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Support Methods for Relatives of Palliative Patients

Heino, Sini-Tuulia & Rihia, Katisha

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Support Methods for Relatives of Palliative Patients

Sini-Tuulia Heino & Katisha Rihia
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Heino, Sini-Tuulia; Rihia, Katisha

Support Methods for the Relatives of Palliative Patients

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The purpose of this study was to study support methods, which are meant to support relatives of palliative patients. We wanted to study what kind of support methods there are to support the relatives of palliative patients. The World Health Organization (2016) defines palliative care as care provided for a person who has been diagnosed with an incurable disease. In palliative care, you cannot only consider the wellbeing the palliative patient but also the wellbeing of the family of the patient (WHO 2016).

The emphasis of the support is on the patient; on the other hand, the relatives should not be forgotten. The disease of the patient affects the whole family. Palliative care impacts the patient's life and it also influences the life of the relatives. The relatives face difficult feelings throughout the palliative care process. (Grönlund, Anttonen, Lehtomäki, & Agge. 2008, 59-62) The National Advisory Board on Social Welfare and Health Care Ethics (ETENE) and Current Care (Käypä hoito) have composed guidelines concerning palliative care, however there are no nationwide guidelines in Finland. (Grönlund et al. 2008, 49-50)

The study was conducted by using literature review. The research method was a qualitative study method. The study was based on eight researches, which were found from academic electronic sources. Different kinds of support methods, which can be provided for the relatives of palliative patients, were searched from the chosen articles.

Support methods were provided by the health care professionals and the social network of the relatives. Interaction was found to be one of the main support methods. Communicating with others about the situation was found to have a positive effect on the relatives. Communication either with the health care professionals or with the social network was experienced to be helpful.

There were not many studies concerning support methods for the relatives of palliative patients. This topic should be further researched in order to have more information on the topic and thus be able to support the relatives of the palliative patients better. Supporting the relatives should be emphasized more in the health care system.

Keywords: Palliative care, support, relatives, patient

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1 Introduction

Palliative care is care provided for a patient with an incurable disease. The goal of palliative care is not only to improve the patient's wellbeing but also the wellbeing of the patient's family. Palliative care covers different aspects of the patient's wellbeing such as physical, psychosocial and spiritual aspects. Palliative care is a broader aspect of end-of-life care. End-of-life care is care provided near the patient's immediate death whereas palliative care is not related to the closeness of death. (WHO 2016)

Serious illness does not only affect the patient's life but also the life of the patient's whole family. A palliative care patient has to face changes in all angles of his or her life: a patient has to give up for example working life, family relationships and forthcoming plans. The changes touch the patient's family as well. The patient's family has to encounter several difficult feelings. (Grönlund et al. 2008, 59-68)

In palliative care the health care professionals may focus more on supporting the patient and the patient's family may not get as much support and attention as needed. However, it is also important to remember the needs of the family as they all go through difficult times during the palliative care of their family member. According to WHO (2016) it is one part of palliative care to take care of the family's coping as well as the patient's. In this paper we discuss the various support methods which are aimed for the relatives of the palliative patients. It is important for a nurse to notice the needs of the patient's relatives even when the nurse is taking care of the patient. In this paper we will go through the different support methods that we found with our literature review search.

The thesis topic rose in a clinical setting in a hospital in an encounter with a patient who expressed that she hoped her relatives to receive more support. This clinical experience worked as a starting point for the thesis topic and rose the willingness to search for more information on what kind of support methods have been used in order to help the palliative patients' relatives. The thesis will examine the support methods, which are aimed for the relatives of palliative patients. Palliative care may be a very challenging phase of care for the patient but also for the relatives of the palliative patient.

The purpose of the bachelor's thesis work is to study support methods meant for the relatives of palliative patients. This study is implemented by doing a literature review based on academic electronic databases. In forming the theoretical background of the thesis, academic electronic sources and books are used.

2 Palliative Care

The life expectancy was much lower before the industrial revolution began (Saarto, Hänninen, Antikainen & Vainio. 2015). Most people died at a young age, most of them were newborn babies, children and expecting mothers. The major factors which caused a large amount of deaths were starvation, epidemics and wars. Nowadays in Europe's developed countries, the life expectancy is twice the amount it used to be before the industrial revolution. (Saarto et al. 2015)

According to Saarto et al. (2015) during the pilgrimages in the Middle Ages, houses were built along the routes in Europe for those who no longer had the strength to continue the journey. These houses were called hospices. The sick and dying were taken care of in these hospices. The word hospice comes from the Latin word *hospes*, which means host and guest. Hospice also originates from the Latin word *hospitium*, which means hospitality and meeting point.

In 1967, the first hospice home was built in the United Kingdom. After this, other hospice homes were built throughout the country and soon they reached out to other parts of Europe also such as Norway, Sweden and Italy. The hospice movement spread throughout more widely in Europe in the 1980s. In the United States of America, the first hospice home was founded in 1974. (Today many of the hospice homes are heavily based on volunteer work and home care.) In the 2000s, the movement spread to Australia and parts of Asia also. Afterwards palliative care has become part of the nation's health care system. (Saarto et al. 2015)

The first hospice homes in Finland were established in the 1980s (Grönlund et al. 2008, 121). According to Grönlund et al. (2008, 121-122), volunteer work has been an essential part of palliative care ever since the hospice- movement had started. During the last decade, palliative care's position has progressed globally. The most progress has been made in Europe, in which Finland has also been a part of. In Finland the most progress with palliative care plans has been made in larger cities and in health care districts. The amount of hospice care units has increased and hospice care is being implemented even more at home. (Saarto et al. 2015). Finland does not have a national unified palliative care method. However, palliative care is implemented along the recommendations and guidelines of The National Advisory Board on Social Welfare and Health Care Ethics (ETENE) and Current Care (Käypä hoito) (Grönlund et al. 2008, 49-50).

People's perception of death has changed over the years. Saarto et al. (2015) refers to sociologist Norbert Elias who says that death has become forbidden in our modern society. In today's society people try to invent ways on how to live a healthier lifestyle and longer life without getting illnesses or diseases. Health care professionals try everything to prevent death from happening. Back in the days the dead person was bathed and dressed by his or her

loved ones. Today these so called rituals are done by nurses and these tasks are given for the funeral directors. Saarto et al. (2015) states that palliative care is a way to try to make death less medicalized, which means accepting death and making it less fearful.

2.1 Definition and Purpose of Palliative Care

According to WHO (2016), palliative care is holistic care of the patient and of his or her significant others when there is no longer curing treatment available for the patient's illness. One of the objectives of palliative care is to alleviate suffering in all its forms as well as to improve the quality of life for the patient and his or her family. Definition of palliative care for children involves the same elements as the definition for adults. It involves taking care of the patient's mind, spirit and body without forgetting the bereaving family. End-of-life care is part of palliative care but it takes place in the closeness of death whereas palliative care is started usually in an earlier stage when death is still further in the future (WHO 2016).

It is very important to make the decision of palliative care well in advance, before the patient's condition is severely deteriorated. Making the decision is for the benefit of the patient as he or she is still able to make an informed consent concerning the future care and is thus able to express his or her will. It is advised to involve the significant others of the patient in the decision making and planning of the care. Too sudden decisions impair the possibilities of the patient and relatives to prepare for the coming death. The patient and the family should understand the care plan and after that it should be documented in the patient's files. (Käypä hoito 2012)

Dying is something normal and belongs to life. This is an attitude that should be remembered in providing palliative care to a patient. Death of the patient should be neither fastened nor postponed but the focus should rather be in alleviating patient's symptoms and thus providing the patient the highest possible level of active life till the end. Symptom management can be applied in the palliative care although a curative solution is no longer available. (Saarto et al. 2015)

Patient's autonomy and right for self-determination should be respected to the greatest possible extent. According to the Finnish law (Finlex 1992/758) the patient has to be taken care of in mutual understanding with the patient. If for some reason the patient is unable to make the decision, if possible, the patient's significant other should be heard in order to find out what could possibly be the patient's will and the best interest in the care. (Finlex 1992/758)

In defining the purpose of palliative care, quality of life is one of the keywords. Quality of life is a subjective experience of each individual. However, all kind of suffering is an impairing

factor in the quality of life the person. Good quality of life includes aspects of physical, psychological or social wellbeing. For this reason, the purpose of palliative care focuses on reducing suffering as it is seen as a factor impairing quality of life. (Saarto et al. 2015)

Death is something expected in the life of a person who has been seriously ill for a longer time. However, the significant others of the patient have to deal with the symptoms of grief and sorrow even after the patient has already gone. The family's need for support does not disappear even though the patient no longer needs palliative care. (Saarto et al. 2015)

According to Saarto et al. (2015) palliative care is not an opposite of curative care. Both forms of helping the patient should go hand in hand as long as the curative treatment is seen efficient. When the curative treatment does not give the expected response the palliative form of care starts to have more importance in the care planning of the patient. This assures that the patient can have the care in which way the patient's wellbeing can be maintained in the best possible way. (Saarto et al. 2015)

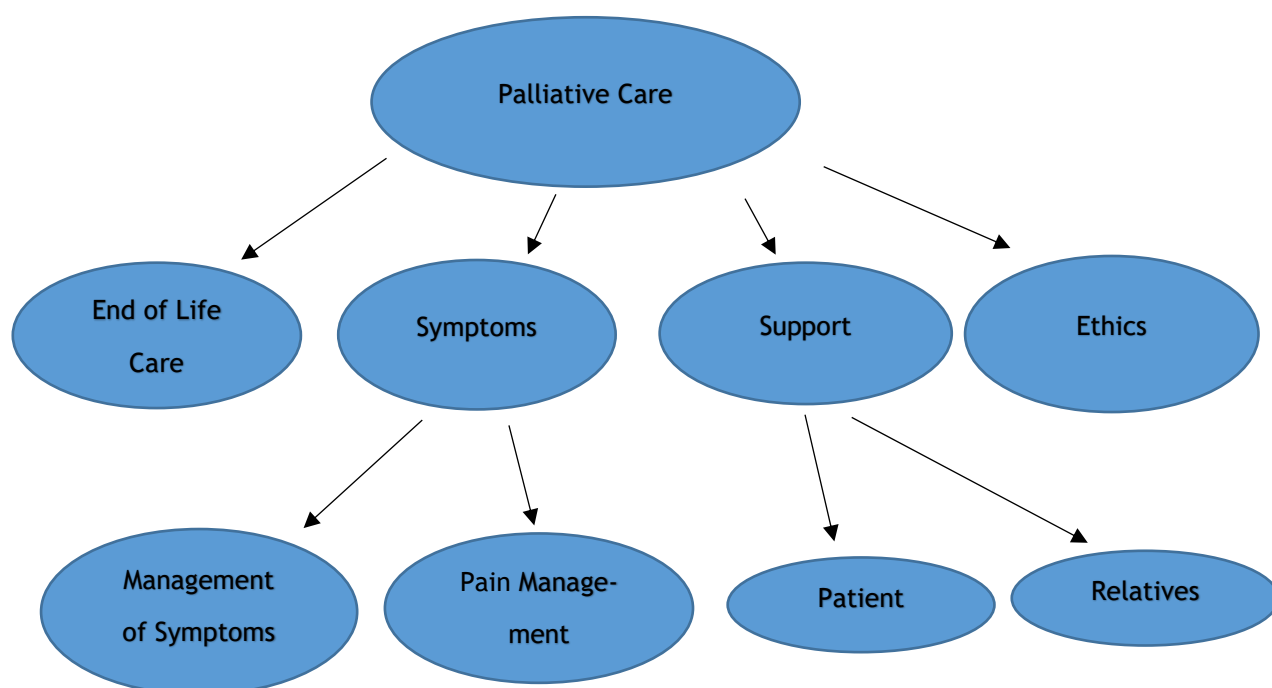


Figure 1: Elements of Palliative Care

2.2 End of Life Care

When discussing about palliative care, the topic of end of life care also rises. However, these two do not have the same definition. As stated by Grönlund et al. (2008, 23-24) the difference between palliative and end of life care is the time scale they have in relation to death. End of life care is part of palliative care. As palliative care is health management, which reduces suffering from an incurable disease, end of life care means the care phase nearest to the patient's death. (Grönlund et al. 2008, 23-24) On the other hand, Grönlund et al. (2008, 23-24) states that it is difficult to define when end of life care starts. The palliative patient's state of health, how far the disease has progressed, determines at a certain level, whether the patient is in the end of life care or not. (Grönlund et al. 2008, 23-24)

The end of life care decision is made by the physician (Grönlund et al. 2008, 26). Before the decision is made, the care plan needs to be discussed with the patient and also with the patient's relatives. The requirements of the decision include that the patient has a difficult and incurable disease, which is spreading and that the patient has difficult symptoms as well as short life expectancy. The end of life care itself does not differ from palliative care. In end of life care the patient's sufferings are minimized, the patient is provided with support and support is also provided for the relatives. End of life patients are also encouraged to be active even though they are in end of life care. (Grönlund et al. 2008, 26-31)

2.3 Symptoms in Palliative Care

Palliative care can also be described as symptomatic care. The symptoms vary from patient to patient depending on the diagnosis the patient has. However, there are certain symptomatic similarities that can be detected in palliative care patients that are not necessarily related to a certain disease only. (Saarto et al. 2015)

According to Saarto et al. (2015) the symptoms that occur most often in palliative patients are fatigue (60-70%) and deterioration of patient's daily functioning (65%) as well as sleeping disorders and pain. Symptoms are experienced differently, some symptoms are more disturbing than others. Some of the symptoms are more visible and thus easier to detect and taken care of by the medical team. (Saarto et al. 2015)

Accumulation of symptoms may cause considerable discomfort for the patient. It may not be a question of many separate symptoms but there may rather be one symptom that may lead to many other symptoms. For instance, constipation or other bowel malfunctions, if not treated properly, can cause nausea, loss of appetite and even pain. That is why it is important to evaluate the medical care from a holistic point of view trying to see the results

and consequences of various medications intended for different symptoms. (Saarto et al. 2015)

One of the symptoms during palliative care is shortness of breath. It can be described as feeling of choking or laboured respiration. Patient's quality of life can be remarkably affected by breathing difficulties, which can reduce the quality of sleep and lead to psychological symptoms. Some other respiratory symptoms are cough, increased secretions from the respiratory tract, bloody coughs, hiccups and pulmonary edema. (Saarto et al. 2015)

Symptoms in the gastrointestinal tract include difficulties swallowing, vomiting and nausea and dryness as well as infections in the mouth. Constipation and diarrhoea are also common symptoms of palliative patients. Ascites means accumulation of fluids in the abdominal cavity and it can also appear in palliative patients. Symptoms may also appear in urinary system in the form of urinary incontinence or ischuria. In the cutaneous level there can be bleeding, infections, wounds or sweating. As a reaction of the central nervous system delirium may appear. In the haematology of the patient, different variations may appear in the blood, for example anaemia. (Saarto et al. 2015)

Palliative patients often suffer from dehydration as a result of the body fluids moving to the space between the cells, which may lead to confusion and delirium. (Käypä hoito 2012). According to Saarto et al. (2015) fatigue is a symptom that can drastically reduce patient's quality of life. It is a holistic feeling of weakness and often apathy is connected to it. Fatigue is not just ordinary tiredness after stress but it can also be described as depressive or agonizing. (Saarto et al. 2015)

An extreme form of malnutrition, also called as cachexia, can be a characteristic feature of palliative patients especially when death is already near. In this condition cells experience continuous lack of nutrition, which leads to atrophy of the body and ultimately to death. It is a characteristic symptom at the end phase of many diseases although it can also be related to aging. (Saarto et al. 2015)

Physical and psychological symptoms often go hand in hand. When the patient experiences more physical symptoms, he or she is more likely to experience depression or anxiety as well. However, it is not always easy to distinguish depression from normal sadness that is combined to the approaching death. Losing weight and loss of appetite can be linked to the symptoms of palliative care as well as to symptoms of depression. The depression of palliative patients is thus not easy to detect as many similar symptoms may be related to the phase of disease or depression. (Saarto et al. 2015)

2.3.1 Management of Symptoms

There are specific means to treat specific symptoms that an individual patient experiences. It is however important to see the whole picture and relations of reasons and consequences. Specific antiemetic medications or haloperidol, which is normally used as a psychiatric medication, can bring relief for gastrointestinal symptoms, such as nausea. Constipation in turn should be taken care of with laxatives, but the use of laxatives should be controlled in order to avoid diarrhea. (Käypä hoito 2012)

If coughing appears as a respiratory tract symptom, its management is based on finding the ultimate reason that is causing the cough. Depending on the ethology of the cough, opioids, inhaled local anesthetics or sodium chloride can be considered as a treatment. However, shortness of breath can be caused by ascites and can be relieved by removing the accumulated fluid from the abdominal cavity by drainage. (Käypä hoito 2012)

Increased secretions from the respiratory tract can be managed with medical interventions but there are also non-medical interventions. One good example is the use of PEP-bottle (positive expiratory pressure) by inhaling through a drinking straw into a bottle that is half full of water. This enables the excretion of the secretions from the respiratory tract. (Saarto et al. 2015)

For cachexia there is no effective treatment. However, its' management is based on the control of patient's primary disease and the use dietary and exercise counselling. Cachexia of a palliative patient will ultimately lead to death even though some relief can be provided. Before starting to take care of the extensive fatigue, the ethology of the symptom, should be searched, if there is for example something in the hematology that would need attention. (Saarto et al. 2015)

It is stated in Käypä hoito (2012) that if the pain, anxiety and physical or mental suffering is overwhelming for the patient, the option of palliative sedation can be considered. It does not mean that the patient's death would be fastened but its purpose is to relieve patient's intolerable suffering. It is the last option after all other means have been tested without sufficient results. (Käypä hoito 2012)

2.3.2 Pain Management

Pain is a symptom that may cause a lot of distress and even fear in patients. Regardless of the diagnosis, it can be said that all patients experience it at least during the last month before death. Its management should be started well in advance in order to secure the comfort and

wellbeing of the patient to the greatest extent. The pain level should be evaluated and documented on a regular basis. This enables the right choice of medication and its dose. (Käypä hoito 2012) Factors affecting the medical care of pain are the location, intensity and its effects on the life of the patient. Understanding the mechanism of pain helps the physician to choose an appropriate medication but it can also help the patient to understand the medical therapy that he or she is receiving and thus to have its maximum effects. (Heiskanen, Hamunen, Hirvonen, Saarto & Tarkkanen 2013)

The cornerstone of pain management in palliative care is to find the suitable opioid treatment and to keep the secondary effects of opioids under control. Opioids are medications that affect through the central nervous system in a similar way as morphine does. Opioids can be classified according to their strength into weak, medium or strong opioids. They can be administered orally, intravenously, to the epidural space or muscle. (HUS 2016)

They are efficient in treating several types of pain. In palliative care they are especially efficient in the care of cancer pain. The pain diminishing effects of opioids are based on existence of opioid receptors in the spinal cord, midbrain, brain stem and cerebral cortex. (Kalso 2009) The secondary effects of opioids include for instance nausea and vomiting, constipation and itching. One of the most dangerous side effects is respiratory depression but it is also one of the least common secondary effects. (Heiskanen et al.2013)

Management of light pain can be taken care of by administering milder painkillers such as paracetamol or ibuprofen. However, if ibuprofen cannot be considered because of its secondary effects in the stomach and intestines, COX-2 selective nonsteroidal anti-inflammatory drugs (NSAIDs) can be taken into consideration. (Heiskanen et al. 2013)

In the care of moderate or strong pain, use of strong opioids can be considered. In the contrary, the use of weak opioids, such as codeine, is usually not recommended in palliative care because their efficacy when combined with NSAIDs is not very remarkable and it may prolong the start of strong opioids. Strong opioids bring more relief for the pain in combination with paracetamol or ibuprofen. This combination is also more likely to reduce the possible secondary effects of both medication groups. Anyway, it should be noted that when using opioids, the use of laxatives should be started as well. (Heiskanen et al. 2013)

When the patient experiences neuropathic pain, tricyclic depression medication can be included in the care. Neuropathic pain is pain caused by nerve damage. (Terveyskirjasto 2016) In this way the sedative effects of the medication can be used for example in ameliorating sleep. Certain epilepsy medications (Gabapentin and Pregabalin) can enhance the analgesic effects of opioids so they can be used to improve the pain relieving effects of opioids as well.

They may also have effects in reducing anxiety that often appears in palliative care. In the most severe cases of very strong pain when the treatment does not bring the expected results, there are still some forms of treatment that can be tried. According to Heiskanen et al. (2013) these options include the use of methadone or ketamine, parenteral administration of medicines, patient controlled analgesia, spinal analgesia, neurosurgical techniques or radiation therapy in case of palliative care for cancer patients. (Heiskanen et al. 2013)

2.4 Support in Palliative Care

A palliative care patient may be unstable psychiatrically due to the information of an incurable disease. An incurable disease may cause the patient anxiety and depression. The palliative patients may fear of the unknown and losing control of their lives. Palliative care is not about taking care of a disease; it is about taking care of the palliative patient as a holistic being. The patient's relatives also need support and they should not be forgotten during this time. Taking care of a palliative patient requires team work with a multi professional team consisting of nurses, physicians, therapists and social workers. (Saarto et al. 2015)

Palliative care consists of physical, psychological, social and mental care. All of these fields determine the quality of life. (Saarto et al. 2015) Saarto et al. (2015) refers to WHO's description that with palliative care, we can increase the quality of life of the patient and his or her relatives by reducing their amount of stress and concerns. Support methods are forms of help which are aimed to support the people in need. In our paper we study support methods that are aimed for relatives of palliative patients.

2.4.1 The Palliative Patient

The patient's control of life fades away as the disease develops, the patient has to give up certain factors in different areas of his or her life. The patient may experience feelings such as sadness, fear, shock, anxiety, anger and denial. (Grönlund et al. 2008, 37) According to Saarto et al. (2015) the palliative patients need support to help them get through the difficult time they are going through.

Saarto et al. (2015) states that there are different forms of support that can be offered to the palliative patient. Psychiatric support is one of the forms of support that can be provided. Palliative patients need emotional support such as having someone who listens to them, they need empathy and need to feel taken care of and to feel loved. During the last stage of a palliative patients' life, they need understanding, compassion and presence of their loved ones. The health care staff and volunteer workers have an important task to make sure that the

palliative patient who does not have many social relationships, does not feel lonely. It is essential that patients in palliative care receive support, since it affects their quality of life. (Saarto et al. 2015)

In addition to psychiatric support, the patient may also need spiritual support and practical support. Spiritual support means giving the patients the possibility to deal with matters related to religion, spirituality and identity either with their relatives or with a professional. Support of the palliative patients also includes practical matters such as providing the patients enough information of their disease, care plan, available services, financial aid, organizing property matters, guidance, living will and testament issues. (Saarto et al. 2015)

2.4.2 The Relatives

The palliative patient is not the only one who needs support, but also the patient's relatives since the situation of the patient may cause the relatives to feel fear, anxiety, anger and sorrow (Åstedt-Kurki, Jussila, Koponen, Lehto, Maijala, Paavilainen & Potinkara 2008, 47-49). According to Saarto et al. (2015) it is normal for the relatives of the palliative patient to feel that way. The palliative patient's relatives have to go through changes in their life also. It can be very difficult for the relatives to be able to adjust to the changed situations in the family during their loved one is in palliative care and even after they have passed away. (Saarto et al. 2015)

Åstedt-Kurki et al. (2008, 47-49) describes that the factors related to the patient's well-being such as the patient's pain, suffering, dependency on other people and the patient's possibility to survive, cause the patient's relatives to feel fear and be concerned. Relatives need emotional support as well as practical support. As Saarto et al. (2015) says, relatives may feel insecure about various matters. They need support with financial matters such as debt and properties, but also how to manage all the matters with the authorities. The relatives of the palliative patient support the patient and give the patient strength and because of this, the support given by the relatives is essential for the patient and part of his or her palliative care. (Saarto et al. 2015)

2.5 Ethics of Palliative Care

Everyone who works as a professional in the health care field has a duty to work for the best of the patient in such manner that his or her rights are fulfilled (Saarto et al. 2015). There are certain ethical regulations that guide nursing practice (Grönlund et al. 2008, 12-20). These regulations include principles such as preventing and curing diseases and alleviating suffering, which are the goals of nursing. Nursing practices that are generally accepted and proven valid by experience can be implemented in the work of a nurse. However, what kind

of influence these practices have on patients, needs to be evaluated from time to time. (Finlex 1994/559) Nurses also have responsibility to maintain their professional knowledge and to educate themselves. (Finlex 2015/1659) These ethical principles can be implemented without greater difficulties when the patient is capable to make autonomous decisions and willing to receive the care offered. It is the most desirable situation when the patient is informed about his or her condition and about the care options, after which the patient is then capable to state his or her informed consent. (Grönlund et al. 2008, 12-20)

In cases where patients are not capable of making the decision about their care, their significant others or a legal representative should be heard instead. It is important to try to find out what could be the will of the patient in this situation. Patients' right for autonomy has a significant role in the decision making process concerning patients' care. Patients should be taken care of against their will only in cases where the law states that (for instance law for mental health). If the patient's will cannot be known should the justified medical care be started. (Grönlund et al. 2008, 12-20)

These same ethical guidelines are valid in the care of a palliative patient as well. When the disease proceeds, and the curing care options do not have as significant meaning as earlier, the goals of the care need to be set again. Pain management and maintaining patient's autonomy till the greatest possible extent as well as basic care may become new goals in the care. Changing goals should be discussed already beforehand with the family and the patient. This may prevent ethical dilemmas where for instance the family's will is different from the will of the medical personnel. There can be a situation where the family does not want to give up of curing treatments although they no longer help the patient, but the physician has to take care of the patient according to the medical principles, which means the ending of the curing treatments. (Grönlund et al. 2008, 12-20)

One of the main goals in palliative care is actually enabling as good life as possible till death. Good life and good death are both important values when considering palliative care. It is essential for a health care professional to respect the uniqueness and autonomy of each patient and what are the wishes of the patient and the family related to the end-of-life care of the patient. (Surakka, Pupita-Mattila, Åstedt-Kurki, Kylmä & Kaunonen 2015, 7-16)

Patient has the right for self-determination till the very end. Patient has the right to refuse even from the care that maintains his or her life, for example from the respirator care. However, the patient needs to be lucid and to be able to understand the consequences of the ended care. It is not a hastily made decision, but may need some preparation even from the medical personnel. There is anyway a clear distinction between respecting patient's autonomy in ending of the care and assisting the patient in suicide. The latter is forbidden in Finland although it is allowed in some other countries. (Grönlund et al. 2008, 12-20) Previously

euthanasia used to mean a good end-of-life care when patient is taken care of in a such way that his or her suffering is minimized. Nowadays the concept of euthanasia has a meaning of assisting person to die when the patient has an incurable disease and when the patient wishes to die. (Saarto et al. 2015) Even though a suffering patient may ask for help in ending his or her life, a health care professional does not have the right to do so in Finland. If a patient expresses a will to die it cannot be overtaken without proper discussion. Even though it cannot be implemented it should be discussed openly. There has been a lot of debate about assisting a patient to die. Whereas others agree with the Finnish Law, some others would see assisting a patient to die as an option to alleviate his or her suffering. (Grönlund et al. 2008, 12-20)

3 Study Design

Our thesis is a literature review. We aimed to follow the systematic literature review guidelines. We chose to do a literature review because we wanted to study scientific articles about the possible support methods provided for relatives of palliative patients. We gathered different support methods researched in the articles and analyzed them in our paper. We used various search engines which we were able to access in databases of Laurea University of Applied Sciences and elsewhere in the Internet. We chose our articles based on their reliability, access, language, publication date and the topic. We thought by doing a literature review, that we will get a larger view of our chosen topic. For example, doing an interview for a small group would have not provided us with a broad view of the chosen topic.

3.1 Literature Review

A literature review is a research method where the chosen topic's discussion is based on various literature sources. A literature review does not mean directly quoting someone else's text, neither does it mean expressing your own opinions. It gathers material from different sources on the chosen subject and compares them together and analyzes if they have any differences or similarities. In a literature review you should critically evaluate the accuracy and trustworthiness of the literature you use. (Coughlan, Cronin & Ryan 2013, 1-7)

3.2 Data Screening

We used academic electronic sources in the search of articles for our thesis work. In our search we used databases such as CINAHL with full text (EBSCO), Sage Premier 2012, PsychARTICLES (ProQuest) and Melinda. We also used an article that we found from the NCBI electronic database.

In the beginning we started our search by trying different combinations of key words. We first thought our topic would be related to the patients' significant others' experiences, we started searching with the keywords "significant other", "support" and "palliative care". We

tried to replace significant other with “next-of-kin” and instead of “palliative care”, we searched with “palliative ward”, “cancer ward” and “hospice care”. We also searched with the keywords “nurse” or “nursing care” combined with “significant other” or “next of kin” and “palliative care” or “serious illness.

In the end we decided to stick to the relatives of palliative care patients and their experiences of support. We got best search results when we used the word “relatives” instead of “significant other”. However, in most cases the significant others of patients are their relatives and family members. According to Merriam-Webster’s Collegiate Dictionary (2001) the word “relative” means “a person connected with another by blood or affinity”. Based on our search results and personal experience we can say that in most cases the significant other can be said to also be the relative of the patient.

By including “palliative care” instead of our other options into our key words we got the best search results. Palliative care is a demanding phase of life for the patient as well as to the relative. In this phase of care there may be significant lack of support for the relatives of the patient although their need of support still continues after the patient is gone.

At this point, we came up with our key words being “palliative care”, “experience”, “support”, “relatives” and also adding “patient” as it was recommended to us by our supervisors. We did not want to limit the palliative care environment for only hospital or home environment because in both environments the relatives’ need for support is remarkable.

However, we came to a conclusion that the articles we found did not respond to our research question as precisely enough as we wanted. This is why we eventually decided to redefine our research question to our current topic. We chose to use the following keywords: “palliative care”, patient, relatives and support. We decided to use these keywords in our final search since they responded well to our new thesis topic. With the previously mentioned keywords we found articles that fitted out topic well.

3.3 Data Extraction

The databases from where we searched for our articles, we eventually found that the best results were found from CINAHL with full text (EBSCO) and SAGE Premier 2012. We used our keywords in the advanced search option in CINAHL. We searched without any exclusions and got 153 results. Excluding results which did not have full text available gave us 76 results. We limited our search for academic journals only which left us with 75 results. We wanted to use articles only in English and after that we had 74 results. We limited our publication date from 2006-2015 and received 51 results. We wanted to use the latest resources for our thesis work and this is why we stuck with a ten-year time frame recommended by our teachers. We only

to use articles which had references available due to the fact that we can estimate their reliability. This left us with 32 results, this is the final number of articles that we decided to go through in order to find the most suitable articles for our study. We eventually used four articles from CINAHL.

In SAGE Premier 2012, we got 3090 results with our keywords. In the database, there were articles accessible from the year 1847-2017. After that we limited the publication date from January 2006 to August 2016 and got 2075 results. We then limited our keywords to be all found in the abstract of the articles and the number of results were decreased to 16. We examined the 16 results and chose to use three of them for our study.

Search engine	Key words	Extractions	Results	Number of Chosen Articles
CINAHL	“palliative care”, patient, support, relatives	With keywords without extractions	153	4
		Full text	76	
		Academic journals	75	
		English language	74	
		Time frame: 2006-2015	51	
		References available	32	
SAGE Premier 2012	“palliative care”, patient, support, relatives	With keywords without extractions	3090	3
		Time frame: January 2006-August 2016	2075	
		Keywords in abstract	16	
NCBI				1

Table 1: Process of data extraction

Authors	Year and Publisher	Search Engine	Names of the Articles	Study Design
Lees, C., Mayland, C., West, A. & Germaine, A.	International Journal of Palliative Nursing 2014, Vol. 20, No 2	CINAHL	Quality of end-of-life care for those who die at home: views and experiences of bereaved relatives and carers	Self-completed questionnaire
Henriksson, A. & Andershed, B.	International Journal of Palliative Nursing 2007, Vol. 13, No 4	CINAHL	A support group programme for relatives during the late palliative phase	Qualitative interviews
Benzein, EG. & Saveman, B.	International Journal of Palliative Nursing 2008, Vol. 14, No 9	CINAHL	Health-promoting conversations about hope and suffering with couples in palliative care	Semi-structured interviews
Cronfalk, B.S., Strang, P. & Ternstedt, B-M.	Journal of Clinical Nursing 2009, Vol. 18	CINAHL	Inner power, physical strength and existential well-being in daily life: relatives' experiences of receiving soft tissue massage in palliative home care	Open-ended semi-structured tape-recorded interviews
Bussmann, S., Muders, P., Zahrt-Omar, C.A., Escobar, P.L.C. & Claus, M.	American Journal of Hospice & Palliative Medicine 2015, Vol. 32 (1) 44-51	SAGE	Improving End-of-Life Care in Hospitals: A Qualitative Analysis of Bereaved	Cross-sectional study using questionnaire with open-ended questions

			Families' Experiences and Suggestions	
Benkel, I., Wijk, H. & Molander, U.	Palliative Medicine 2009, Vol. 23, 2: pp. 141-149	SAGE	Family and friends provide most social support for the bereaved	Questionnaires and interviews
Bolmsjo, I.A.	American Journal of Hospice and Palliative Medicine 2008, Vol. 25, 4: pp. 328-338	SAGE	Review Article: End-of-Life Care for Old People: A Review of the Literature	Systematic literature review
Melin-Johansson, C., Hensch, I., Strang, S. & Browall, M.	The Open Nursing Journal 2012, 6: 1-12	NCBI	Living in the Presence of Death: An Integrative Literature Review of Relatives' Important Existential Concerns when Caring for a Severely Ill Family Member	Literature review

Table 2: Data extraction

3.4 Data Analysis

We have used inductive data analysis in our study. According to Kankkunen & Vehviläinen-Julkunen (2013, 167) inductive data analysis is used when the topic has not been studied much previously and when the available material on the topic is fragmented. In an inductive

data analysis, the process proceeds from singular concepts to generalization (Tuomi & Sa-
rajärvi 2011, 95). In order to get an answer for a research question one must create catego-
ries from the available material. The categories are made according to the research question.
Previous material or theories do not guide the analysis process because one has to create a
new theoretical entity. (Kankkunen & Vehviläinen-Julkunen 2013, 167)

Inductive data analysis process includes three phases: simplification, categorization and ab-
straction (Kankkunen & Vehviläinen-Julkunen 2013, 167). In our inductive data analysis pro-
cess, we had to create our categories based on the material we used in our paper. The infor-
mation of our research topic was scattered throughout the articles we used. The articles we
found were not entirely about our research topic so we had to gather the information availa-
ble in the articles and try to combine them together.

We started our inductive data analysis process by printing the chosen articles. We read them
through carefully and as we were reading, we underlined and highlighted the support meth-
ods, which were mentioned and discussed in the articles. After reading through each article
we either formed mind maps or made some notes in order to help us understand each article
better. In addition to finding the material for our research question we also analyzed our ma-
terials' trustworthiness, reliability and ethicalness and made notes about them.

After reading all the articles the material we found was scattered and was not categorized at
all: all concepts and support methods were not particularly organized into categories. We dis-
cussed and argued of different ways how to organize our findings. We overviewed all of the
support methods found from our articles and searched for similarities between them. We
tried to find some hierarchy in the support methods and tried to analyze which methods
would form larger entities. Our intention was to create main- and subcategories of the sup-
port methods for the relatives of palliative patients. Eventually we chose to divide our re-
search topic (support methods for the relatives of palliative patient) into two main catego-
ries: support methods provided by the health care professionals and support methods pro-
vided by the social network of the relatives (Figure 3).

Our topic is about support methods for the relatives of palliative patients, so naturally we de-
cided to make it the topic of our findings. From this topic, we formed two main categories
which one of them were "Support Methods Provided by the Social Network of the Relatives".
We will explain how we formed this part of the findings. Our material emphasized the mean-
ing of support methods provided by the social network of the relatives. Especially in the arti-
cle by Benkel et al. (2009) they stated: *"...a combination of practical and psychological/social
support was most frequently needed and provided. The social network that provided such
support consisted of the immediate family, relatives and friends in various combinations."*

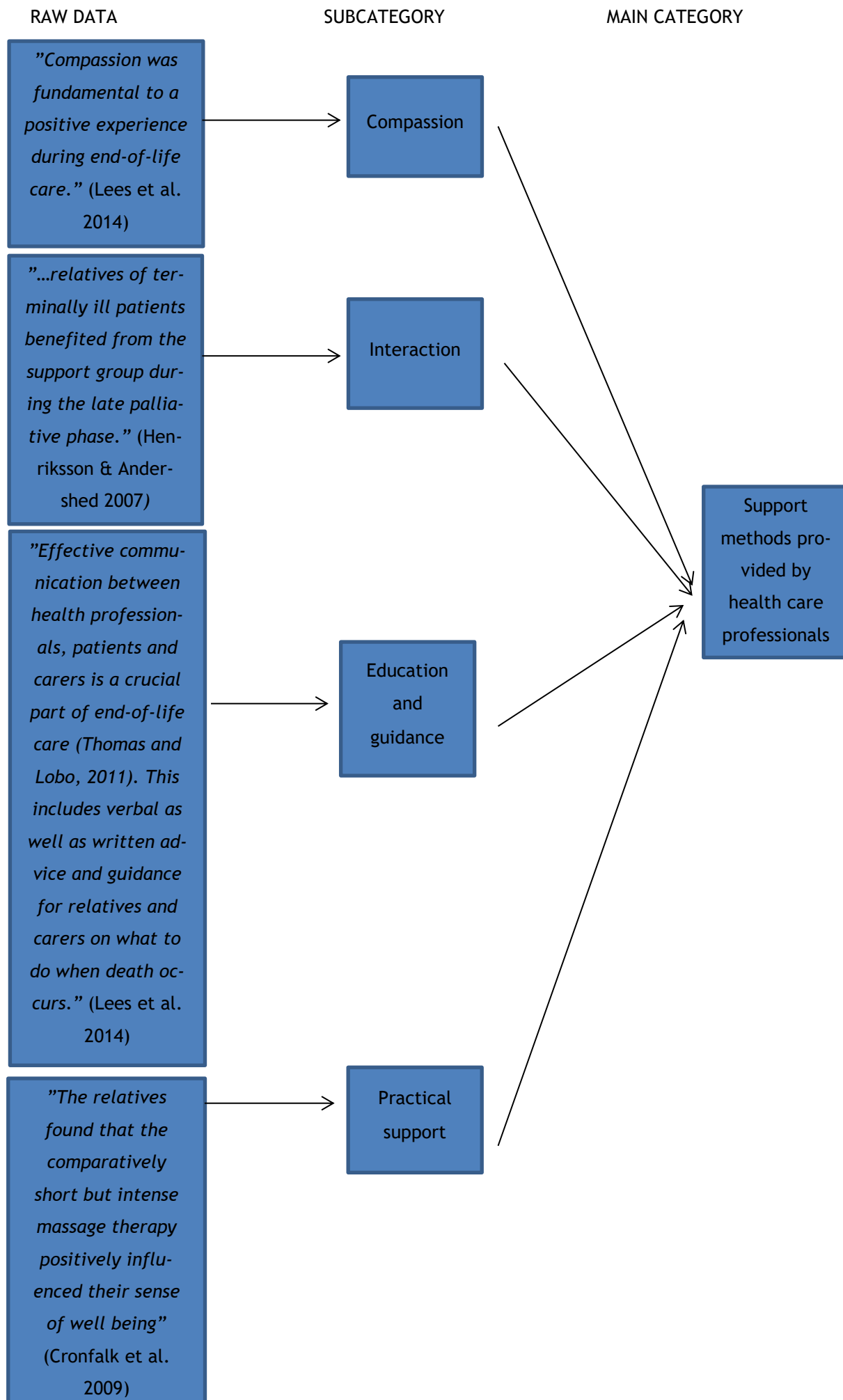
We found that support methods provided by the social network could be divided into practical support and social support just as Benkel et al. (2009) stated.

Support methods provided by the social network of the relatives were divided into two sub-categories: practical support and social support.

“Many of the respondents were greatly comforted by people sending flowers, giving a phone call or writing a letter. Such practical gestures played an almost ritual role as an expression of compassion.” (Benkel et al. 2009)

The practical support subcategory includes for instance such practical matters, which Benkel et al. (2009) discussed in their study. Social support, which is the other subcategory of support methods provided by the social network of the relatives is about discussing your situation, fears and worries with your social network (friends, family and relatives). According to Benkel et al. (2009) the relatives of palliative patients wanted to talk to other people during their difficult time:

“... social support was characterized by the need to talk to other people during the grieving process, and many respondents described how they chose the person they wanted to confer with carefully.” (Benkel et al. 2009)



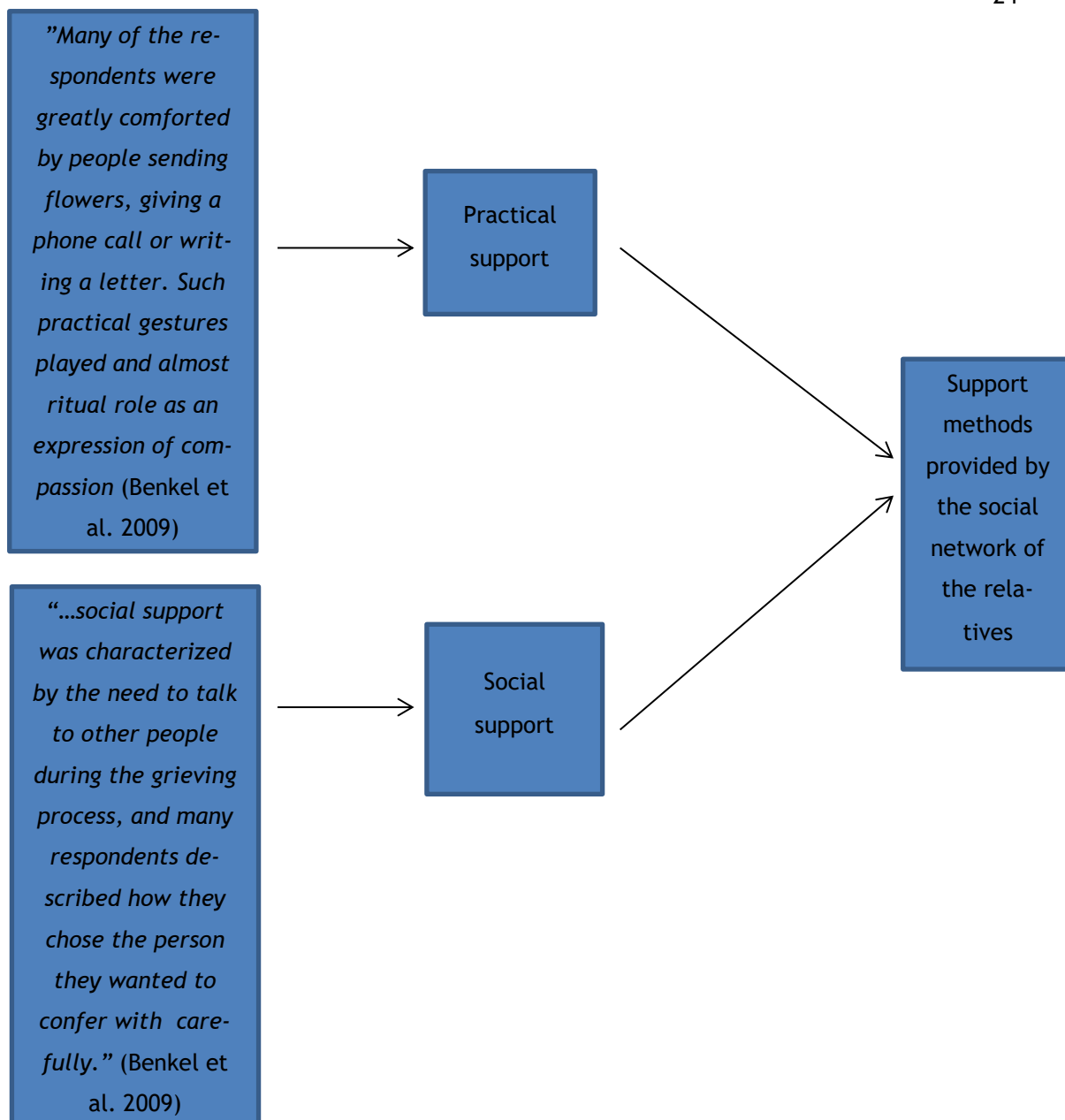


Figure 2: Analysis of Data

4 Findings

The chosen articles showed support methods for the relatives of palliative patients. The support methods found were compassion, interaction, education and guidance, practical support and social support. These support methods were divided into two main resources of support: support methods provided by health care professionals and support methods provided by the social network of the relatives (Figure 3).

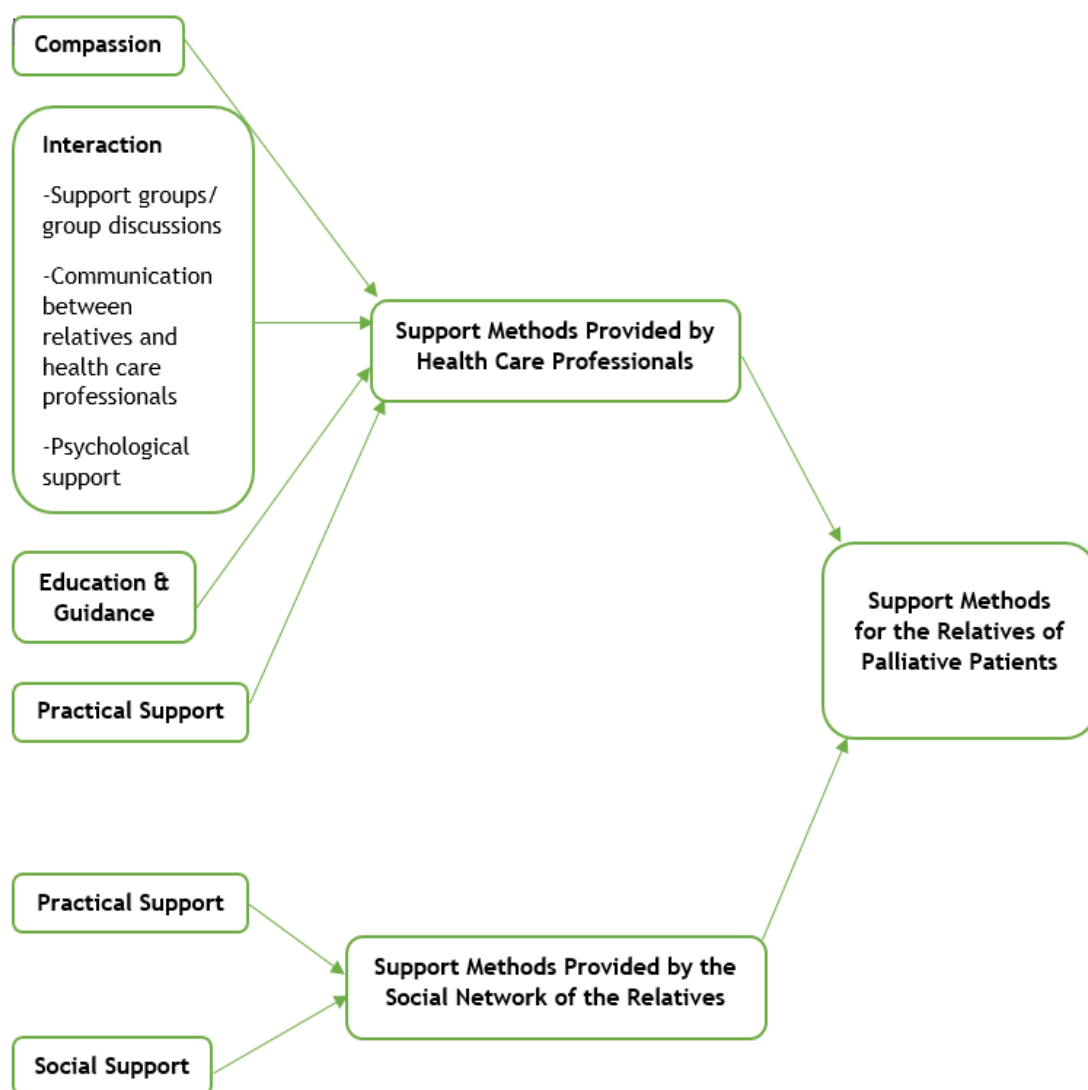


Figure 3: The Categories of Findings

4.1 Support Methods Provided by the Health Care Professionals

Compassion, interaction, education, guidance and practical support are support methods provided by the health care professionals. One of the support resources was support provided by health care professionals. Health care professionals mean all the professionals who work in the health care field and are part of supporting the patient's relatives.

Compassion is an essential element of support methods that can be provided by the health care professionals. Compassion was shown by respecting, supporting and caring for the patient as well as the whole family. Kindness, sympathy and professionalism were factors, which influenced in a good care experience. These elements were experienced to be supportive by the relatives. (Lees, Mayland, West & Germaine 2014) According to Bussmann, Muders, Zahrt-Omar, Escobar, Claus, Schildmann & Weber (2015) relatives said sympathy would have been supportive although they lacked it in their case.

According to Henriksson & Andershed (2007) support groups for the relatives of patients in palliative care were considered helpful. However, Benkel, Wijk & Molander (2009) also states that they used group meetings as a support method but in this study this method was not experienced as a useful tool. Most participants in the study of Henriksson & Andershed (2007) experienced that **interacting** with others who were also in the same situation helped them to handle their situation. Cronfalk, Strang & Ternstedt (2009) also mentioned group discussions as one of the main alternatives of support for relatives.

Communication between the family and the health care staff is a support method found from the articles. Communication was seen to be an essential support factor in the studies of Benzein & Saveman (2008) and Lees et al. (2014). Communicating about the facts and the reality of the situation helped to support the relatives without giving them any false hopes. When the relatives knew about the care plan, they felt more secured and did not have a false perception about their significant other's case. Spiritual and religious support was not considered to be entirely important for the health care professionals to inform about. However, it is an important support method to help the relatives in their situation although everybody does not consider it appropriate for the health care professionals to discuss about. (Lees et al. 2014; Melin-Johansson, Henoch, Strang & Browall 2012) Cronfalk et al. (2009) also states that individual consultations are part of main supporting methods for the palliative patients' relatives. Talking about existential issues is an important factor in creating a trustful relationship between the family and the nurses. Existential issues refer to discussions about fundamental topics such as hope and suffering as well as maintaining the fullness of life. (Benzein & Saveman 2008; Melin-Johansson et al. 2012)

Psychological support given by professionals was mostly needed as additional to the psychological social network support. The meaning of psychological support provided by professionals is emphasized in the end-of-life care phase. Psychological support refers to talking with a professional during the process of grieving. (Benkel et al. 2009)

In the study of Lees et al. (2014), **guidance** can also help to lessen stress of the relatives of palliative care patients. In this study guidance is stated to be important in end-of-life care. Guidance can be either in a written form or given verbally by the health care professionals. According to Cronfalk et al. (2009), information and **education** offered to the relatives of palliative patients is one of the main alternatives of support. Realistic and precise information of the palliative patient's condition should be given to the relatives (Melin- Johansson et al. 2012).

According to Benkel et al. (2009), **practical support given by the health care professionals** was about helping with funeral arrangements, legal and financial issues. The professionals aided the relatives with these duties, which used to be on the shoulders of the palliative patient. Support from the professionals was needed most when the relatives' social network did not provide relatives the support they needed. Discussing with a doctor was another support method used by the relatives if needed. In the study of Benkel et al. (2009), it was found that the need for professional support was emphasized nearest to death and shortly after death of the palliative patient. Massage was used as a support method for relatives in the study of Cronfalk et al. (2009). Three different forms of massage were used: therapeutic back massage, Swedish massage and soft tissue massage (Cronfalk et al. 2009).

4.2 Support Methods Provided by the Social Network of the Relatives

Social network was one source of support for the relatives of the palliative patient. **Practical support** for the relatives was shown in various ways such as giving flowers, making a phone call, writing a letter. These actions of kindness showed the relatives that they cared for them. Practical support was also given as financial and legal aid. (Benkel et al. 2009)

Social support provided by the social network included supportive discussions and expression of feelings. It was helpful that the relatives had many friends and family to talk to about different issues. (Benkel et al. 2009) It was also supportive to talk to people who had gone through similar experiences (Benkel et al. 2009; Henriksson & Andershed, 2007).

5 Discussion

The purpose of this study was to study the support methods for the relatives of palliative patients. We studied this topic by using literature review as a study method. We read articles concerning what kind of support methods there are or have been used to help the relatives of palliative patients. The findings showed us that support methods can be provided by health care professionals and social network of the relatives.

5.1 Discussion of Findings

Most of our findings concerned about support methods provided by health care professionals and only one of the articles that we found concerned support methods provided by social network. There were more studies concerning support methods provided by health care professionals, this could be because health care professionals try to improve the methods they use to support the relatives of palliative patient. On the contrary, it may not be as easy to influence on the support provided by the social network of the relatives of palliative patients.

Interaction was found to be the main support method provided by the health care professionals. Interaction as a support method consisted of support groups, group discussions, communication between relatives and health care professionals and psychological support. Discussing about your concerns openly helps you to go through the time when your significant other is in palliative care. Expressing emotions freely is essential when you have to cope with the fact that your significant other is going to die soon. For instance, support groups were a good way in reducing feelings of loneliness of the relatives and gives strength to help face the reality and future after losing a significant other (Henriksson & Andershed 2007).

Most of our findings showed that support groups and group discussions had a positive effect on their lives. However, according to Benkel et al. (2009) group meetings did not influence the relatives positively. Some people may not feel comfortable discussing about their personal issues in a group of people they do not know. On the other hand, others may find it much easier to talk to people who have gone through a similar experience even though they do not know them. It depends on how the person would rather express their feelings.

Discussing issues with health care professionals was found to be a helpful support method. Talking with for instance nurses, gives relatives relief and a feeling of a reduced burden. Sharing your thoughts and emotions with another person (for example with a health care professional) reduces stress. Talking with health care professionals can also be referred to as psychological support (Benkel et al. 2009). According to the study of Benzein & Saveman (2008), nurses were good listeners and did not judge the relatives when they expressed their

thoughts. It may be easier to talk to a health care professional because they are experienced in talking with people about difficult topics for example concerning death. Another reason why it might be easier to talk to a professional is because you can talk to them with confidentiality. Health care professionals have a responsibility to keep the information they encounter confidential.

Support methods provided by the social network of the relative were divided into practical support category and social support category. Most relatives of palliative patients received support from their social network. If the relative of a palliative patient had a sufficient support from their social network, the need for professional support was not needed as much as for those whose social network was not so supportive. (Benkel et al. 2009) The meaning of support provided by the social network is huge for the relative. Having friends and family around you with whom you can share your emotions is a base for recovery. Knowing that you still have people who are important for you and care about you helps you through the grieving process. In the study of Benkel et al. (2009), the respondents were taken by the friendly and caring gestures they received. People feel delighted when they experience acts of kindness from people around them. These gestures show the relatives that they are not alone in their sorrow and they have people around them that they can turn to.

The findings of our paper were categorized into main- and subcategories. However, if we look at the support methods from a broader point of view, we can say that all the ways to support the relatives are strongly linked to each other. Talking, listening, showing compassion and helping in practical ways are all important. For example, talking with a relative of a palliative patient without paying attention to what they are saying is not very supportive. If you talk and listen to a relative it shows them that you care. If a health care professional only uses one support method, it is not as effective and helpful as supporting the relative in a holistic way: showing compassion, interacting, guiding, educating, providing practical support. However, it is not always possible for one person to consider all these aspects. Eventually, supporting a relative of a palliative patient can be quite simple: it is about being humane towards a grieving person. Supporting a relative of a palliative patient depends on the individual: with simple use of support methods one can make a positive effect on other person's life.

5.2 Trustworthiness

Trustworthiness can be evaluated by reliability and validity of the study. Reliability means that a certain study can be repeated again and the same results can still be gained. When a research studies what it is supposed to or what the researchers claimed to study, a research is valid. (Tuomi & Sarajärvi 2011, 136; Hirsijärvi, Remes & Sajavaara 2010, 231) However, it can

be argued whether these concepts are suitable in qualitative studies or not because the concepts have been created mainly for quantitative studies (Tuomi & Sarajärvi 2011, 136). The concept of validity is shown differently in qualitative and quantitative studies. In qualitative studies the more precisely and better the researcher describes how they have categorized their findings and why they have categorized their findings in a certain way indicates the validity of their study. (Hirsijärvi et al. 2010, 232-233) In our study we tried our best to describe our categorizations precisely in order to maximize the validity of our study.

Trustworthiness is essential for an academic paper's reliability. In order to ensure the trustworthiness of our paper we considered the following elements: time frame, quality of the study, scientific references, reliable search engines, accuracy of the articles and coherency of the articles' results. Tuomi & Sarajärvi (2011, 140) also stated that the data collection methods affect the trustworthiness of the study.

The time frame we used in this paper is ten years. We chose this time frame because we did not want to use outdated information and due to the fact that there is a lot of progress and new care methods invented continuously in the nursing field. During our study, we wanted to ensure we use only sources which are academic journals based on scientific and reliable research. We did not want to use magazines and we chose articles which we evaluated as qualified academic texts for instance based on their academic writing style, whether they used ethical guidelines or not, what kind of study methods and sources they used throughout their papers or studies.

Most of our studies were from Sweden and this may reduce the trustworthiness of our thesis. Some other factors that may affect the trustworthiness of our study are for instance the small number of participants in some studies that were included into our thesis. We cannot generalize these results. We were unable to find many articles on our thesis topic, however we tried our best to choose the articles which best suited our topic.

According to Tuomi & Sarajärvi (2011, 140) the way the data is analyzed affects the trustworthiness of the study. Data can be interpreted in various ways depending on how the person thinks. One person can interpret certain data differently than the other even though both of them aim to be as objective as possible. Everyone has their own way to understand the data. (Hirsijärvi et al. 2010, 233) In our study we have understood and interpreted our findings in a certain way, however it is also possible that others may see it differently. There may be many right interpretations and not just one.

To ensure the best findings for our literature review, we chose articles which were accurate to our topic and which answered our research question. The articles we chose were consistent with each other's findings. This way, they did not give us controversial results.

5.3 Ethical Considerations

We did our study in an ethical way respecting the ethical norms. According to Day and Gastel, (2011, 24-26), these ethical norms include for instance the norm of authenticity, referring correctly and thus giving credit to the authors' work of which we used in our thesis as sources. Authenticity means that we analyzed our sources thoroughly and made our conclusions based on the analysis of the sources. By doing this way we gave credit to the authors of the articles we used. By avoiding plagiarism, we tried to do our best to describe topics in our own words. Whenever we used a text written by somebody else we immediately wrote down the reference. This way we could not forget to use references properly and to deny authors' credit for their work.

According to Coughlan et al. (2013, 123) plagiarism can be defined as a crime because another person's work is claimed to be your own. Plagiarism is "presenting the work of another author without due recognition or acknowledgement" (Coughlan et al. 2013, 123).

Whether your work is to be published or not you must always recognize the original source. Even though if you used your own previous work as a source you must still remember to refer to yourself. Nowadays it might seem easy to use plagiarism because there are many accessible sources in the Internet, however modern technology also helps us to find out whether something is plagiarized or not.

5.4 Recommendations

During our study process we found out that there were not many reliable studies concerning this topic which means that this topic has not been studied much previously. However, we find that it is very important to support relatives during palliative care of their significant other. Due to this, we think that this topic should be studied more in the future. To help relatives of palliative patients, we need to use different kinds of support methods and possibly invent new methods of support. Although the emphasis of the care is in the ill patient, the relatives of the patient should not be forgotten during palliative care. Support for the relatives is even more emphasized in palliative care because it causes more anxiety, stress and grieving not only in the patient but also in the relatives. To lose a loved one, is a difficult situation for anyone who encounters it.

We suggest hospitals and health care facilities to take into consideration the relatives as well when taking care of dying patients. We recommend to create support groups which provide professional support and peer support, since it was one of the main topics of our findings. However, if there are not enough resources to organize such groups, even considering the situation of the relatives may help. Creating a good and trustful relationship with the relatives can be healing in the middle of difficult times.

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