering, making the life quality even a bit better. Perhaps due to the human's long-standing experience about dying, these aspects are passed with not much thought put in them; this is how we are supposed to do when a person is dying, even common sense tells us to. Nevertheless, it does not mean that these maybe-obvious aspects and routines should not be mentioned separately in studies. This might be one reason why some pediatric units did not mention by a word that they supported family-centered care, or that the care is provided by multi-professional teams; are these so "old" routines in pediatric care, that they are taken for granted?

With no doubt, pediatric units see memories as important parts of a mourning process and healing. Taking pictures of the child was named to be the most used way to save these memories, but also crafts like handprints were mentioned many times. This is yet another typical characteristic of pediatric terminal care, a detail that is not used in for example geriatrics. Collecting the personal belongings of the deceased and giving them to the mourning family is a natural thing to do in any environment, but seeing the collected item (for example pacifier or favorite toy) as remembrance of the child is more characteristic to pediatric care.

Cultural competence in pediatric care is nowadays taken more and more into account due to multiculturalism. Religious beliefs are typically seen as something personal that is not shared with other people. As the patient groups become more heterogeneous, also cultural and religious aspects in nursing care are brought out to discussion. When in the past "taking religious factors into consideration in care plans" could have meant a visit by a priest on Sundays, nowadays it might mean more holistic approach to the patient's care. For example, many pediatric units announced that they have a (Christian) Bible in the book shelf, if someone would like to read it, but none said the same about Quran or Torah. The participating units also suggested lighting a candle (LED or regular candle depending on the unit's policies) into the room, but this can be very offending for Muslims or atheists, who might see that kind of religious symbols defamatory, depending on the individual opinions. (Laukkanen, 2001).

Simply asking about the family's wishes provides the best information about that particular family. This is already used when asking about the daily rhythms, the child's favorite meals, medicinal needs and so on, but can easily be expanded to reveal religious beliefs and cultural behaviors. After all, the family members themselves are the experts in what comes to their own traditions. Collisions might occur if professionals do not have basic knowledge about most common differences and special features, as Laukkanen (2001) mentioned. Fortunately pediatric care is nowadays focusing on the family-centered care, which makes the broadening of attention into cultural aspects easier, as the foundation for individual care already exists. Moreover, the pediatric units already have free visiting hours; it would not take much effort to officially expand them to concern also the relatives, and not just the closest family members, as in the future the perception of a family will be different for everyone.

Post mortem care is a situation where cultural traditions are clearly visible. (Hänninen, 2006a, 21). Most of the participating units said that they do not have any special post mortem care sets in use, mainly because there is no set made for children. Adult's post mortem care sets were used partially, or not at all. Many mentioned white boxes, which are used for deceased babies. Apart from the equipment used, hesitation arose in what came into clothing; sometimes the child's own clothes are encouraged to be used, but some doubt that the clothes will disappear along the way from possible autopsy to the funerals. Some use the unit's clothing, usually white in color but also pretty and colorful children's clothing is used, and some let the parents decide. A favorite toy or pacifier can be put onto the child's chest together with flowers. These routines varied a lot between pediatric units, especially in details. The one to perform post mortem care varied also within health care districts and pediatric units; usually the parents are allowed to participate, but sometimes it is not possible, depending on the unit type, overall premises or the fact that the child's corpse might be injured; seeing a possibly mutilated corpse might not help the parents in mourning process, and some parents do not want to see it, either. Nevertheless, some hospitals have special rooms for the purpose, and some hospitals recommend using any peaceful room that is available. Privacy and calmness was appreciated and cherished by every pediatric unit.

Supporting the mourning family shows another characteristic of pediatric care; the terminal care period does not end in the child's death, on the contrary it includes support for the parents and the family also after the child's death (Kübler-Ross, 1976, 122; Ivanoff et al., 2001, 298). The family-centered care is part of holistic pediatric care, and it includes the

time after the child's death. Some participating units took this into consideration by sending their condolences after a month has passed, some participate in the funerals and some can only arrange a meeting with the parents after a few months. Here we can see the differences between health care districts; some do only the actions which are considered to be necessary, such as the final meeting with the parents, and some use resources to support the family also in more creative ways. Each pediatric unit should investigate their possibilities and willingness to support for the mourning family in different ways, continuing the individual care until the very end of the caring relationship. For example, one unit calls to the parents six months after the death and simply asks how they are doing. The phone call may sound as a tiny thing to do, but it may have a huge effect to the family's memories. As we know, the time phase around the child's death is best remembered by the parents; all the gestures, smiles and most importantly words stick in the parents minds for the rest of their lives. Therefore attention should be paid also to the small details, and determine what kind of image the pediatric unit wants to give to the family during these hard times.

Similarity of recommendations about pediatric terminal care in literature showed well in this thesis, as many different writers from different decades say almost exactly same things. The same happened with the participating units; all health care districts provide similar pediatric terminal care, varying only in details. Not only are they similar with each other, the similarity is also seen between the literature's recommendations and the pediatric terminal care provided in practice. This indicates that pediatric terminal care in Finland is congruent, competent and follows the published recommendations. Deliberately or not, the main aspects of pediatric terminal care are obtained by the pediatric units just as the literature says they should. Regular schooling about the topic may be praised, as during the last years more attention is put to the phenomenon, but this common trend of holistic pediatric care has its roots in deeper than that. The reason might be the tacit knowledge progressing from the most experienced nurses in the field, passing the best instructions to younger generations and therefore influencing the modern care recommendations. The instructions and recommendations might be improved time to time when scientific research validates the old know-how, but they can never be automatically used as care plans; they are missing the individualistic touch nurses need to embrace in their work. This is the stumbling block that every guideline meets; being universal while focusing on individuals is indecisive battle.

## 8 Critical examination

For examining the quality of this thesis Lincoln and Guba's framework for quality criteria from 1985 is used. (Polit & Beck, 2012, 584). Trustworthiness overall is built from credibility, transferability, dependability, confirmability and authenticity (Polit & Beck, 2012, 175, 584), each one of them supporting the other aspects in reliability. The aim of this study was to find out how pediatric terminal care and post mortem care for up to 12-year-old children in Finland is performed. Information was collected from participating health care districts and their pediatric units by a questionnaire. To have these questionnaires' answers to be reliable and able to be compared to the literature, objectivity was required from the participating units; that the pediatric unit would give the same answer about their current care practices even if some other professional from the unit would have answered the questions. Own subjective judgements were asked to be left out, as Polit and Beck (2012, 191) guide about objectivity, which leads to confirmability or the study. Credibility and reliability are ensured by using several references, which are from different decades with still consistent information. The participating units' answers from the health care districts were also similar and consistent to the literature and the opposite, supporting the reliability of information gained and witnessing against researcher's interpretations or bias.

Objectivity in the participating units' answers and examining numerous books, articles and other reliable sources were aiming towards transferability; that these care practices can be transferred also into other settings. (Polit & Beck, 2012, 180). Qualitative studies do not typically aim to generalizability (Polit & Beck, 2012, 180) because it requires extrapolation which is not reasoned in qualitative studies where their findings are never free from their context. (Polit & Beck, 2012, 524). However, this particular study does also have characteristics of analytic generalization, where findings from particulars are strived to be generalized into a broader theory. (Polit & Beck, 2012, 525). Almost all health care districts did participate in the study, many of them sent answers from different pediatric units and therefore the results of the survey are representing the current pediatric terminal and post mortem care practices in Finland. The answers do also serve as a qualitative sample being generalized into a theory about a phenomenon, being strengthened by maximum variation sampling. No matter what word we use, the results represent general practices throughout the country.

Moreover, hand-picking the participants can easily lead to unwitting bias (O'Leary, 2010, 168), meaning only choosing participants who are known to support the hypothesis. However, in this study this was avoided by selecting numerous participating units to ensure that the variety of answers would be as high as possible. This means that all the participating units were as different from each other as possible in this narrow field. By choosing only few representatives the chances for finding the specific information sought with this study increased, as contacting professionals who do not provide care for these patients would not give applicable answers. This method is called sample selection, as this sample is broad enough to be a representative, large enough to be analyzed and small enough to be managed. (O'Leary, 2010, 162). This sampling type suited well for this thesis, and openly narrating about the methods in the name of transparency increases the level of credibility.

The reference literature is comprehensive, congruous and using sources from recently published books to few-decades-old theories. Even though some literature may be questioned due to the publishing year, the information in them is not outdated. The books and articles are classics in their area of expertise (Kübler-Ross, 1987; Kolcaba, 1994; Käypä hoito 2012), and used as references in further researches about the topics. Newer publications also agree with the older literature's key points; especially in terminal care the guidelines have been quite the same for decades. The multiplicity of textbooks, although from different times, and similarity in their contents establish the reliability of the study.

Offering the thesis to be used in different pediatric units across Finland creates certain expectations to the work; only properly performed and would be taken seriously in the health care districts. Therefore every action to make the study reliable was aimed to make. Fear of sample quality being jeopardized by small sampling was noted, but according to Polit and Beck (2012, 515) small, non-random samples are often used in qualitative studies, as they are aiming to different results than quantitative studies. The sample quality was therefore not seen as jeopardized, and using hand-picking strategy was acceptable under these circumstances. Using methods providing the best possible results without letting the scientific research process suffer in the process was well accomplished.

## 9 Discussion

The aim of this study was to disclose the current practices in pediatric terminal care and post mortem care for up to 12-year-old children in Finland; including narration about how nursing professionals can support and care for the child and the family in culturally competent way in variety of different nursing environments. The intention was to clarify what nurses need to think, ask and observe when caring for a child in terminal care. Focus was also on determining how nurses can take into account different cultures and religions while giving this care, because beliefs will with no question affect the child and the family. The study examined how literature describes the general practice guidelines that should be used in children's terminal and post mortem care and how the pediatric units really take care of these children in real life situations. The goal was to create comprehensive and public recommendations for nursing care actions in pediatric terminal care and post mortem care to be used in Finnish pediatric care units, because there seems to be no profound general guidelines available about the topic. The research questions for this thesis were:

1. What nursing actions are included in pediatric terminal care and why?
2. How do nurses in pediatric terminal care support the dying child and his/her family?
3. What do nurses need to acknowledge when giving culturally competent care in pediatric terminal care?

The research questions in this thesis examined closely the present status on pediatric terminal and post mortem care in Finland. The focus was on what kind of nursing care actions are included to the pediatric terminal care and why, how can nurses support for the dying child and his/her family but also what the nurses need to acknowledge when aiming for culturally competent pediatric terminal and post mortem care. A whole phenomenon was inspected. The study provided an answer for each research question. On the downside, all the different aspects and details in the pediatric units' terminal care plans cannot be seen when summarizing the results into a guideline. Unfortunately also the length of the thesis set some limits to the examining of the results; it was not suitable to present all the differences, all the smallest details and all the experience and knowledge the participating units have in a thesis.



The weakness in the results was the fact that the answers were so similar to each other and to the literature; it of course makes the researcher's work easier, but does not really bring up something new about the topic. However, now all the different, particular caring actions and know-hows that are the some pediatric unit's specialty are now spread to everyone. Hearing hints and different protocols from other health care districts is likely to be interesting for the participating units, as comparison in methods to give care is not usually done as extensively. It sets wonderful possibilities to brainstorming and improvements. This thesis will hopefully inspire the professionals to improve the nursing care provided in future and to modify the current protocols about the topic (as already known, some units have already made their own guidelines about pediatric terminal and post mortem care). Developmental processes continue in the background, aiming to elaborate the current protocols.

The pediatric terminal care in practice is similar to how it's presented at literature; know-how and tacit knowledge goes hand in hand with the articles, study books and guidelines. Does this imply, that the care provided is adapted to the literature's recommendations or that the literature is actually just narrating the characteristics of the pediatric terminal care given in the field, without any proofs to be evidence-based practice? Or does it mean that the health care professionals are caring for the family with common sense; are the characteristics of pediatric terminal so predictable, that the adequate care is given naturally without deeper thinking? I wonder, does a nurse act according to the thought of "this method is recommended in the literature" or "this method is proven to be good by the senior nurses", or which thought comes first? If all the experts say the same, does it mean that the public opinion is scientifically proofed? The main thing of course is that we use evidence-based practices in nursing sciences. The nursing field has an eagerness to create different recommendations that are easy to follow, aiming to help nurses at their work. Sense of security after following orders is one thing, but also the feeling that the nurse has done "everything needed" is a major part of the reasons why these guidelines are used. Helpful tools are generally accepted, and so are different check-lists in other areas. They also help new nurses to master their profession.

Nurses are constantly studying and refreshing their memory about diseases, medicines and operations; pediatric terminal care does not differ from them one bit. Therefore, care for terminally ill children can be given in different health care districts, in every pediatric unit there is; there is no need for centralizing the care into some special areas. Another question is that when the focus in pediatric terminal care is in home care, can the municipalities and

health care districts provide it to the families? The support measures that they offer differ significantly, depending where the family lives and in which health care district the child is taken care of. This makes the families in unequal positions; the distance from the family's home to the hospital should not affect to the care nor should it force the families move from their home. The municipalities should not decide the forms of support, the hospital should. Now, two families can receive a whole kind of different supportive actions when their child is dying, the only difference between them being the fact that they live in different municipalities, although just as far from the hospital.

There are differences also in the nurses' jobs, as care provided in multi-professional teams set limits to where each profession focuses on. Nurses are taught to see the patients holistically, including all the aspects of a person (physical, mental, social, emotional, spiritual and environmental). Many of these collide with the specialties of other professions in the team; physiotherapist focuses on physical part, priest or other religious mentor on the spiritual issues, psychologist with the mental resources and so on. What is left for the nurse is maybe controlling and surveillance of the patient's care. If some of the aspects are not taken care of, the nurse's responsibility is to work with that. If some other professional is already covering one need, the nurse mainly observes and evaluates if more actions are needed. In pediatric terminal care it is on every single nurse's conscience that the recommendations are followed and the best care possible is given to the child. The care is already greatly affected by the type of ward it is offered in. Still, family-centered care is in focus in almost every pediatric unit, even in intensive care units, where it is usually not considered to be the most important aspect in the care. Hurry and possible emergency situations tend to take attention away from holistic caring and support, which is understandable. The nature of an intensive care unit is different from a regular ward, as it should be, and therefore also the ideologies behind the care differ. On the other hand, in different types of caring environments providing family-centered care by multi-professional teams seems to be considered self-evident in pediatric units; so obvious that it might not even be separately mentioned.

Other thing that affects to the pediatric terminal care is that not all pediatric units have many of terminally ill children in a year. As understandable, this can effect to the nurses' skills and knowledge about the topic; if a nurse resuscitates a patient many times a week versus once in five years, it certainly affects to the nurse's skills in resuscitation. Same happens with pediatric terminal care; nurses cannot have as good knowledge and skills if they do not care for these children as those who do it every day. It is only understandable!

Not everything in nursing can be learned from literature, some things you must do by hand yourself. However, new nurses are not usually being the personal nurses for these children due to required level of experience. Interesting is, that new nurses should somehow gain the experience without taking care of these cases; how can a nurse learn these highly important things without any practice? When does the new nurse become skilled? I see high contradiction in the requirements, as everyone is working with their own personality; if under guidance from fellow nurses, how can new nurses care for these children “wrong”? Jokes are made from the superiors in the nursing field who have not actually worked in the field, but are still able to guide others. Are we going to the same direction when not letting the new nurses take care of these children? I advise for careful observation of contradiction. However, how can nurses gain experience without making the family suffer from unexperienced care? Working in senior-junior nurse pairs could solve this problem without causing ethical dilemmas.

After the child’s death, the length of support is determined by the family’s needs and wishes but also by the pediatric unit’s policies and resources. Recommendations talk about 1-2 months, some even about six months, and some pediatric units may struggle to have resources for even one month. All this makes it difficult for the nurse to maintain professionalism and on the other hand care for the family in a way they want. Some emphatic nurses after a long therapeutic relationship with the family cannot say farewells to the family immediately after the child’s death, and does not even make sense. But for the longer the relationship continues, the harder it is to end. After the final official meeting with the parents the hospital ends the interaction, but can a nurse who has become friends with the family do that? It requires mental strength, naturally, but can the work place determine what relationships nurses have on their free time? No matter what, the type of relationship changes into friendship where every party is equal to each other, without any protection of privacy from being a professional. Depending on the person, this might be even a wanted result; now s/he can be an actual friend without the limitations set by the workplace.

Can the nurse’s own belief and cultural traditions affect to the care provided? Yes. Can the nurse wittingly work towards cultural competence and give the family a chance to break the traditions and perform them in their own way? Are the nurses really culturally competent if they wonder and question the family’s beliefs? Nurses, too, are just humans, and sometimes differences and special wishes are seen as extra effort, affecting to the nurses’ attitudes towards the families (although nurses should always, always keep their

professionalism). Education can ease the collision between Western medicine and cultural traditions, as might simple conversation; motivating and reasoning the wishes make them seem more understandable than just demanding preferential treatment. The only tool against ignorance is education. We all know that it is easier to respect someone's actions when we know the reason behind it. On the other hand, nurse's task is not to be an expert in what comes to cultures, it is just additional way to respect individuality. Nurse is not a spokesman for different religions, but is only the patient's guardian in what comes to making the patient's wishes come true. To be that guardian, some basic knowledge is required about different cultures, but there is no need for higher education about the topic, unless of course if the nurse is interested in it.

The person's responsibility of own life covers some cultural wishes. The health care districts' purpose is not to offer different culturally competent services, but to show a place where the family can arrange wished services. It is not expedient for the hospital to provide shrouds or religious items. Being culturally permissive on the other hand is what we are aiming for, but no more. Of course equality is required; nurses cannot say they are culturally permissive if they only do that when the patient is Christian. In my opinion, if the hospital has a Bible they should also have a Quran, to be really culturally competent and permissive. To be permissive to some, and intolerant to some, shows only the person's immature and ignorance.

A child's death does not have to be a taboo, and scientific research is required also in this area of nursing. In future studies, researchers could focus on developing official Käypä hoito recommendations or other official nationwide guideline for pediatric terminal care. Improving our work is the only way to get better at it, and as a saying in nursing says, "*hoitaja ei ole koskaan valmis*" [translation: a nurse will never be finished (with learning)]. Therefore recommendations should neither be finished, but constantly updated. This thesis examined pediatric terminal and post mortem care broadly. Future studies could concentrate on particular areas mentioned in this topic: analgesia for children, cultural competence in post mortem care procedures with examples of religions or supportive actions that should be offered to every mourning family after loss of a child. The opportunities are endless. Also comparison to the adults can be done: how does pediatric terminal care differ from the care adults get? How does the pediatric post mortem care differ from the adult's? Or should the guidelines meant for adults be updated and changed to concentrate on similar things that pediatrics focus; multi-professionalism that is truly visible in the person's final moments, supporting family-centered care and home-like

environment, respecting individualism and supporting the patient's personality until the end? And even investigating how does the holistic care show with adult patients. There are many questions yet to be answered.

Further interest could also be guided into development of pediatric post mortem care sets. Nowadays there is only one set available, for adults, which does not serve all cases. We have other equipment adjusted for the children, everything from beds and clothes to smaller masks and intravenous cannulas, but no post mortem care set for children. Some pediatric units have solved this problem by creating own sets for children. It shows that there is an actual need for the sets, although not in the same way like adults' sets are needed. Some differences are required, though: clothing for children's corpses is not maybe needed, as the parents might want to dress the child in own clothes. Choosing the child's clothing is an important part of the farewells, and no parents will want their child to be treated "as anyone else". White clothing could be available in the units just in case, but maybe not in the sets.

In the future, pediatric terminal care will hopefully be even more carefully and holistically performed, with greater multicultural understanding and experience. Inspiring the nursing professionals to critically observe their own actions and improving their quality of nursing care is the best thing that a thesis can do. Further studies about the topic are expected with great interest.

## **10 Conclusion**

Pediatric terminal care is all about quality of life in the terminally ill child's final days. The child's family is closely attached to the care, and the caring environment is often the child's home. Nursing professionals' work is highly determined by the child's and the family's needs and wishes. This mentally challenging job is not for everyone; only experience will make a person become better at facing a dying child and comforting the mourning family. This thesis aimed to clarify different aspects of pediatric terminal and post mortem care, and provides recommendations for pediatric terminal care and post mortem care (Appendix 4) for the use of professionals in pediatric units all across Finland. The study found out that the recommendations in literature and the current caring methods in practice are very similar, but that both can give additional suggestions to one another,

aiming to increase the amount of ideas and tools to be used when caring for these children. Awareness of cultural collisions in terminal care was also increased, as time of death is one of the rare moments where the person's own beliefs truly become visible. Verification for the caring methods now used in the field was obtained, indicating that nursing professionals truly strive towards good quality in pediatrics but especially in pediatric terminal and post mortem care.

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## Appendix 1 Research permission form

14.06.2015

YRKESHÖGSKOLAN  
**NOVIA**

### LUPAHAKEMUS

Allekirjoittanut pyytää ystävällisesti lupaa suorittaa opinnäytetyön aineiston kerääminen Teidän työyhteisöenne avustuksella. Opiskelen englanninkielisessä Nursing-koulutusohjelmassa Yrkeshögskolan Noviaassa Vaasassa ja tulen valmistumaan sairaanhoitajaksi joulukuussa 2015. Opinnäytetyö (15 op) on osa sairaanhoitajan koulutustarjontaa ja sen aiheena on pediatrien terminaalihoidon ja lapsivainajan hoito rajaten lapsen iän 12 ikävuoteen asti. Opinnäytetyöni ohjaajina toimivat Ann-Helén Sandvik sekä Anita Ståhl-Levon. Aihevalintani pohjautuu yleisten toimintamallien puutteeseen pediatriassa terminaalihoidossa; tällä hetkellä yleisessä käytössä on vain Käypä hoito -suositus kuolevan potilaan oireiden hoidosta, joka valitettavasti keskittyy lähinnä aikuispotilaisiin eikä ota huomioon lapsipotilaiden erityistarpeita. Tarkastelenkin opinnäytetyössäni lapsipotilaiden terminaalihoidon nykytilaa Suomessa.

Tarkoitukseni on tehdä kyselytutkimus sähköpostin välityksellä, johon saa vastata kuka tahansa sosiaali- ja terveysalan ammattilainen, joka on hoitanut/hoitaa/voisi teoriassa hoitaa terminaalihoidovaiheessa olevia lapsia. Kysely koskee yksikön toimintatapoja ja -malleja lapsipotilaan terminaalihoidosta sekä lapsivainajan hoidosta. Vastaus annetaan työyhteisöyhteisenä ja sitä edustavana, vaikka vastaaja voikin olla yksittäinen henkilö. Aikeni on analysoida ja vertailla eri työyhteisöjen toimintatapoja sekä koostaa yhtenäinen toimintamalli käyttäen apuna kyseisiä vastauksia sekä kirjallisuutta. Valmis opinnäytetyö tulee olemaan nähtävillä ammattikorkeakoulujen opinnäytetöiden tietokannassa Theseuksessa ([www.theseus.fi](http://www.theseus.fi)) loppuvuodesta 2015.

Haluaisin saada aineistoni kerättyä heinäkuun loppuun mennessä, jos se vain on Teidän puolestanne mahdollista. Vastausaikaa voidaan pidentää kesälomien ja muiden ylityöaikojen syiden takia. Vastaaminen on täysin vapaaehtoista ja siitä voi peräytyä koska tahansa, ilman syyä ilmoittamista. Vastauksia tullaan käsittelemään nimettöminä, eikä yksittäisen työyhteisön vastauksia voida tunnistaa. Lähetän erillisen muistutuksen kyselystä noin viikko ennen heinäkuun loppua. Kyselyyn voi vastata lähettämällä liitteenä olevan kyselyn sekä suostumuslomakkeen sähköpostilla/kirjeenä johonkin alleolevaan osoitteeseen. Jos Teillä on kysyttävää aiheesta, pyydän ottamaan rohkeasti yhteyttä allekirjoittaneeseen tai opinnäytetyön ohjaajaani.

Ystävällisin terveisin,

Julia Kallinki  
Yrkeshögskolan Novia

Ann-Helén Sandvik (ohjaava opettaja)  
Yrkeshögskolan Novia

Liitteet: kysely  
suostumuslomake

## Appendix 2 The questionnaire

14.06.2015

YRKESHÖGSKOLAN  
**NOVIA**

### KYSELYLOMAKE

Allekirjoittanut pyytää ystävällisesti lupaa suositaa opinnäytetyön aineiston kerääminen Teidän työyhteisöenne avustuksella. Opiskelen englanninkielisessä Nursing-koulutusohjelmassa Yrkeshögskolan Noviassa Vaasassa ja tulen valmistumaan sairaanhoitajaksi joulukuussa 2015. Tämä yhteydenotoni koskee opintoihini kuuluvaa opinnäytetyön suorittamista, joka käsittää 15 opintopistettä. Opinnäytetyöni aiheena on pediatriinen terminaalihoido ja lapsivainajan hoito rajaten lapsen iän 12 ikävuoteen asti. Opinnäytetyöni ohjaajina toimivat Ann-Helén Sandvik sekä Anita Ståhl-Levon. Aihevalintani pohjautuu yleisten toimintamallien puutteeseen pediatriassa terminaalihoidossa; tällä hetkellä yleisessä käytössä on vain Käypä hoito -suositukset kuolevan potilaan oireiden hoidosta, joka valitettavasti keskittyy lähinnä aikuispotilaisiin eikä ota huomioon lapsipotilaiden erityistarpeita. Tarkastelenkin omassa opinnäytetyössäni lapsipotilaiden terminaalihoidon nykytilaa Suomessa.

Tarkoitukseni on tehdä kyselytutkimus sähköpostin välityksellä, johon saa vastata kuka tahansa sosiaali- ja terveysalan ammattilainen, joka on hoitanut/hoitaa/voisi teoriassa hoitaa terminaalihoidovaiheessa olevia lapsia. Kysely koskee yksikön toimintatapoja ja -malleja lapsipotilaan terminaalihoidosta sekä lapsivainajan hoidosta. Vastaus annetaan työyhteisön yhteisenä ja sitä edustavana, vaikka vastaaja voikin olla yksittäinen henkilö. Aiheeni on analysoida ja vertailla eri työyhteisöjen toimintatapoja sekä koostaa yhtenäinen toimintamalli käyttäen apuna kyseisiä vastauksia sekä kirjallisuutta. Valmis opinnäytetyöni tulee olemaan nähtävillä ammattikorkeakoulujen opinnäytetöiden tietokannassa Theseuksessa ([www.theseus.fi](http://www.theseus.fi)) loppuvuodesta 2015.

Pyydänkin Teitä käyttämään aikaa ja vastaamaan kyselyyni, jos tunnette kuuluvanne kohderyhmääni. Vastaaminen on täysin vapaaehtoista ja siitä voi peräytyä koska tahansa, ilman syytä ilmoittamista. Vastauksia tullaan käsittelemään nimettömänä, eikä yksittäisen työyhteisön vastauksia voida tunnistaa. Haluaisin saada aineiston kerättyä heinäkuun loppuun mennessä, jos se on vain suinkin Teidän puolestanne mahdollista. Vastausaikaa voidaan kuitenkin tarvittaessa pidentää esim. kesälomien takia. Lähetän erillisen muistutuksen kyselystä noin viikko ennen heinäkuun loppua. Kyselyyn voi vastata lähettämällä liitteenä olevan kyselyn sekä suostumuslomakkeen sähköpostilla/kirjeenä johonkin alleolevaan osoitteeseen. Jos Teillä on kysyttävää aiheesta, pyydän ottamaan rohkeasti yhteyttä allekirjoittaneeseen tai opinnäytetyön ohjaajaani.

Ystävällisin terveisin,

Julia Kallinki  
Yrkeshögskolan Novia

Ann-Helén Sandvik  
Yrkeshögskolan Novia



Hyvä vastaaja!

Ole hyvä ja vastaa mahdollisimman moneen kysymykseen. Vastaukset saa kirjoittaa joko tietokoneella tai käsin erilliselle paperille. Vastaus saa olla kuinka pitkä tai lyhyt tahansa, mutta toivonmitä kohteliaimmin kattavia sekä kuvailevia vastauksia. Käytähän myös selkeää käsialaa. Oheen saa liittää kuvia, toimintamalleja sekä muita käytössänne olevia ohjeistuksia, jos haluat. Lapsella tässä kyselyssä tarkoitetaan 0-12-vuotiaista ja terminaalihoidolla lapsen viimeisiä elinviikkoja/-päiviä.

1. Määrittele ensin työyksikkönne (valitse kaikki sopivat vaihtoehdot).

- a) ☐ julkinen sektori ☐ yksityinen sektori ☐ kolmas sektori
- b) ☐ yliopistosairaala ☐ keskussairaala ☐ aluesairaala ☐ terveyskeskus  
☐ hoitokoti ☐ muu; \_\_\_\_\_
- c) ☐ teho-osasto ☐ vuodeosasto ☐ poliklinikka ☐ kotisairaala  
☐ muu; \_\_\_\_\_

2. Kuinka usein hoidatte terminaalihoidossa olevaa lasta? Ketkä hoitavat häntä; kaikki vai vain osa henkilökunnasta? Kerrottehan myös ammattinimikkeet.

3. Miten lapsen terminaalihoito toteutetaan yksikössänne? Mitä lapsen terminaalihoito teille tarkoittaa? Kertokaa toimintamalleistanne.

4. Miten yksikkönne huomioi perheen uskontoon sekä kulttuuriin liittyvät toiveet?

5. Miten hoidatte lapsivainajan? Käytättekö valmista (aikuisten) exitus-settiä? Onko yksiköllänne omia tapoja/traditioita? Kuka hoitaa vainajan laittoa; saako perhe osallistua?

6. Koetteko tarvitsevanne lisäkoulutusta tai -ohjeistusta lapsen terminaalihoidosta tai lapsivainajan laitosta? Jos kyllä, minkälaista? Oletteko jo saaneet koulutusta aiheesta? Voisiko tästä opinnäytetyöstä olla hyötyä yksiköllenne?

Meiltä saa tarvittaessa kysyä lisätietoja yksikkömme toimintatavoista:

Ei ☐ Kyllä ☐ puh. \_\_\_\_\_

Kiitos vastauksistanne!



## Appendix 3 Informed consent

14.06.2015



### SUOSTUMUSLOMAKE

Pyydän mitä ystävällisimmin Teitä osallistumaan opinnäytetyöni aineiston keräämiseen vastaamalla ohessa olevaan kyselyyn. Opinnäytetyö (15 op) on osa sairaanhoitajan koulutustani ja aiheenani on pediatrisen terminaalihoidon ja lapsivainajan hoito rajaten lapseniä 12 ikävuoteen asti. Opinnäytetyöni ohjaajina toimivat Ann-Helén Sandvik sekä Anita Ståhl-Levon. Aiheeni on analysoida ja vertailla eri työyhteisöjen toimintatapoja lapsen terminaalihoidossa ja lapsivainajan hoidossa sekä koostaa yhtenäinen toimintamalli pediatrialle hoitoyksiköille käyttäen apuna kyseisiä vastauksia sekä kirjallisuutta. Aihevalintani pohjautuu yleisten toimintamallien puutteeseen pediatriassa terminaalihoidossa; tällä hetkellä yleisessä käytössä on vain Käypä hoito -suositus kuolevan potilaan oireiden hoidosta, joka valitettavasti keskittyy lähinnä aikuispotilaisiin eikä ota huomioon lapsipotilaiden erityistarpeita. Tarkastelenkin opinnäytetyössäni lapsipotilaiden terminaalihoidon nykytilaa Suomessa. Pyytäisinkin mitä nöyrimmin Teitä käyttämään aikaa ja vastaamaan kyselyyni, jos tunnette kuuluvanne kohderyhmääni.

Kyselytutkimus tehdään sähköpostin/kirjeen välityksellä, ja siihen saa vastata kuka tahansa sosiaali- ja terveysalan ammattilainen, joka on hoitanut/hoitaa/voisi teoriassa hoitaa terminaalihoidovaiheessa olevia lapsia. Kysely koskee yksikön toimintatapoja ja -malleja lapsipotilaan terminaalihoidosta sekä lapsivainajan hoidosta. Vastaus annetaan työyhteisön yhteisenä ja sitä edustavana, vaikka kirjoittaja voikin olla yksittäinen henkilö. Vastaaminen on täysin vapaaehtoista ja siitä voi peräytyä koska tahansa, ilman syytä ilmoittamatta. Vastauksia tullaan käsittelemään nimettömänä, eikä yksittäisen työyhteisön vastauksia voida tunnistaa. Kyselyyn voi vastata lähettämällä liitteenä olevan kyselyn sekä suostumuslomakkeen sähköpostilla/kirjeellä johonkin alleolevaan osoitteeseen. Vastausaikaa on heinäkuun loppuun asti. Vastausaikaa on kuitenkin mahdollista pidentää kesälomien ja muiden ympärilläsemättömien esteiden takia. Jos haluatte kysyä lisää aiheesta, pyydän ottamaan rohkeasti yhteyttä allekirjoittaneeseen tai opinnäytetyön ohjaajaani.

Julia Kallinki  
Yrkeshögskolan Novia



Ann-Helén Sandvik (ohjaava opettaja)  
Yrkeshögskolan Novia



Suostun yksikköni puolesta vastaamaan yllä mainittuun kyselyyn, jossa tarkastellaan yksikköämme käyttämiä lapsen terminaalihoidon sekä lapsivainajan hoidon toimintamalleja. Olen tietoinen opinnäytetyöstä, sen tarkoituksesta ja tavoitteista. Vastaan kyselyyn vapaaehtoisesti, ja minulla on milloin tahansa mahdollisuus keskeyttää vastaaminen syytä tarkemmin ilmoittamatta.

Päiväys

Kyselyyn vastaajan allekirjoitus



## Appendix 4



### **Suositus pediatriisesta terminaalihoidosta sekä vainajan laitosta**

### **Recommendations for pediatric terminal care and post mortem care**

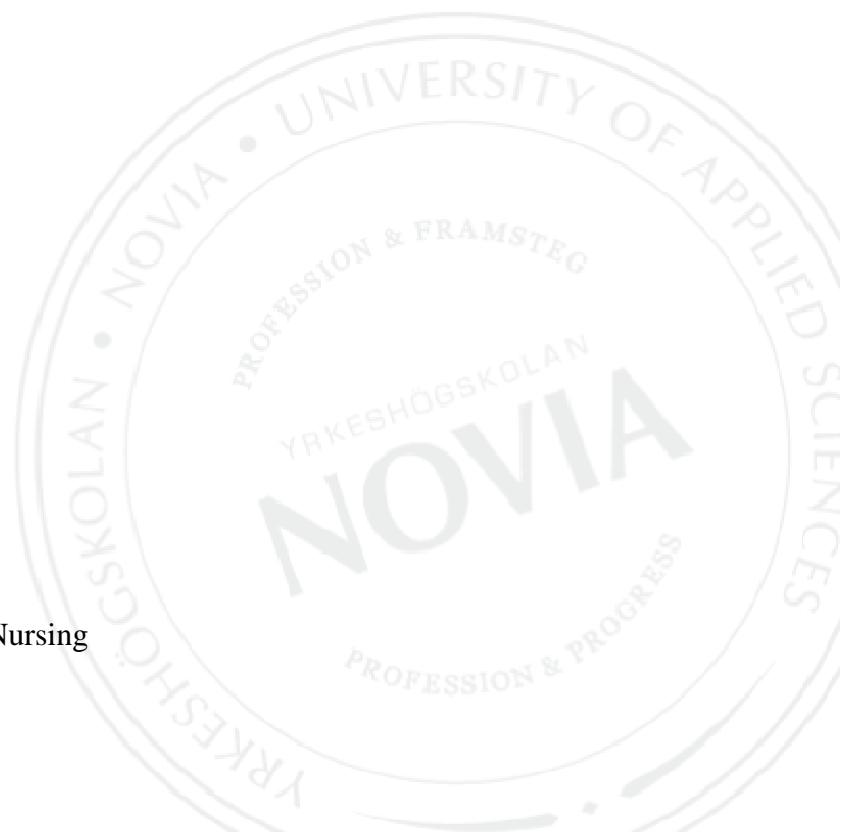
Julia Kallinki

NU12

The Degree Programme in Nursing

Yrkeshögskolan Novia

Vaasa / 2015



# Terminaalihoito

## Yleistä

Pediatriisella terminaalihoidolla tarkoitetaan lapsen viimeisiä elinviikkoja ja –päiviä. Se eroaa kestoaltaan saattohoidosta, joka voi kestää useita kuukausia. Terminaalihoidossa perheen tukipalvelut ovat olleet jo jonkin aikaa käynnissä ja mahdollinen apuvälineistö on hankittuna. Perhe on saanut jo käsitellä ajatusta lapsen kuolemasta ja luopumisprosessi on alkanut. Lapsen aktiivisuus on vähentynyt, eikä hän jaksa enää samalla tavalla kuin aikaisemmin.

## Pediatriisen terminaalihoidon periaatteet

Pediatriisella terminaalihoidolla on muutamia erityispiirteitä, jotka erottavat sen aikuisten terminaalihoidosta. Lapsi on lapsi loppuun saakka, ja hänen maailmaansa kuuluu olennaisesti leikkiminen. Lapsi nähdäänkin ensisijaisesti aina omana itsenään, ei kuolemansairaana potilaana. Toiseksi, lapsi on aina perheensä jäsen, jolloin huolenpito ulottuu aina myös perheenjäseniin. *Perhekeskeinen hoito* tarkoittaa usein vierailuaikojen puuttumista, perheenjäsenten huomioimista sekä heidän tukemistaan lapsen sairastaessa.

Kuten sanottu, lapsi on aina yksilö. *Yksilöllinen hoitotyö* koostuu lapselle tehdystä yksilöllisestä hoitosuunnitelmasta sekä lapsen ja perheen toiveiden kuuntelusta. Tavoitteena on tehdä terminaalihoidosta lapselle niin elämänmakuinen, turvallinen ja kodinomainen kuin mahdollista. Aikuisten tulee tehdä kaikkensa, että lapsi saa olla oma itsensä, sairaudesta huolimatta. Lapsen omia mielipiteitä tulee kuunnella ja *itseäänmäärittämisoikeutta* kunnioittaa. Tarvittaessa lapsen huoltaja toimii lapsen edunvalvojana, jos lapsen mielipidettä ei voida kuulla tai lapsi on liian nuori päättämään hoidostaan.

Terminaalihoito keskittyy lapsen voinnin kohentamiseen sekä elämänlaadun ylläpitämiseen juuri ennen kuolemaa. *Palliativisesta eli oireita lievittävästä hoidosta* jäljelle ovat usein jääneet vain hyvä perushoito sekä kivun hoito. *Hoidon jatkuvuus* pyritään turvaamaan *omahoitajuudella* sekä *tutulla hoitoympäristöllä*. Perhe saa valita hoitoympäristön, jolloin vaihtoehdot ovat kotihoito, laitoshoido tai näiden yhdistelmä.



Hoitoympäristön saa vaihtaa milloin vain, ja vanhemmilla on oltava mahdollisuus olla yhteydessä sairaalaan ympärivuorokautisesti. Vaikka lapsen ensisijaiset hoitajat kotihoidossa ovatkin vanhemmat, on hoitovastuu aina sairaalalla. Monien mielestä paras paikka lapselle on koti.

Saattohoitovaiheessa lapsesta huolehtii *moniammatillinen tiimi*. Tiimityö voi jatkua niin kauan terminaalihoidon edetessä, kunnes ammattihenkilö kokee, ettei voi enää parantaa lapsen elämänlaatua. Lapsen väsyessä ja erilaisten oireiden ilmaantuessa tulee terminaalihoidon muokkautua lapsen senhetkiset tarpeet huomioon ottaen; todennäköisesti lapsen tila ei enää kohennu, ja hänen osaamistasonsa ja jaksamisensa taantuu väsymisen mukaan. Silti esimerkiksi ravitsemusterapeutin avusta voi olla suunnatonta hyötyä lapsen viimeisten elinpäivien aikana, kun mietitään lapselle maistuvaa ruokavaliota ja sen toteuttamista. Myös muut tukimuodot voivat olla lapselle hyödyksi jatkuessaan mahdollisimman pitkään, tietenkin lapsen yksilöllinen tilanne ja yleisten hoitotarpeiden luonne huomioon ottaen.

*Psykologinen tuki* on olennainen osa pediatria terminaalihoidoa. Sekä kuoleva lapsi että perheenjäsenet, sisaruksia ja myös isovanhempia unohtamatta, tarvitsevat ammattilaisten tukea tunteiden sekä ajatusten läpikäymiseen. Vanhempien surun osoittaminen auttaa myös lasta ilmaisemaan omia tunteitaan. Lapsen ymmärrys kuoleman luonteesta sekä lopullisuudesta kehittyy lapsen kasvaessa, mutta se ei estä aikuisia kertomasta lapselle hänen tulevaisuudestaan, tietenkin hänen ikätasonsa ja kehityksensä mukaisesti. Rehellisyys on tärkeää, sillä lapsi vaistoa salailun ja valehtelun, jolloin luottamus lapsen ja aikuisten välillä kärsii, ja lapsi voi jäädä yksin pohtimaan vaikeita asioita. Tutkimukset sanovat, että jo pienet lapset aistivat kuoleman läheisyyden, ja he tarvitsevat silloin luotettavan aikuisen turvaa. Lapset saattavat esittää suoria kysymyksiä kuolemasta, ja aikuisten tulee olla valmiita näihin kysymyksiin. Terminaalihoidoon kuuluu aina perheen kunnioittava kohtelu, kuunteleminen sekä aito läsnäolo. Yleisesti ottaen sekä lapsi että perhe tarvitsevat paljon tukea, ja hoitohenkilöstön tulisi selvittää alueellansa tarjottavat mahdolliset *tukimuodot* näille perheille ja kannustaa perhettä käyttämään niitä. Suru ja sen käsittely on jokaiselle yksilöllistä, eivätkä perheenjäsenet ikinä toivu täysin ennalleen lapsen kuoleman jälkeen. Elämän on kuitenkin jatkuttava, ja jotkut perheet tarvitsevat tähän enemmän tukea kuin toiset.

*Kulttuurien huomiointi* kuuluu läheisesti terminaalihoidoon, sillä harva asia on niin kulttuurisidonnainen kuin kuolema. Kuolemaan liittyvät traditiot ja valmistelut, sekä erityisesti vainajan laitossa esiintyvät kulttuuriset erityispiirteet näkyvät myös

lapsipotilaiden hoidossa. Lisäksi, kuolevalla ihmisellä on monia henkisiä kysymyksiä alkaen kuoleman kivuliaisuudesta jatkuen olemassaolon tarkoitukseen. Vaikka henkilö ei olisi ikinä ennen eläessään ollut uskonnollinen, voivat toiveet muuttua kuolinvuoteella. Näitä toiveita ja pyyntöjä tulee kunnioittaa, ja hoitohenkilöstön tulee tehdä osansa näiden toiveiden toteuttamisessa. Pediatrinen hoitotyö panostaa *kokonaisvaltaiseen hoitoon*, johon kuuluu myös henkisistä tarpeista huomioiminen. Kuolevalla on oikeus sairaalapastorin tapaamiseen mihin kellonaikaan tahansa, ja tarvittaessa hoitohenkilöstön tulee tukea kuolevaa hengellisen tukihenkilön poissaollessa. Pelkkä läsnäolo sekä kuunteleminen riittävät, henkilön ei tarvitse osata yksityiskohtia eri uskonnoista. Hengellisten kirjojen tarjoaminen tai kynttilän sytyttäminen sallittaessa ovat pieniä tekoja, jotka voivat merkitä kuolevalle paljon. Jos tukihenkilö on itse uskonnollinen ja jakaa saman uskon kuolevan kanssa, voi tuntua luonnolliselta esimerkiksi rukoilla yhdessä. Suomessa hengellisyys on perinteisesti nähty yksilön omana asiana, mihin ei haluta puuttua, mutta kuolinvuoteella pienikin uskon tarjoama lohtu tulisi taata.

Erilaiset kulttuurit voivat näkyä myös lähisukulaisten määrässä, puhutussa kielessä, vaatetuksessa, huoneen sisustuksessa, hoitotavoissa sekä kuolevan lapsen tarpeissa. Vainajan laitto on viimeinen mahdollisuus (hautajaisia lukuunottamatta) kunnioittaa yksilön uskoa, jolloin siihen yleensä panostetaan erityisellä halulla. Myös henkilöt, jotka eivät ole uskonnollisia tai eivät esitä erityisiä toiveita vainajan laitosta haluavat toimituksen olevan mahdollisimman kaunis ja erityinen. Lapsi voidaan pukea omiin juhla-vaatteisiin tai muuten erityisiin vaatteisiin. Kunnioitus kuolemaa ja vainajaa kohtaan näkyy rauhallisuutena sekä asiallisuutena. Lisää vainajan laitosta myöhemmin tässä suosituksessa.

### **Terminaalivaiheen hoidot**

Terminaalivaiheessa keskitytään hyvään perushoittoon sekä kivunlievitykseen. Perushoittoon kuuluu ravitsemuksesta sekä nesteytyksestä huolehtiminen, ihonhoito sekä mahdollinen haavanhoito, yleisestä hygieniasta sekä erityisesti suuhygieniasta huolehtiminen, erityistoimintojen ylläpitäminen, tarvittavasta lääkehoidosta huolehtiminen sekä muista erilaisista tarpeista huolehtiminen. Lapsella on lapsen toiveet, ja hänen yksilöllisyytensä tulee tukea viimeiseen asti. Tavoitteena on parantaa elämänlaatua kaikin mahdollisin keinoin; myös haavanhoidolla on merkitystä mm. hajujen eliminoimisessa ja

kivun ennaltaehkäisyssä. Vaikkei haavan mahdollinen parantuminen elinaikaan vaikuttaisikaan, lapsen yleinen kokemus omasta voinnista paranee.

Mainitsen kivun hoidon erikseen sen tärkeyden vuoksi. Lasten kivunhoitoa ja sen tarpeellisuutta on pitkään vähätelty, mutta nykyisin ymmärretään sen tärkeys lasten hoidossa. Lapset tuntevat kipua samoin kuin aikuisetkin, jopa herkemmin, joten kivun ennaltaehkäisy ja asiallinen hoito on terminaalihoitovaiheessakin perusteltua ja vaadittua. Eri lääkemuodot sopivat eri lapsille, ja parhaan yhdistelmän löytäminen on avainasia. Terminaalihoitovaiheessa ei enää huolestuta sietokyvyn kasvamisesta samoin verroin kuin palliatiivisen hoidon aikana; pääasia on saada lapsen kiputuntemus katoamaan. Vanhemmat saattavat pelätä lapsen tajunnantason muutoksia, mutta tavoite tulisi olla tehokkaassa kivunlievityksessä niillä annoksilla, jotka lapsi tarvitsee. Aluksi lapsi voi itse rajoitetusti annostella boluksia, mutta lapsen voinnin heikentyessä tulee lapsen kehonkieltä tarkastella säännöllisesti. Jokaisella kuolevalla on oikeus turvalliseen ja kivuttomaan kuolemaan, vaikkeivät he tahtoaan osaisikaan kertoa.

Muut mahdolliset hoidot, kuten antibioottien, verivalmisteiden sekä erilaisten toimenpiteiden ja operaatioiden käyttö, ovat hoitavan lääkärin päätettävissä. Turhia toimenpiteitä vältellään, ja ainoastaan lasta hyödyttäviä hoitoja harkitaan. Monitorointi ja laboratoriotestien otto on yleensä turhaa; ainoastaan oireita ja niiden hoitoa tulee arvioida jatkuvasti. Loppuvaiheessa perushoito tulee välttämättä pääosaan, ja elintoimintojen heikentyessä hygieniasta huolehtiminen nousee fyysisistä tehtävistä tärkeimmäksi.

## Oireet

Kuolevalla lapsella voi ilmetä monia oireita. Ylimääräisiä sekä turhia hoitoja ei enää tulisi tehdä, mutta oireiden lievittäminen parantaa lapsen vointia sekä elämänlaatua. Tavoitteena ei ole pidentää lapsen elämää, vaan tehdä viimeisistä hetkistä mahdollisimman siedettäviä sekä lapselle että hänen perheelleen.

Yleisiä oireita ovat:

- kipu
- ruokahaluttomuus
- pahoinvointi
- oksentelu
- ummetus
- ripuli
- limaisuus
- hengenahdistus
- heikkous
- levottomuus
- masennus
- unettomuus
- hourailu

Lapsi voi oireilla myös muilla tavoin. Taantuminen kehityksessä on yleistä, samoin käyttäytymisen muutokset; ennen varsin itsenäinen esiteini kaipaakin vanhempien syyliä, kuivaksi oppinut taantuu vaippoja tarvitseväksi tai ennen niin rauhallinen lapsi onkin yhtäkkiä aggressiivinen ja äkkipikainen. Oireet määräytyvät suurilta osin sairauden laadusta ja sen etenemisnopeudesta, mutta myös kehon toimintojen hidastumisesta ja lopulta pysähtymisestä, samoin lapsen luonteesta. Kuoleman lähestyessä oireet pahentuvat, mikä voi järkyttää sekä lasta että hänen perhettään. Oireiden suunnitelmallinen hoito on perusteltua, eikä esimerkiksi kivunhoitoa tule ”säätellä”. Hyvään perushoitoon kuuluu oireista huolehtiminen, niiden ehkäiseminen sekä potilaan voinnin parantaminen.

Oireiden hoito on tavoitteellista, tehokasta sekä ennakoivaa. Kivun lääkehoitoa voidaan tukea vaihtoehtohoidoilla ja ruokahalua tuetaan tarjoamalla mieliruokia helposti nieltävässä muodossa. Usein raikkaat maut maistuvat kuolevalle parhaiten. Pahoinvointia ehkäistään lääkehoidolla sekä ruokailun rutiineilla, mutta sairauden edetessä voi pahoinvointi vaikuttaa suuresti ruokahaluun: miksi syödä, kun pian taas oksettaa? Kuitenkin kuihtuminen laskee elämänlaatua nopeasti, ja syömisellä on monia, myös mielenterveydellisiä, vaikutuksia. Elintoimintojen hidastuessa ummetus ja myöhemmin ripuli ovat haaste vuodelevossa olevalle kuolevalle, ja mahdollisten makuuhaavojen ilmentuminen ei paranna lapsen oloa. Esiteini-ikäiselle voi vaippojen käyttö aiheuttaa suurta häpeää ja epämukavuutta.

Hengitysteiden oireet voivat aiheuttaa ylimääräistä stressiä sekä kuolevalle lapselle että läheisille. Limarohina voi kuulostaa pelottavalta omaisten korvissa, kun taas lapsi itse ei välttämättä häiriinny tästä. Yskä voi taasen vaikeuttaa unta, ja sattua kylkiin vaivan pitkittyessä. Liman imemistä, höyryhengitystä sekä muita lääkkeettömiä tapoja kannattaa hyödyntää, muttei unohtaa lääkkeiden apua vaivoihin.

Terminaalivaiheen oireiden hoidossa lopputulos ratkaisee enemmän kuin tapa, jolla siihen päästään. Läsnaololla ja kuuntelulla voi olla yllättävä vaikutus särkyihin, ja mieliruualla voi joskus paha olokin haihtua. Jos lapsi haluaa keskustella, tulee aikuisten olla valmiita siihen. Lapsi ei välttämättä halua uskoutua vanhemmilleen, vaan ajautua keskusteluun myös muiden aikuisten ja jopa lasten kanssa. Elämän tarkoitus ja muut suuret kysymykset mietityttävät myös lapsia, ja he rakastavat kuulla tarinoita siitä, miten he vaikuttivat muiden elämään täällä ollessaan, ja miten heitä tullaan kaipaamaan. Pienikin lapsi etsii syytä elämälleen, vaikkei sen tarvitsekaan olla kummoinen. Joskus tieto siitä, että äiti ja isä rakastavat juuri heidän omaa pientä lastaan ja että he ovat onnellisia siitä kun saivat hänen kanssaan leikkiä, riittää.

Pelko ja ahdistuneisuus tuntemattomasta on yleinen oire kuolevalla. Ymmärrettävästi; varmaankin jokainen tuntee pelkoa elämän päättymisestä jossain kohdin elämäänsä. Jäljellä olevan elämän takia ahdistuneisuutta tulisi hoitaa ja pelkoja hälventää; ei kannata etukäteen uhrata koko ajatusmaailmaansa asialle, jolle ei voi mitään. Asia on tietysti helpompi sanoa, jos ei ole itse kuolemaisillaan. Näitä tunteita ei siis tule missään nimessä väheksyä, vaan ymmärtää ajatusten kumpuaminen ihmiselle luontaisena toimintana. On osoitettu, että jopa pieni lapsi ymmärtää kuolevansa, vaikkei sitä osaa erikseen nimetä. Suurin pelko voi hyvinkin olla yksin jäämisen pelko, mutta kuoleman mahdollinen kivuliaisuus aiheuttaa myös pelkoa. Omien ajatusten läpikäyminen onkin kuolevan suurin voimia kuluttava taakka, jota ilman hän ei saa rauhaa. Lapsen tukeminen tässä aikuisiakin järkyttävässä pohdinnassa ja oman elämänsä hyväksymisessä on erityisen haastavaa, mutta myös erittäin tärkeää.

## **Kuolema**

Kun kuolema on lähestymässä, luota pelkän läsnäolon riittävyyteen ja kosketuksen voimaan. Perhe saa olla keskenään, jos he niin haluavat, mutta omahoitajan läsnäolo voi olla myös tervetullutta. Tarjoa koko perheelle tukea. Jos perheenjäsenet eivät ole paikalla, kun lapsen olo huononee, tulee heille ilmoittaa tilanteesta mihin vuorokaudenaikaan tahansa. Tärkeintä tässä vaiheessa on hoitaa lapsen kipua; yliannostusta tai lääkkeiden vaikutusta lapsen tajunnantasoon ei ole enää asianmukaista pohtia, jos lapsella selvästi on kipuja. Muistakaa kysyä hätäkasteen antamisesta jo etukäteen, jos lapselle ei ole annettu vielä nimeä.

Läheisille tulee antaa riittävästi aikaa jäähyväisille. Viimeiset hetket perheenä ovat kallisarvoisia ja ne tullaan muistamaan koko loppuelämän ajan. Enää ei ole kiire, kenelläkään. Viimeistään tässä vaiheessa vanhempia kehoitetaan taltioimaan muistoja lapsesta; videoita ja kuvia otetaan tarvittaessa sairaalan kameralla, hiustupsuja leikataan ja tehdään käden- ja jalankuvat paperiarkille. Lasta saa pitää sylissä vaikka koko ajan. Taustalle voidaan halutessa laittaa rauhallista musiikkia soimaan, tai lapsen omaa lempimusiikkia. Tilanteesta tehdään mahdollisimman kaunis, rauhallinen sekä lapsen itsensä näköinen. Perheelle voidaan tarjota kahvia ja teetä sekä pientä syötävää hyvien käytöstapojen mukaisesti.

Ammattilaisten tehtävänä on toimia perheiden käytännön apuna kuolemaa koskevissa kysymyksissä. Paras vaihtoehto on käydä asiat läpi jo ennen lapsen kuolemaa, aloittaen kuoleman toteamisesta ja päättyen vainajan laittoon ja siihen mahdollisesti liittyviin erityistoiveisiin. Surun keskellä on vaikeaa sisäistää ohjeita, joten selkeitä lyhyitä lauseita tulisi käyttää. Ylimääräistä informaatiota ei kannata antaa samasta syystä. Yksiköllä voisikin olla lista rutiineista, jotka perheen tulisi huomioida, sisältäen hautauslupien saamisen ja lapsen tavaroiden keräämisen. Lisäksi annetaan puhelinnumero, johon saa ottaa yhteyttä kuoleman sattuessa (jos hoito ei tapahdu sairaalassa). Myös hautaustoimistot auttavat hautaamiseen liittyvissä käytännön asioissa.

Jos lapsi kuolee kotona, ei ruumista tarvitse heti tuoda sairaalaan. Jos kuolema tapahtuu illalla/yöllä, voi ruumiin kuljettaminen odottaa aamuun. Kotona ollessa täytyy ottaa huomioon asiat ruumiin säilytyksestä, hautaustoimistosta saa lisätietoja. Lapsen ruumiin saa myös ottaa kotiin; ruumiin käsittelylle ei ole muita sääntöjä kuin että sen tulee olla vainajaa kunnioittavaa ja ruumis on pakko haudata tietyn ajan kuluessa. Hoitohenkilöstön täytyy muistaa eri kulttuurien tavat esimerkiksi ruumiinvalvojisista.

Henkilökunnan yhteydenpito perheen kanssa ei saisi päättyä lapsen kuolemaan, vaan tulisi jatkua myös sen jälkeen, perheen tarpeiden sekä toivomusten mukaan. Yhteydenpito on väliaikaista ja tapahtuu ammatillisuuden rajoissa, mutta hoitoyksiköt voivat itsenäisesti päättää, miten tukevat perheitä ja kuinka kauan. Tärkeintä on, että perhe kokee ammattilaisten olevan kiinnostuneita heidän hyvinvoinnistaan myös lapsen kuoleman jälkeen. Ensimmäinen tapaaminen on yleensä järjestetty omalääkärin sekä omahoitajan kanssa pian kuoleman jälkeen. Silloin tulisi käydä läpi lähinnä konkreettisia asioita. Yleisesti suositellaan toista tapaamista muutaman kuukauden kuluttua, jossa käydään läpi tarkemmin lapsen hoitoa, mahdollisen ruumiinavauksen vastauksia tai vanhempien mieltä vaivaavia asioita. Heidän kuulumisiaan sekä arjen sujumista tulee arvioida, ja tarvittaessa

ohjata lisäävun piiriin. Näiden tapaamisten lisäksi vaihtelevia tapoja on soittaa perheelle lapsen kuolemaa seuraavana päivänä ja kysyä voinnista ensimmäisen yön jälkeen, tai lähettää osanotto-kortti muutaman viikon päästä kuolemasta. Jotkut yksiköt osallistuvat hautajaisiin kutsuttaessa, ja jotkut lähettävät perheelle kortin tai soittavat lapsen kuoleman vuosipäivän aikoihin. Myös haudalle on viety kynttilöitä. Riippuu täysin sairaalan resursseista sekä yksikön luonteesta, millä tavoin voidaan perhettä muistaa surun keskellä.

Lapsen kuolema koetaan erityisen raskaaksi myös hoitohenkilöstössä. On sanottu, ettei kukaan kykene hoitamaan ainoastaan kuolevia, ja tämä korostuu lasten kanssa työskennellessä. Omien lasten olemassaolo muuttaa myös hoitajan asennetta terminaalihoidossa oleviin lapsipotilaisiin. Loppuunpalamisen estämiseksi sekä omien tunteiden purkamiseksi tarvitaan työyhteisössä avointa ilmapiiriä, sallivuutta sekä suunniteltuja työnohjauksia. Hoitajan omat käsitykset kuolemasta joutuvat myös koetukselle, eikä ihminen ikinä täysin hyväksy omaa kuolevaisuuttaan. Pysyäkseen työkykyisenä tulee jokaisen kuolevia tapaavan henkilön tietoisesti pyrkiä käsittelemään tunteensa ja ajatuksensa sekä tarvittaessa ryhtyvän toimiin henkistä kuormitusta vastaan. Tunteiden ilmaiseminen on aina sallittua, mutta ammatillisena pysyminen kuuluu työnteekoon; lapsen kuollessa henkilökunnan tulee lohduttaa vanhempia, eikä toisin päin. Oman esimiehen puoleen saa kääntyä, jos kokee oman jaksamisensa horjuvan.

## **Vainajan laitto**

Ennen varsinaista vainajan laittoa tulee ruumiinavauksen tarpeellisuus selvittää. Jos ruumiinavaus tehdään, tulee kaikki hoitovälineistö jättää ruumiiseen (esim. kanyylit, dreemit, katetrit) niin kuin ne lapsen kuollessa oli. Jos asiasta ollaan epävarmoja, on ne parasta jättää koskematta. Jos lapsi on kuollut pitkällisen sairauden uuvuttamana ja kuolinsyy on selvä, ei ruumiinavausta välttämättä tehdä. Tällöin kaikki ylimääräinen poistetaan ruumiista, ja vainaja saa olla niin luonnollinen kuin mahdollista.

Myös vainajalla on oikeus omaan vakaumukseensa, joka hänellä oli ennen kuolemaansa. Kulttuurinen pätevyys on osa myös vainajan laittoa; kaikkia eri kulttuurien tai uskontojen erityisistoiveita ei tarvitse tietää, mutta niistä täytyy osata kysyä. Vanhemmat tai tarvittaessa heidän uskonnollinen tukihenkilönsä osaavat kertoa tarvittavista käytännöistä ja tavoista.

Esimerkkikysymyksiä perheille kulttuurista riippumatta voivat olla:

- Haluavatko perheenjäsenet olla läsnä vainajan laitossa? Haluavatko vanhemmat hoitaa siistimisen, vai ovatko hoitajat mukana? Saavatko hoitajat olla läsnä tilanteessa? Onko hoitajien sukupuolella väliä?
- Millaisia tapoja teidän kulttuuriinne/uskontoonne liittyy vainajan laitosta? Tulisiko tiettyjä rituaaleja ehdottomasti noudattaa? Tarvitsetteko mitään erityistä sairaalalta asiaan liittyen? (Esim. erillinen pesuhuone, suojavaatteita, hoitajien apua yms).
- Mitä perheenne arvoja toivotte hoitohenkilökunnan kunnioittavan?
- Saako huoneessa olla uskonnollisia tunnuksia? Haluatteko musiikkia/kynttilän/Raamatun tai Koraanin/jotain muuta?
- Kutsunko sairaalapapin tai jonkun muun henkilön paikalle teidän puolestanne? Jos perheen oman uskonnon edustajaa ei ole saatavissa, saako ev.lut. pappi tulla paikalle? Saako lapsen siunata? Haluatteko hätäkasteen? Sallitaanko huoneessa rukoulu/laulaminen?
- Pestäänkö lapsen keho kokonaan vai siistitäänkö vain? Kuuluuko vainajan pesu osaksi sakramenttia/saako hoitohenkilökunta pestä vainajan?
- Puetaanko lapsi omiin vai sairaalan vaatteisiin? Kapaloidaanko pieni vauva?
- Haluatteko laittaa lapsen mukaan hänen tuttinsa/lempilelunsa/piirustuksen/jotain muuta? (Muistuta, että on olemassa riski näiden esineiden katoamisesta!)
- Onko lapsella itsellään tiettyjä toiveita? Miten vanhemmat toivovat, että hoitajat käyttäytyvät tilanteessa; haluaako perhe hoitajan läsnäoloa?
- Saako sairaala tarjota kahvia/teetä perheelle? Onko mahdollisille tarjottaville rajoituksia?
- Saako ikkunan avata kuoleman jälkeen (jotkut uskovat sielun poistuvan sitä kautta)? Saako huoneessa olla peilejä/tulisiko peilit peittää (jotkut uskovat sielun jäävän sinne jumiin)?

Vanhemmille tulee täsmentää, ettei vastauksia tarvitse tietää nyt, vaan vanhemmat voivat jatkuvasti kertoa toiveistaan niiden ilmaantuessa. Kysymykset ovat lähinnä hoitajan tietoisuuden lisäämiseen ja apuvälineenä takaamassa väärinkäsitysten välttämisen. Tavoitteena on hyvä hoito loppuun asti.

Kuollutta kunnioitetaan, muttei pelätä. Vainajan käsittely pyritään pitämään ulkopuolisten silmien ulottumattomissa, myös esimerkiksi siirrettäessä vainajaa patologian osastolle. Vainajaa kohdellaan yhtä kunnioittavasti kuin hänen eläessään, ja lyhyt hiljainen hetki



pidetään aina ennen kuin aloitetaan vainajan laitto. Hienotunteisuutta noudatetaan, vaikkei omaisia olisi paikalla.

Vainaja asetetaan selälleen ja raajat suoristetaan. Jalat sidotaan yhteen (paitsi vauvoilla). Kaikki ylimääräiset letkut, haavasidokset ja muut hoitotarvikkeet poistetaan, jos siihen on saatu lupa. Jos vainaja pestään kokonaan, tehdään se erityisellä pesulaverilla; muutoin ruumis siistitään pesulapuilla. Erittäville haavoille voidaan laittaa uudet haavalaput. Silmät suljetaan, ja silmäluomien päälle laitetaan kostutetut vanut. Vaipan käyttöä lapsipotilailla suositellaan, sillä usein heidät puetaan omiin vaatteisiin. Jos käytetään exitus-setin valkoista kuolinpaitaa, voi vuodesuojakin riittää. Hiukset kammataan. Vainaja tehdään mahdollisimman luonnollisen näköiseksi, mutta toiveita kunnioittaen: jos esim. esiteini haluaa ehdottomasti huulikiiltoa tai kynsilakkaa, voidaan toive täyttää (edellyttäen, ettei ruumiinavaus aseta sille estettä). Tunnistelaput kiinnitetään lapsen jalkoihin.

Vauva kapaloidaan valkoiseen lakanaan. Isompi lapsi voidaan peitellä nukkuvan näköiseksi nättien lakanoiden alle, ja peittää sitten valkoisella lakanalla. Lakanasta voidaan muotoilla risti, jos lapsen uskonto sen sallii. Päälle voidaan asettaa oikeita kukkia/muovisia tekokukkia/virkattuja kukkia. Hoitovälineet siivotaan huoneesta pois ja huone tuuletetaan jos perhe niin tahtoo/jos mahdollista. Ympäristöstä tehdään niin kaunis kuin mahdollista, olosuhteet huomioon ottaen. Huoneeseen voidaan sytyttää kynttilä, jos se ei loukkaa perheen uskontoa. Taustalle voidaan myös halutessa laittaa musiikkia soimaan. Perheelle annetaan tarpeeksi aikaa hyvästelyihin, juuri niin kauan kuin he tarvitsevat.