Nurses’ experiences of ethical problems in the end-of-life care of patients
A literature review

Sjuksköterskors upplevelser av etiska problem i vården av patienter i livets slutskede
Enlitteraturöversikt
Abstract

Background: In the background section the following terms are described: Palliative care and holistic view, care at the end-of-life, ethical problems in the end-of-life care and ethical problem and ethical dilemma.

Aim: The purpose of this literature review was to describe nurses’ experiences of ethical problems in the end-of-life care of patients.

Method: A literature review was selected as a method in this study based on eight scientific articles. Articles were reviewed and analyzed critically by the author. Travelbees’ theory (1971) “human-to-human relationships” was selected as a theoretical basis.

Results: The result presents six themes as follows: Decision-making, ineffective treatments and therapies, insufficient communication, the lack of cooperation, inadequate respect for patient’s autonomy and uncertainty in caring role. These themes present how nurses deal with end-of-life care and in which situations ethical problems arise.

Discussions: The result was discussed in relation to Travelbees’ theory (1971) “human-to-human relationships”. Nurses’ different experiences according to their different responsibilities such as insufficient communication and cooperation, decision-making processes, uncertainty in caring role and inadequate respect for patients’ autonomy were discussed.

Keywords: End of life care, Ethical problems, Nurses’ experiences.
Sammanfattning

Bakgrund: I bakgrunden beskrivs följande termer: Palliativ vård och holistiskt synsätt, vård vid livets slutskede, etiska problem i livets slutskede och definitionerna av etiskt problem och etiskt dilemma.

Syfte: Syftet med denna litteraturöversikt var att beskriva sjuksköterskers upplevelser av etiska problem i vården av patienter i livets slutskede.


Resultat: Resultatet presenterar sex teman enligt följande: Beslutsfattande, ineffektiva behandlingar och terapier, otillräcklig kommunikation, bristande samarbete, otillräcklig respekt för patientens autonomi och osäkerhet i vårdande roll. Dessa teman presenterar hur sjuksköterskor hanterar vård vid livets slutskede och i vilka situationer etiska problem uppstår.


Nyckelord: Vård vid livets slutskede, Etiska problem, Sjuksköterskers upplevelser.
Table of Content

1. INTRODUCTION .......................................................................................................................... 1

2. BACKGROUND ............................................................................................................................... 1
   2.1 PALLIATIVE CARE AND HOLISTIC VIEW .............................................................................. 1
   2.2 THE CARE AT THE END-OF-LIFE ....................................................................................... 2
   2.3 ETHICAL PROBLEMS IN THE END-OF-LIFE CARE ........................................................ 4
   2.4 DEFINITION OF THE TERMS ETHICAL PROBLEM AND ETHICAL DILEMMA .............. 4

3. PROBLEM AREA ............................................................................................................................. 5

4. PURPOSE .......................................................................................................................................... 5

5. THEORETICAL BASIS .................................................................................................................... 5

6. METHOD ........................................................................................................................................... 7
   6.1 DATA COLLECTION .................................................................................................................. 7
   6.2 SELECTION .............................................................................................................................. 8
   6.3 DATA ANALYSIS ...................................................................................................................... 8

7. ETHICAL CONSIDERATIONS .......................................................................................................... 8

8. RESULTS ........................................................................................................................................... 9
   8.1 DECISION-MAKING ................................................................................................................ 9
   8.2 INEFFECTIVE TREATMENTS AND THERAPIES ................................................................. 10
   8.3 INSUFFICIENT COMMUNICATION ....................................................................................... 11
   8.4 THE LACK OF COOPERATION .............................................................................................. 12
   8.5 INADEQUATE RESPECT FOR PATIENT’S AUTONOMY .................................................... 12
   8.6 UNCERTAINTY IN CARING ROLE ......................................................................................... 13

9. DISCUSSION ................................................................................................................................... 13
   9.1 METHOD DISCUSSION .......................................................................................................... 13
   9.2 RESULTS DISCUSSION ........................................................................................................ 14
   9.3 CLINICAL IMPLICATIONS ...................................................................................................... 18
   9.4 SUGGESTIONS FOR FUTURE RESEARCH .......................................................................... 18

10. CONCLUSIONS .............................................................................................................................. 19

REFERENCES ....................................................................................................................................... 20

APPENDIX 1. ARTICLE SEARCH IN DATABASES CINAHL AND PUBMED ....................................... 23

APPENDIX 2. MATRIX OF SELECTION OF ITEMS ........................................................................... ОШИБКА! ЗАКЛАДКА НЕ ОПРЕДЕЛЕНА.
1. Introduction

During my internship in the lung department I met a palliative patient who had lung infection and also an infection in her leg’s wound. She felt very sad and desperate as a result of the diseases she suffered from. Several days passed while she still had a lot of pain, which made her decide to stop taking her tablets because she didn’t want to live anymore. We stopped by and checked her several times while offering her tranquilizer tablets, however she declined each time. Once I saw her crying I asked her if she needed to talk to someone, but she took my hand instead quite firmly and started to cry even more. I started wondering how much I should respect patient’s autonomy and decisions while at the same time do not violate professional duties as a nurse. Nursing as a professional job may have ethical challenges and therefore nurses have to be ethically sensitive to distinguish these challenges in their professional job. I thought about what other ethical situations might exist and in what other situations they come up. This motivated me to study how nurses describe their experiences of different ethical situations in relation to patients, relatives and other professionals in the end-of-life care.

2. Background

In this section the definitions of the following terms will be described: Palliative care and holistic view, Care at the end-of-life, Ethical problems in the end-of-life care and Ethical problem and ethical dilemma.

2.1 Palliative care and holistic view

Palliative care is about the ways that enhance the life quality of patients that are dealing with life-threatening illnesses (World Health Organization[WHO],2015). Palliative care is an approach that tries to prevent suffering by early identification and also treatment of pain and other problems. Such problems include social,psychosocial problems or physical problems in addition to spiritual aspects. Palliative care considers death as a normal process and provides relief from pain and other distressing symptoms. This process should not be accelerated, neither postponed. It helps patients to live as much as possible. Palliative care on the other hand helps the family of the patient during the illness by supporting them.

A good palliative care meets the patient’s needs and will be a valuable time for both individual and patient’s family (Socialstyrelsen, 2005). A good death is based on self-imagination, self-determination, and integrity to maintain social relationships, symptom relief
and take the opportunity to understand life and health meanings (Ternestedt, Österlind, Henoch & Andershed, 2012). Palliative care should be designed according to Socialstyrelsen (2005) and the four cornerstones as follows: symptom relief, multi-professional cooperation, communication as well as support for relatives.

Izumi, Nagae, Sakurai and Imamura (2012) argue that the term “end-of-life care” is often used alternately with different terms such as terminal care, hospice care and palliative care. During the last 30-40 years there have been changes in the setting of these terms and also specific meanings of them. Meanings and definitions of these terms vary from organizations and countries. The study discusses that the death should not only be medically treated. Death must therefore be treated in a more holistic manner. To provide a “holistic care”, nurses have to have a holistic view of people and their lives (Dahlberg, Segesten, Nyström, Suserud & Fagerberg, 2003). Holistic view means that nurses have to see the person as a whole and do not only see some special physical parts, mental aspects or even social aspects of the person. The entire view of the person gives much more information than his/her specific parts mentioned above. Izumi et al. (2012) found that the definition of the term end-of-life is still in draft and must be examined by different perspectives to have clear and empirically valid definitions. Definition of the term end-of-life makes nurses aware of their ethical responsibilities, which furthermore leads to distinguish people who are in need of end-of-life care. The lack of end of life definition and people who should be considered as such, create ethical problems for nurses.

According to Brown and Vaughan (2013), the end-of-life care means that the skilled professionals should meet patients’ needs and also their relatives’ requirements. Communicational strategies should be developed as quickly as possible in an efficient way to identify such needs. Furthermore, patients’ needs must lie on the heart of all decision making. Education about end-of-life care should be implemented during the last year of nursing education. In addition end-of-life care should be more accessible for caregivers and give them the opportunity to enhance their knowledge and experiences. In order to ensure a better future for patients, a structure for practical work of health professionals should be developed.

2.2 The care at the end-of-life

It is not easy for nurses in terms of emotions to be involved at the end of patient’s life (Kamaromy, 2004). In an ideal situation the dying people would articulate their needs so that caregivers understand their needs and try to fulfill them. Difficulties arise when the dying
person cannot express their needs and nurses must do necessary judgments on their behalf.

Patients who are about to lose the ability to communicate need advanced planning to improve end-of-life care. Study of Brinkman-Stoppenburg, Rietjens and Heider (2014) shows that care planning have positive effects at the quality of end-of-life care for patients who are going to lose the ability of communication in the future. Care planning is proven to be more effective than written documents alone. Study of Verschuur, Groot and Sande (2014) claims that one of the important matters in WHO’s definition about palliative care is early identification of problem. This study shows that nurse’s experience of problem identification in proactive palliative care in an early stage needs communication, professional development, cooperation, education and empowerment of nurses. This research indicates that the patients don’t tend to speak about death and they try to avoid relevant conversations as much as possible. They wait until the family members or caregivers bring up these issues. This research has shown that if they discuss it as soon as possible a better quality of life for the patients would be achieved.

The study of Iranmanesh, Abbaszadeh, Dargahi and Cheraghi (2009) indicated that nurses, who have managed to successfully take care of people at the end-of-life, have developed their ability for caring relationship. In addition to develop this ability, the integration of palliative care and education are necessary. The amount of education that the nurses obtain plays a key role to enhance their ability to observe their own and patients’ rights, and this improves quality of care.

Nurses should have extensive knowledge to help the patients to live with their disease (Lindqvist & Rasmussen, 2009). In addition they should talk to patients and allow them to share their attitudes, perspectives and feelings about dealing with disease and possibly dying because of it. This way, nurses may realize the patients’ points of view about difficulties of their situations. This knowledge is necessary for caregivers to be able to help and support the patients to maintain a normal life as much as possible. Nurses must use both the biomedical and narrative knowledge to provide “holistic care”.

The study of Raphael, Waterworth and Gott (2014) shows that a lot of people in palliative care receive their nursing from primary healthcare providers who have limited education and skills in end-of-life care. On the other hand the older population is increasing which motivates the necessity to obtain the right knowledge and skills to improve the quality of palliative care.
2.3 Ethical problems in the end-of-life care

The most serious ethical problems are not about death but are related to the small-scale daily life, which are actually every day questions such as washing a person with dementia and force or preventing someone to do something (Reitinger & Heimerl, 2014). In addition, feelings are important in ethical problems. By sharing experiences and perspectives on ethical problems in group discussions, nurses can better understand the difficult ethical questions and find appropriate ways to deal with them. This requires communicational structures for ethical discussions that allow nursing staff to reflect their everyday decisions. They can also encourage each other in ethical decision-making processes related to these small-scale daily life problems.

The study of Fernandes and Moreira (2012) describes ethical problems such as end-of-life decisions, integrity, cooperation, teamwork and access to health care in the final stages of life. The most significant strategies to solve these problems are personal and group resources, moral development and education. Studies emphasize that most significant strategies to solve these ethical problems are to share experiences, feelings and perspectives on ethical problems in group discussions (Reitinger & Heimerl, 2014; Fernandes & Moreira, 2012).

2.4 Definition of the terms ethical problem and ethical dilemma

Nurses deal with ethical principles and values in practical situations all the time (Sarvimäki & Stenbock-Hult, 2008). An ethical problem arises when ethical principles come into conflict with values such as autonomy. Nurses need ethical knowledge of integrity and justice to make a decision in these situations. Nurses need to have ethical sensitivity, awareness and ability to see the situation from an ethical point of view. An ethical problem can usually have a solution but it is problematic to access the solution when nurses face two or more different solutions to the problem because of different values, which comes to conflict with each other. Ethical dilemma means to choose between two or more options that none of them gives the best solution (Malmsten Gedda, 2008). The similarity between the ethical problem and the ethical dilemma is that in both cases there is a problem or a situation, which needs a person to choose between alternatives.

Two different tools are usually applied in decision-making: Dialogue and reflection (Malmsten Gedda, 2008). One example of ethical dilemma could be to force a patient to do something when he/she doesn’t want while respecting his/her choice and autonomy might result in damages to the patient. Nurses may feel that they have to choose the best decision
between alternatives but no matter what they choose, it might be ethically wrong. They have to reflect the conflict with other professionals and have some dialogues with other nurses to determine which decision is the best in this specific situation. Having dialogues with other professional groups make nurses reflect the best decision between different alternatives. But ethical problems cannot be solved by just knowledge because knowledge can propose two different solutions to the problem (Sarvimäki & Stenbock-Hult, 2008).

In this literature review the term ethical problem will be used instead of ethical dilemma. According to MalmstenGedda (2006) ethical dilemma is one dimension of ethical problem that’s why ethical problem will be used, which is more comprehensive.

3. Problem area
Nurses who work with patients in end-of-life encounter different ethical situations in relationship with patients, family members and health professionals. Previous studies in the background section shows that the good palliative care at the end-of-life should meet the patient’s and family’s needs and nurses require knowledge and education to identify their needs. Previous studies also indicate that most of the ethical problems are not related to the death, instead related to every day questions such as forcing someone to do something. Hence it is important to create a comprehensive picture of the nurses’ required knowledge regarding ethical problems that they face in different situations.

4. Purpose
The purpose of this literature review was to describe nurses’ experiences of ethical problems in the end-of-life care of patients.

5. Theoretical basis
The Travelbee’s Human-to-Human relationships theory (1971) has been used in this literature review because this theory describes interpersonal relationship between nurse-patient, their communication and cooperation. Cooperation and communication are useful ways to minimize ethical problems in the care, which is the main subject matter in the Travelbee’s Human-to-Human relationships theory. The theoretical starting point that has been used in this literature review is Human. The theory Human-to-Human relationship was selected because both the nurse and the patient as a unique human being cooperate with each other in the planning care. Both parties are involved
in an interaction, which makes it possible for them to have a relationship with each other (Travelbee, 1971). Human-to Human relationship in this case between a nurse and ill person is a nursing situation with the purpose of assisting an individual and his/her family to decrease their suffering and helping them to find the meanings of these ethical situations. The nurse knows that the patient is thinking, acting, feeling and experiencing and then he/she structures nursing intervention to use available knowledge and understanding. The task for the nurse is to become aware and recognize the uniqueness of this human being as a patient and also meet the patient’s needs. The nurse should access similarities and differences between him/herself and the individual in order to help the patient in an empathic way. The nurse may use both the individual and family that will guide her to meet the nursing needs. Nursing needs mean that any requirement of the ill person and family can be met in the interactions.

According to Joyce Travelbee's Human-to-Human relationships theory (1971) a nurse should have a common understanding between himself/herself and the patient in a meeting and also have an understanding of what they are communicating about. Human, communication, meaning of life, suffering and human relationships are important concepts in the theory (Sarvimäki & Stenbock-Hult, 2008). In this theory it is important that the nurse understands and cares about another person’s suffering and the interactions between them are also discussed. In addition these interactions between them includes any contact during communication verbally or non verbally. Every individual is unique and experiences suffering differently. Most patients have difficulties to communicate their suffering and it is not always possible to communicate this with someone else. That’s why nurses need communication technique as a method to assist the patient to create a comprehensive picture of herself/himself and her/his illness. Nurses also need communication technique to identify patients’ needs and finally assist them during the decision-making process. The unique human have the opportunity to progress by trying to create a sense of what is happening. Human to-Human relationship is a series of experiences between a nurse and a sick person (Travelbee, 1971). The nurse meets the needs of the individual and the family. The human being is always in the process of changing, and this process is not time dependent. In addition this process does not happen immediately, whereas it builds up day by day in interaction between the nurse and ill person and family members. In fact there are no patients, there is only individual human beings in need of the care. Nurses should assist individuals to maintain hope and avoid hopelessness by being available and willing to help for example by listening to the ill person. Travelbee’s theory and her thinking are based on another nursing theorist named Ida Jean Orlando, born in 1926 (Masters, 2014).
Travelbee’s theory describes four metaparadigm concepts: Person, Health, Environment and Nursing; Travelbee’s theory describes that Persons become patients when they have needs that cannot be met independently because they have difficulties to communicate their needs. Sometimes any aspect of the Environment even though it is designed for therapeutic purpose can cause the patient to become distressed and sorrowful. Freedom from mental, physical discomfort or feelings of disabilities and well-being contribute to the term Health. Three elements, which create the Nursing process, are patient’s behavior, nurse’s reaction and the nursing actions.

The author of this literature review considered that the Person as a metaparadigm concept was related to selected subject of this literature review and theoretical basis because as mentioned above patients’ needs in the end-of-life care can not be met independently and they have difficulties to communicate their needs.

6. Method

A literature review was selected as a method to find out the existing research in the area of nurses experiences of ethical problems in the end-of-life care.

6.1 Data Collection

The database CINAHL and PubMed were used to find scientific journals and theses. The aim was drafted in the first step and keywords were identified in English with the help of Swedish MeSH. According to Östlundh (2012) for obtaining materials, the words should not be in any grammatical format because databases are not looking up all the word’s conjugations. Therefore one can use the truncation (*) to get all forms. In step two, words and combined words were searched. In addition three operators AND, OR and NOT were used in the search. The search history is used to keep track of searches and give information about number of hits. In both CINAHL and PubMed, Ethical dilemma, Ethical problems, Palliative care, Nurse’s experience, End-of-life care, Nurs*, Nurses’ experiences, Experience*, Ethical*, Nursing, End-of-life, Care, Ethic, Problem, Ethics and Nurse-patient were searched with and without the truncation (*). The results were reported in appendix 1. According to Östlundh (2012) used words should be understood, and also how they are combined to get a better idea of the article’s content. Therefore an attempt was made to combine different types of keywords that were synonyms of each other.
6.2 Selection

According to Friberg (2012) when you have made a literature review, a thorough analysis should be done and consideration of both quantitative and qualitative studies should be performed. The analysis of a literature review is different from the analysis of raw data such as interviews, observations and questionnaires. Articles have to support the purpose of this study. This requires a critical approach in the selection of studies. The reviewed articles in peer-viewed with Full Text were published between the years 2000-2015 and were written in English and Swedish except for one which has been written in both English and Spanish. Articles, which were elected in the data analysis section, were qualitative articles dealing with nurses’ experiences of ethical problems in the end-of-life care. In step three, the title of the articles, abstract and purpose were read and in step four the articles’ methodologies and results were read to see if the articles’ results were consistent with literature’s purpose. Searches are presented in the search matrix appendix 2.

6.3 Data analysis

First, the articles’ results were read several times and were translated into Swedish and Persian to understand the content and context, and then the author tried to find some parts of the articles’ results which addressed the purpose of this literature review. After that these findings were analyzed, in addition differences and similarities among the articles’ results were identified. In the next step, the differences and similarities among articles’ results were compared with each other. These parts of the articles were categorized and were highlighted in different colors. The colored parts were read and processed several times to place under the appropriate and similar headings and then to emerge themes. These themes were presented under the result’s section. Under these themes similarities and differences between articles were presented. Finally the author read the articles several times to identify mistakes of results or some important information.

7. Ethical considerations

This literature review is part of the education for nursing program, therefore an application was not sent for Ethical Review. Ethical review only needs to be done in the case of empirical research that involves people or development works (http://codex.vr.se/forskarensetik.shtml). It is important to use an objective way for the results presentation and note that all the items that will be used have an ethical approval for their studies and that they have received
approval by an ethics committee. Since the articles are in English, there is a risk that misunderstanding of the content happens when using only one dictionary. Therefore, different dictionaries should be used, which is already addressed in the study. LexinPersian was used because of the author’s native language. One should refrain to falsify and fabricate scientific data and results and always follow the rules for a good research and avoid from expressing own perspectives.

8. Results
The analysis of articles resulted insix themes as follows: Decision-making, Ineffective treatments and therapies, Insufficient communication, The lack of cooperation, Inadequate respect for patient’s autonomy and Uncertainty in caring role.

8.1 Decision-making
Nurses experienced ethical problems at the end-of-life care with regards to decision-making processes (Oberle & Hughes, 2001; Schaffer, 2007; Cheon, Coyle, Wiegand & Welsh, 2015). Nurses felt that doctors were responsible for decisions and they had to accept them and live with these decisions (Oberle & Hughes, 2001). Nurses expressed concern and uncertainty because they felt that doctors didn’t always make the right decisions. They also felt that decisions were difficult to make. In addition decisions were about care and treatment, discontinuing or continuing the treatment and in some cases it was hard to know who’s values had the most moral weight. These ethical problems became clear especially when the patient didn’t have the ability to express himself/herself. Nurses were concerned about how to involve patients in their decision-making processes (Schaffer, 2007). Patients didn’t want to speak about death, therefore nurses couldn’t discuss with them. In addition nurses had most problems with family members who were too dominant and decided for the patient and consequently nurses couldn’t reach patients’ real wishes and decisions. Nurses experienced ethical problems in relation to decision-making process when the patient didn’t have any family members and could not express himself/herself (Cheon et al., 2015). Nurses felt that they had difficulties to know who the right person was to do the best decision for patient in such cases.

Nurses experienced conflicts as ethical problems between patient and family members in the decision-making process at the end-of-life care (Cheon et al., 2015; Schaffer, 2007; Karlsson, Roxberg, Barbosa da Silva and Berggren, 2010; Karlsson, Karlsson, Barbosa da
Silva, Berggren & Söderlund, 2012). Nurses experienced that patients wished to die at home but family members didn’t want this and therefore most of the times patients died in the hospitals (Karlsson et al., 2010; Karlsson et al., 2012; Izumi, 2010). Nurses also expressed that most of the decisions about treatments were made by family members and not by patients (Oberle& Hughes, 2001).

Nurses also experienced conflicts as ethical problems with other health care professionals in the decision-making process at the end-of-life care (Oberle& Hughes, 2001; Schaffer, 2007). Nurses had disagreement with other health care professionals and had conflicts about treatment decisions, how to make decisions for patients, ineffective treatment and treatment versus palliative care (Schaffer, 2007). Nurses experienced frustration in decision-making processes when they had to argue with doctors to prescribe analgesic for the patient who had severe pain (Karlsson et al., 2012; Oberle& Hughes, 2001). Nurses felt uncomfortable, unsure and helpless when the patient needed some medicine and doctors were not available (Karlsson et al., 2012).

Nurses in the study of Karlsson et al. (2010) were free to make decisions but they needed skills and knowledge about their colleagues’ experience to manage decision-making process together. When they didn’t cooperate in this process, they felt powerless, had concern and felt frustration.

8.2 Ineffective treatments and therapies

Studies showed that nurses experienced ethical problems about continuing or discontinuing life-prolonging therapies and treatments in an artificial way (Bezerra do Amaral et al., 2012; Cheon et al., 2015; McLennon et al., 2013). Nurses experienced that they could not make any difference with these unnecessary actions and death was inevitable (Bezerra do Amaral et al., 2012). They also experienced that illness caused suffering to patients and these unnecessary actions couldn’t help. Nurses expressed that they wanted to reflect patients’ desire to maintain life as much as possible and they didn’t want to perform actions that cause suffering for the patients. Nurses wanted to give a worthy death to patients in the end-of-life care and not let them die during these unnecessary actions. Nurses in another study had discomfort with stopping the life-prolonging therapies such as nutrition and hydration (Cheon et al., 2015). Nurses experienced that they could resolve problems by using available resources and ethics consultation and in some cases issues resolved by the patient’s death. Nurses were concerned about some of the patients’ treatments, which had no benefit to patients because
they expressed that they wanted to increase the quality of life and give the patients as long life as possible (McLennon et al., 2013). Nurses experienced that some of the treatments and therapies at the patient's end-of-life care were ineffective and they only caused suffering (McLennon et al., 2013; Cheon et al., 2015).

**8.3 Insufficient communication**

Nurses experienced inadequate communication with doctors, patients and their families in the end-of-life care (Cheon et al., 2015; Oberle & Hughes, 2001; Schaffer, 2007; Karlsson et al., 2012; Bezerra do Amaral, Do Rosario de Menezes, Martorell-poveda & Cardoso Passos, 2012; Izumi, 2010). Nurses experienced ethical problems with regards to insufficient communication when all of the family members did not have enough information and they did not have discussed goals of care, they couldn’t make a realistic decision in the end-of-life care (Cheon, et al., 2015). Nurses were often concerned about if they informed the family and the patient well enough to make a decision and they felt that doctors often did not communicate in a suitable manner (Oberle & Hughes, 2001). In addition nurses had also communication problems with patients in conversations about dying and their decisions (Schaffer, 2007).

Patients didn’t want to talk about dying and death. Nurses felt that there was a lack of open communication with patients and their families, which made it difficult for them to manage these ethical situations (Karlsson et al., 2012). Nurses also expressed that they didn’t want to inform patients about death (Bezerra do Amaral et al., 2012). In addition they thought that patients would become aware of the death when they were close to death and there was no need of communication. Nurses experienced that they could not build trustful relationships with patients when they had sparse communication with them (Izumi, 2010). Nurses experienced that sometimes they couldn’t meet the patient’s need because they didn’t actively listen to them.

Nurses were concerned about patients and family members who did not have the capacity to understand the illness and treatment (McLennon et al., 2013). They experienced that some patients and families didn’t have the knowledge to understand the illness and treatment. They also experienced ethical problems in situations where patients and families were insufficiently informed. Nurses felt that they gave patients and family members false hope about their health status and treatment. Nurses experienced communication problems with patients who had limited language skills and different cultural beliefs.
8.4 The lack of cooperation

Nurses experienced the lack of cooperation with patients, families and other health care professionals (Karlsson et al., 2010; Schaffer, 2007; McLennon et al., 2013). Nurses experienced that they tried to get the family members and the patient together to talk about death and decision-making but they often had to convince family members that not all problems could be resolved at the end-of-life (Schaffer, 2007). They couldn’t reach the patient’s wishes and decisions because both family members and patients didn’t cooperate. Nurses explained that doctors didn’t discuss end-of-life problems about death and dying of cancer for example with their patients and they left these difficult discussions to nurses (McLennon et al., 2013; Karlsson et al., 2010). Nurses also experienced the lack of cooperation when their colleagues didn’t have enough knowledge to meet patients’ needs.

8.5 Inadequate respect for patient’s autonomy

Nurses experienced that families and other health care professionals sometimes ignored patients’ autonomy (Cheon et al., 2015; McLennon et al., 2013; Karlsson et al., 2012; Oberle & Hughes, 2001; Karlsson et al., 2010; Izumi, 2010; Schaffer, 2007).

Nurses reported inadequate respect for patient’s autonomy when families and other health care professionals did not support patient’s wishes and most treatments were opposite to patient’s wishes (Cheon et al., 2015). Nurses also mentioned that family members didn’t want patients to know that they were in the hospice. Most patients’ families didn’t want them to be aware of their diseases (Cheon et al., 2015; McLennon et al., 2013). Family members didn’t want the patient to be active in his/her decision-making process. Nurses reported conflicts among patients and families in the end-of-life care and they experienced that patients’ autonomy was not respected, for example nurses experienced that some families decided about treatments more than patients (Oberle & Hughes, 2001). Nurses experienced that they couldn’t recognize feelings of the patients about death because they didn’t want to talk about death and nurses had to respect them and their autonomy (Schaffer, 2007).

Nurses who provided end-of-life care for the dying patient at home had uncomfortable feelings because they experienced that the autonomy and integrity of the patient and his/her family members were not always respected (Karlsson et al., 2012; Karlsson et al., 2010; Izumi, 2010). Nurses described that the patient and family had conflicts about the place of care and nurses experienced that the patient’s tendency to die at home was not taken seriously and the patient died in the hospital alone (Karlsson et al., 2012; Izumi, 2010). Nurses knew
that transportation of the patient could speed up the death but the family were upset and forced nurses to do this even if they knew that this was against the patient’s wishes (Karlsson et al., 2010).

**8.6 Uncertainty in caring role**

Nurses experienced uncertainty as an ethical problem in caring role and they reported that most uncertainties were how to act in order to become ethically right in the caring role and which moral principles or values that they should apply in different situations (McLennon et al., 2013; Karlsson et al. 2012; Oberle & Hughes, 2001). Nurses experienced that they did not give enough certainty about the caring role to patients’ families and missed open communications with both patients and families because of their uncertainties to apply moral principles and values (Karlsson et al. 2012). Nurses experienced that they couldn’t fulfill patients’ needs and perform their own duties toward patients who needed their professional help at patients’ homes. The care at patients’ homes made situations even more difficult and also made nurses unsure to handle these ethically difficult situations. Nurses experienced uncertainty as ethical problems of what the best action was in situations when a treatment had to be finished (Oberle & Hughes, 2001). Some nurses also experienced uncertainty about information that they gave to their patients (McLennon et al., 2013). Moreover they experienced uncertain feelings about the lack of information during discussions with patients. They also expressed that patients and family members became angry when they didn’t have enough information about their diagnosis.

**9. Discussion**

In this section method and results of discussion will be described. Under the method discussion weaknesses and strengths of the literature review will be discussed and under results of discussion the theoretical basis in relation to results will be discussed.

**9.1 Method discussion**

Results articles that were used in this literature review are from databases *CINAHL* and *PubMed*. This is a weakness that only two databases were used since the articles related to this literature’s purpose were limited and both databases gave almost similar results. It is both a weakness and a strength to have articles from different countries. In addition, the result of literature review can be broad because of articles’ multicultural values and principles from
different countries.

Eight scientific articles were chosen due to limited time, material and resources. Search word end-of-life was selected because it was broad in content and involved all specialized care in this area. It was also a weakness that the author used Full Text option to search articles because it will restrict the search results and therefore the search and number of articles were limited.

The initial search were performed with the time range of 2010 - 2015, however due to the limited materials were found in this time range, the search year was extended to 2000-2015. Sometimes multiple hits were emerged that did not respond to the purpose. Articles were also translated into Swedish and Persian to understand the contents better and get an overall picture of them. I used the Persian dictionary because of my native language in order to understand articles’ content better. It can be a weakness that the author was only one person and had no opportunity to discuss with another author in order to understand better the contents of articles. However it was a strength that the author could speak more than one language to translate into different languages.

The choice of articles and analysis were carried out individually. All articles used a qualitative method. They all used interviews for data collection but just one of the articles had sent e-newsletter to the participations in the form of open questions such as: “Describe the most recent ethical dilemma that you have encountered? Was the situation resolved? If yes how?” (Cheon et al., 2015).

The analysis of the articles’ results showed that most articles were used ten or eleven times in the result section. However, the studies by Izumi (2010) and Bezerra do Amaral et al. (2012) were used only a few times due to their results touched this literature review’s purpose very little.

### 9.2 Results discussion

The purpose of this literature review was to describe nurses’ experiences of ethical problems in the patient’s end-of-life care. The analysis of the articles’ results showed that nurses in the result section of this literature review did not experience the same ethical problems and reflected different perspectives of ethical problems. In addition this may be because of their different responsibilities and nurses’ individual ethical values were at different levels. Nurses were aware of the ethical problems but they needed more ethical sensitivity.
understanding of integrity and fairness, awareness and ability to see the situation from an ethical point of view in order to make decisions in such situations. The “Results” chapter showed that nurses experienced insufficient communication as ethical problems because patients didn’t want to talk about death and dying. In some cases families didn’t want patients to know about their disease and other health care professionals left such conversations to nurses. Nurses in the study of Blasszauers and Palfi (2005) reported that the most ethical problems and conflicts between them and other health care professionals occurred in exchanging of information during the communication. Nurses also mentioned that the right information had a key role to build a good relationship between all partners in the patient’s end-of-life care. The writer of this literature review believes that nurses need to improve their communication technique during the interaction with patients and family members. Nurses have to assist the patient to create a comprehensive picture of herself/himself and her/his illness. Travelbee (1971) defines communication technique as a method, which is used to achieve the purpose of nursing interaction. Travelbee emphasizes that it is important to have an understanding of what the nurse or patient are communicating about. According to Travelbee a meaningful relationship between the nurse and the patient depends on what is communicated in the interpersonal process between them. The nurse should have an understanding of what the patient communicates in order to use this information in planning care. The author’s opinion is that nurses should use communication technique to create a meaningful relationship with patients in their interactions during the planning of care. Studies of Csikai, Roth and Moore (2004) and Sorta-Bilajac et al., (2011) also mentioned that communication is the key in resolving ethical problems to obtain complete information about patients. Health professionals should discuss with their teams about end-of-life care to obtain the potential help.

The result showed that nurses experienced ethical problems related to decision-making processes in the end-of-life care because of the lack of good communication. A good communication technique can help nurses to guide patients in the decision-making process according to the writer’s point of view. In addition nurses must help patients to make decisions and this is not possible without communication. These vital decisions in the end of life care are so important for patients. Nurses’ roles as a professional are to meet the patients’ needs and help them to decide. Travelbee also (1971) suggests that the observation and communication process are appropriate measures to meet the patient’s need. The nurse has the opportunity to meet the patient’s need during the interaction with him/her. According to Travelbee the observation and communication are two parts of the process of decision-making
during the interaction with the patient and family members. Travelbee indicates that decision-making has an important role in the end-of-life care because decisions determine life or death for the patient. The study of Blasszauers and Palfi (2005) indicates that nurses have important roles for patients to make decisions in the end-of-life care and they should also make them feel that they and their needs are understood in the decision-making process. The study of Sorta-Bilajac et al. (2011) also indicated that nurses experienced the end-of-life decision-making as ethical problems connected with respect for patients’ autonomy. The result indicated that nurses experienced uncertainty as ethical problems of what the best action was in different situations and they also experienced feelings of uncertainty about the lack of information during discussions with patients. Nurses were uncertain about which moral principles or values they should apply in different situations in order to become ethically right in the caring role. The author’s point of view is that nurses must improve their ethical sensitivity to reflect about their actions and have purposeful relationships in their interactions with patients in order to know patients’ needs. Travelbee (1971) mentions that some nurses have ethical sensitivity and can feel the thoughts and feelings of others while other nurses do not seem to have this ethical sensitivity. Those nurses who have the sensitivity understand the purposeful use of the communication process. The lack of both knowledge and ethical sensitivity make nurses respond too quickly without any reflection. The meaning of the communication and what is communicated in the interpersonal process assist nurses to establish their relationships. Travelbee also mentions that no individual can be entirely known without interaction. In addition, interactions provide an opportunity for nurses to know the individual and his/her needs.

The lack of cooperation with patients, families, and other health care professionals could create ethical problems in the end-of-life care for nurses. The author believes that nurses have to involve the patient more in his/her own end-of-life care and meet his/her needs. This may be possible if they have a helpful and useful cooperation with each other. In addition, the author believes that communication and cooperation are complementary and nurses need to communicate with patients in order to involve them in their own end-of-life care and to identify their needs as a goal in nursing planning. A good palliative care provides the following terms according to Socialstyrelsen (2005) and Ternestedt et al. (2012): satisfaction of the patients’ needs, a good death in the end-of-life care, relief of their symptoms, supporting patients’ relatives, making patients involved in the end of life care and providing the cooperation and communication. According to the author, the lack of cooperation and communication may be due to people’s stereotypes about nurses. Travelbee (1971) also suggests
that the patient and others tend to cooperate with the nurse based on their own stereotypes about nurses. Such stereotypes of nurse or patient prevent communication between them as a barrier. Patients, family members as well as health workers explain the role of the nurse in two ways. The first one is what they actually observe of nurse’s manner and activities and the second one is what they actually believe based on their stereotypes about nurses and nursing.

In addition, Travelbee mentions that nurses often were stereotyped because over a long period of time they didn’t let the patients involve and cooperate in the care. However, professional nursing has changed these stereotypes and the nurse became an eligible person to assist human being because of her/his knowledge and ability. Travelbeementions that cooperation includes any contact during communication verbally or non verbally and it arises when the nurse communicates with the patient. Both individuals have to understand each other and leave their own stereotypes about each other. There are so many kinds of cooperation but some kind of them are helpful and useful. It is the nurse’s task to guide the cooperation in a way to expand a relationship. In addition, nurses’ actions are more reflective, purposeful and less automatically. Travelbee mentions that human-to human relationship theory is a kind of cooperation with a purpose to assist the patient and meet her/his needs. The author believes that the lack of cooperation shown in the articles’ result may depend on cultural differences, the need of more ethical knowledge and sensitivity to meet the patients’ needs. Nurses in the study of Blasszauers and Palfi (2005) experienced that many reasons were behind the lack of cooperation. In addition these reasons were related to personal character and cultural differences.

The result showed that nurses experienced ethical problems related to inadequate respect for patients’ autonomy in the end-of-life care. For example when families did not want patients to be involved in their end-of-life care or decided treatments more than patients. The author believes that nurses have to support patients in order to increase patients’ autonomy and integrity. Nurses in the studies of Csikai et al. (2004) and Sorta-Bilajac et al. (2011) experienced inadequate respect for patients’ autonomy from other health care professionals and family members towards patients. Moreover nurses reported negative behaviors such as comments about the patient’s private life, yelling at patients, negative attitudes and undervaluing of the patient in the end of life care as ethical problems.
9.3 Clinical implications

It is important for nurses who work in the palliative care to have ethical sensitivity, knowledge and education in this area. It is also important that nurses in a team reflect and discuss different ethical problems. Otherwise there is a risk that nurses experience negative consequences if they don’t reflect on these ethical problems. In addition nurses’ reflection may have positive consequences for patients’ quality of life and care. Communication and cooperation as two important skills can support nurses to minimize ethical problems in the end-of-life care. Ethical knowledge on the other hand, helps nurses to get an overall picture of how to act to be ethically right in a situation and this also may support patients, their families and other health care professionals. In addition, ethical knowledge also helps nurses by using ethical tools to analyze situations. According to Silfverberg (2005) a genuine dialogue is the main ethical property for nurses and helps them to get new perspectives on ethical situations. In addition, these conversations are characterized by respect, openness and responsiveness for the other and nurses can use this as guidance for ethical situations in the patient’s care. The finding of this literature review can be helpful and useful for nurses in palliative care and helps them to prevent ethical situations mentioned earlier. The finding also helps nurses to understand the importance of ethical education and even makes them to have a tendency to reflect ethical problems, which they encounter. It is recommended that all nurses and other health care professionals participate in group discussions in a team and reflect together on current ethical problems. In addition such discussions may increase their ethical knowledge and knowledge of palliative care for patients in the end-of-life.

9.4 Suggestions for future research

Nurses must be involved in the future research to increase and update their knowledge and provide a comprehensive picture of nurses’ ethical problems and how they can resolve these problems. Future research should put more emphasis on the patients and their family members and not only nurses regarding ethical problems in the end-of-life care. In addition patient’s perspective may be different from health care professionals’ perspectives regarding definition of life quality, which is the goal of care at the end-of-life. Future research should also put more emphasis on young relatives as children in palliative care because it is no less painful and hard for children to lose a parent. It is also important to find some strategies in the future research for health care professionals especially nurses to how much they should offer patients and family members especially children support to not violate their autonomy.
10. Conclusions
The literature review shows that nurses experienced decision-making, ineffective treatments and therapies, insufficient communication, the lack of cooperation, inadequate respect for patient’s autonomy and uncertainty in caring role as ethical problems in the end-of-life care of patients. Results of this literature review show that nurses experience different ethical problems because of their different responsibilities in the end-of-life care of patients. Results also show that most ethical problems in the palliative care are related to the insufficient communication and cooperation with patients, families and other health care professionals. Communication and cooperation as two important skills facilitate relationships among patients, families and nurses at the end-of-life care and decrease ethical problems.
References


Sorta-Bilajac, I., Bazdaric, K., BirkljacicZagrovic, M., Jancic, E., Brozovic, B., Cengic, T.,


*= Results articles*
### Appendix 1. Article search in databases CINAHL and PubMed

<table>
<thead>
<tr>
<th>Database</th>
<th>Searchwords</th>
<th>No. of hits</th>
<th>Limits</th>
<th>No. of read abstracts</th>
<th>No. of read articles</th>
<th>Selected articles to results Appendix 2.</th>
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</table>
### Appendix 2. Matrix of selection of items

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Year, Country, Magazine</th>
<th>Purpose</th>
<th>Method, Selection, Data collection, Analysis</th>
<th>Results</th>
</tr>
</thead>
</table>
| Bezerra do Amaral, M.A., Do Rosario de Menezes, M., Martorell-poveda, M. A., & Cardoso Passos, S. | Ethic and bioethic dilemmas on palliative care for hospitalized elderly: nurses’ experience. | 2012, The city of Salvador-Brazil between May and August 2005, Culture Of Care | The purpose of this article was to discuss ethical and bioethical dilemmas, which experienced by nurses in the palliative care for elderly patients. | **Method**: Qualitative method  
**Selection**: 10 nurses in the age group between 25-45 years, who had experienced palliative care of elderly patients, were interviewed.  
**Data collection**: oral descriptions were used on the basis of the true story from those, who experienced an event.  
**Analysis**: explanatory-descriptive nature with a qualitative approach in the analysis of the information. | Ethical dilemmas such as: ineffective treatments and therapies, obtaining an undesired effect/double effect, inadequate respect for patient’s autonomy and insufficient communication were experienced by nurses. Nurses experienced these ethical and bioethical dilemmas, conflicts of values and contradictions to patients with incurable diseases. It was considered that there were still difficulties for understanding of the principles and philosophies of palliative care in Brazil. A reality, which has been already consolidated in European countries. |
| Cheon, J., Coyle, N., Wiegand, D. L., & Welsh, S. | Ethical issues experienced by hospice and palliative nurses | 2015, USA, Journal of Hospice & Palliative Nursing | The purpose of this study was to identify ethical issues by hospice and palliative nurses. In addition to ethical issues, also identify how the Hospice and Palliative nurses Association (HPNA) could support nurses in such ethical issues. And also identify available resources to nurses if any to their use. | **Method**: Qualitative method  
**Selection**: The Hospice and Palliative nurses Association (HPNA) members were asked to participate in an ethic survey. Several methods used and a link to the survey sent to special interest group members, but 129 nurses completed the online survey, e-newsletter. | The study reported that most significant ethical dilemmas were about telling the truth and ineffective treatments. The ethical dilemmas experienced by nurses were such as: inadequate communication, provision of non beneficial care, patient autonomy violated, issues with symptom management, the use of opioids, issues related to decision-making and issues related to life prolonging therapies. Two-thirds of nurses used the resources to resolve the ethical issues and one-third of |
<p>| Izumi, S. | Ethical practice in end-of-life care in Japan. | 2010, Japan, Nursing Ethics | The purpose of this study was to describe the ethical nursing practice in Japanese end-of-life care and gave a deeper understanding for how ethical practices appears in the clinical situations. | Method: Qualitative method | Data collection: An open-end survey consisted of 3 main questions asking the respondents to describe the most recent ethical dilemma, what resources were available to help them and describe how HPNA could support them. The survey Monkey online website used to develop the survey. Analysis: The content analysis of narrative comments by McLennon et al. nurses mentioned that institutional or personal barrier prevented them to resolve ethical dilemmas. |
| Karlsson, M., Karlsson, C., Barbosa da Silva, | Community nurses’ experiences of | 2012, Sweden, Scandinavian Journal of Caring Sciences. | Purpose of this study was to present a deeper understanding of community | Method: Qualitative method | Selection: 10 female nurses |
| | In the first step two themes appeared: uncomfortable feelings from absence of supporting and another one was the lack of... | | | | | | |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Method</th>
<th>Selection</th>
<th>Data collection</th>
<th>Analysis</th>
<th>Findings</th>
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<tbody>
<tr>
<td>A., Berggren, I., &amp; Söderlund, M.</td>
<td>nurses’ experiences of ethical problems in end-of-life care in the patient’s own home.</td>
<td>10 qualitative interviews with open questions approximately 1 hour and 1.5 hour</td>
<td>A hermeneutic approach by Gadamer is used to analyze the data from the interviews.</td>
<td>from 5 different communities with experience of end-of-life care were interviewed</td>
<td>cooperation with the personal, patients and families. And in the second step one theme appeared: uncertainty from the lack of open communication. Nurses experienced feelings from the lack of control that resulted from uncomfortable feelings, the lack of cooperation and the lack of safety. These themes expressed an entire understanding of nurses’ experiences of ethical problems in the end-of-life care.</td>
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<tr>
<td>Karlsson, M., Roxberg, A., Barbosa da Silva, A., &amp; Berggren, I.</td>
<td>Community nurses’ experiences of ethical dilemmas in palliative care: a Swedish study.</td>
<td>7 community nurses</td>
<td>Written stories about their experiences of ethical dilemma</td>
<td>The content analysis by Polit and Beck</td>
<td>The study showed core themes such as: powerlessness, frustration and concern in relation to ethical dilemmas in palliative care. Nurses felt responsibly for patients, families and their own duties in end-of-life care and they wanted to satisfy all of them. But there was a lack of knowledge and competence about how they should deal with such ethical dilemmas. The study emphasized that there was need of knowledge about how nurses experience ethical dilemmas in decision-making at the end-of-life care.</td>
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<td>McLennon, S., Uhrich, M., lasiter, S., Chamness, A., &amp;Helft, P. (2013).</td>
<td>Oncology Nurses’ narratives about ethical dilemmas and prognosis-related communication in advanced cancer patients.</td>
<td>137 nurses</td>
<td>Nurses wrote their stories by E-mail.</td>
<td>A content analysis according to Elo, Kyngäs and Krippendorff.</td>
<td>The study showed that nurses experienced ethical dilemmas such as uncertainties to tell the truth and familial and cultural conflicts. Nurses offered strategies such as: good communication and knowledge to facilitate these ethical dilemmas.</td>
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</table>
| Oberle, K., & Hughes, D. | Doctors’ and nurses’ perceptions of ethical problems in end-of-life decisions. | 2001, Canada, Journal of Advanced Nursing | The purpose of study was to identify and compare doctors’ and nurses’ perceptions of ethical problems. | Method: Qualitative method.  
Selection: 7 doctors and 14 nurses  
Data collection: Interviews  
Analysis: descriptive approach based on the grounded theory methodology of Strauss and Corbin (1998) | The study showed that both doctors and nurses experienced ethical problems around decision making at the end-of-life. They felt moral stress to reduce patients’ suffering. Uncertainty about choosing the best action was the reason to this moral distress. |
|---|---|---|---|---|---|
| Schaffer, M. A. | Ethical problems in end-of-life decisions for elderly Norwegians. | 2007, Norway, Nursing Ethics. | The purpose of this study was to explore ethical problems experienced by Norwegian health care professionals, patients and family members in the end-of-life decision-making. | Method: Qualitative method.  
Selection: 17 nurses/25 care professionals, 6 patients and 5 family members.  
Data collection: Interviews  
Analysis: A qualitative content analysis. | The study showed health care professionals mostly experienced ethical problems in interactions with family members. Such ethical problems are as follows: they wanted more treatment than was necessary, they had difficulty to understand information and they had disagreement with patients sometimes. Nurses experienced that it was hard to address the patients’ real wishes and decisions because family members interfered with the caring process too much. |