TAMPEREEN
AMMATTIKORKEAKOULU

ETHICAL DECISION MAKING PROCESS IN EUTHANASIA AND PHYSICIAN ASSISTED SUICIDE FROM NURSES' PERSPECTIVE

Hilkka Hopia

Bachelor's thesis
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ABSTRACT

Tampereen ammattikorkeakoulu
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Ethical Decision Making Process in Euthanasia and Physician Assisted Suicide from Nurses' Perspective

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The purpose of this study was to conduct a literature review describing nurses' role and factors affecting nurses' involvement in ethical decision making process in euthanasia and physician assisted suicide. The aim was to illustrate the decision making process of nurses in terms of euthanasia or physician assisted suicide. The objective was to provide a synthesis of a research results to benefit the nurses who are taking care of dying patients. The research questions were: 1) How are nurses involved in decision making process regarding euthanasia and physician assisted suicide? 2) What are the factors affecting nurses' involvement in ethical decision making in euthanasia and physician assisted suicide?

Seven studies were found on the topic. They were carefully analysed and reviewed, revealing five main themes: a quantity of nurses who are taking part in the decision making process of euthanasia and physician assisted suicide, nurses' consultation roles, ways of consultation, taking the initiative and reasons for not consulting the nurses. One to four themes were covered by one article.

According to all reviewed articles, nurses' participation in the process of euthanasia and physician assisted suicide is limited. The findings indicated that nurses do not have a clear voice in the process. For further recommendations, more research needs to be done from the area from nurses' point of view. Common guidelines for nurses' participation in the decision making process in euthanasia and physician assisted suicide would be beneficial to all of the participants of the process.

Key words: euthanasia, physician assisted suicide, ethics, nurse, decision making process

TIIVISTELMÄ

Tampereen ammattikorkeakoulu
Hoitotyön koulutusohjelma
Sisätauti-kirurginen hoitotyö

HOPIA HILKKA:
Eettinen päätöksentekoprosessi eutanasiassa ja avustetussa itsemurhassa sairaanhoitajien näkökulmasta

Opinnäytetyö 35 sivua, joista liitteitä 1 sivu
Lokakuu 2015

Tämän opinnäytetyön tarkoituksena oli tuottaa kirjallisuuskatsaus sairaanhoitajan roolista sekä niistä tekijöistä, jotka vaikuttavat rooliin eettisessä päätöksenteossa eutanasiassa ja avustetussa itsemurhassa. Tavoitteena oli kuvata sairaanhoitajien päätöksentekoprosessia edellä mainituissa tilanteissa koostamalla tulokset yhteen. Tuloksista on hyötyä sairaanhoitajille, jotka hoitavat kuolevia potilaita. Tutkimuskysymykset olivat: 1) Miten sairaanhoitajat ovat osallisena eutanasian ja avustetun itsemurhan päätöksentekoprosessissa? 2) Mitkä tekijät vaikuttavat sairaanhoitajien osallistumiseen eutanasian ja avustetun itsemurhan eettiseen päätöksentekoprosessiin?

Aiheesta löytyi seitsemän tutkimusartikkelia, jotka analysoitiin huolella. Viisi teemaa nousi esille: sairaanhoitajien määrällinen osallisuus, eutanasian ja avustetun itsemurhan päätöksentekoprosessissa, sairaanhoitajien roolit konsultaatiossa, konsultaation tavat, aloitteen tekeminen ja syyt, miksi konsultaatiota ei tapahtunut. Jokainen artikkeli sisälsi yhdestä neljään edellä kuvatuista teemoista.

Tarkasteltujen artikkeleiden mukaan sairaanhoitajien osallistuminen eutanasian ja avustetun itsemurhan päätöksentekoprosessiin oli rajallinen. Tulokset osoittavat, että sairaanhoitajilla ei ole selkeää roolia päätöksentekoprosessissa. Tärkeää on, että jatkossa aihetta tutkitaan lisää erityisesti sairaanhoitajan ja hoitotyön näkökulmasta. Yleiset ohjeet sairaanhoitajien osallistumisesta sekä roolista päätöksentekoprosessissa potilaan elämän loppuvaiheessa voisivat olla hyödyllisiä kaikille asian osapuolille.

Asiasanat: eutanasia, avustettu itsemurha, etiikka, sairaanhoitaja, päätöksentekoprosessi

CONTENTS

1 INTRODUCTION

The object of nursing is to maintain and promote people's and population's health according to their needs. Thus, a nurse's role is to protect life and promote patients' well-being. (Rautava-Nurmi, Westergård, Henttonen, Ojala &Vuorinen 2012, 14–15, 19.) On the other hand, many incurable diseases, such as amyotrophic lateral sclerosis (ALS) and certain types of cancer, cause major decrease in a patient's physical and psychological condition and, in addition, they have an influence on social life (McCluskey 2007, 463–464). It is therefore important to bring up the question of an individual's right to choose euthanasia in a situation in which no curable treatments are available.

Euthanasia and assisted suicide are very debatable topics (Quill 2007, 626). There are a great number of ethical issues concerning them and therefore a great deal of research has been done in the area of euthanasia and assisted suicide. Most of the studies have been made from a patient's or a physician's point of view but not as many have been made from a nurse's perspective. Nevertheless, nurses spend more time with patients and relatives than other health care professionals. Moreover, nurses identify problems in addition to planning and providing care to patients in a variety of settings. In order to provide high quality of practice nurses are required to have different skills, such as the ability to make decisions, effective communication skills and the competence to identify the best available research evidence and integrate it with clinical decisions. (Koubel 2013, 124–125; Polit & Beck 2014, 20–21.)

The ethical decision making process in euthanasia and physician assisted suicide from the nurses' point of view was chosen as a topic because it includes many aspects to be investigated. First, although euthanasia and assisted suicide are not legalized in Finland, it is important to raise the subject because nurses are frequently exposed to dying patients and death at their work. Providing nursing care for patients at the end of their lives can be very emotional work and ethical issues regarding the patient-nurse relationship can occur. Second, nurses act as decision makers using critical thinking skills to make decisions with the patient or on their behalf. Because of this, it is crucial to know what kind of elements are involved in the ethical decision making process in nursing, based on the international studies in the field. Last, there are individual studies of a nurse's role in euthanasia, but a research synthesis is needed to promote the implementation of new findings into nursing

practice. Moreover, this might be beneficial for the nurses who are working with the patients with incurable diseases. The findings would also likely benefit educators who are both designing the curriculum of decision making in nursing and teaching the subject in question. In addition, the ethical decision making aspect from nurses' perspective was chosen as the author will graduate to be one.

Cooperating partner of the thesis is Tampere University of Applied Sciences.

2 PURPOSE, OBJECTIVE AND RESEARCH QUESTIONS

The purpose of this thesis is to conduct a literature review describing nurses' role and factors affecting nurses' involvement in ethical decision making process in euthanasia and physician assisted suicide. The aim is to illustrate the decision making process of nurses in terms of euthanasia or physician assisted suicide. The objective is to provide a synthesis of research results of ethical decision making process in euthanasia and physician assisted suicide to benefit the nurses who are taking care of dying patients.

There are two research questions:

1) How are nurses involved in the decision making process regarding euthanasia and physician assisted suicide?

2) What are the factors affecting nurses' involvement in ethical decision making in euthanasia and physician assisted suicide?

3 THEORETICAL FRAMEWORK

Some of the key concepts are often confused with each other. To have a clear image of the key concepts used in this thesis, their meanings are elaborated in the following section.

3.1 Euthanasia

The word euthanasia is a combination of classic Greek words for "good" and "death". In modern language it refers to the practice of ending life with an intention of minimising suffering when recovery is no longer possible for the patient. (Butcher 2007, 205.) Pappas (2012) defines euthanasia as the causing or hastening of death when the patient is terminally or incurably ill. Euthanasia is executed by someone other than the patient at his or hers request and it can be divided into two categories: active and passive euthanasia. (Darji, Panchal, Kalele, Parmar & Bhagora 2011, 94; Pappas 2012, 170.) Active euthanasia denotes that someone else is ending the life of a patient by his or her request whereas passive euthanasia means discontinuing or not using supplementary life sustain measures to prolong life (Darji et al. 2011, 94–95; Hänninen 2011, 793; Saarelma 2011, 750–751). For example, active euthanasia occurs when someone gives large doses of a drug to hasten death. Passive euthanasia takes place when, for example, a life extending operation is not carried out or life extending drugs are not given to the patient (Darji et al. 2011, 94–95). According to Darji et al. (2011, 94) "letting die" means to give way to an ongoing inner organismic process of disintegration, without supporting or sustaining patient's vital functions.

Euthanasia has been a controversial issue for a long time. The World Medical Association (2013) actively opposes euthanasia for the reason that there is inconsistency between euthanasia and the ethical principles of medical practice. The association also advice physicians not to take part in euthanasia regardless its lawfulness in the area, and if the patients request for it or not. The Finnish Medical Association (according to Saarni, Kattelus & Nummi 2013, 159) indicates that the term passive euthanasia should not be used since it is contradicted. On the other hand, Saarni, et al. (2013, 159) argue that ending a treatment is a normal component of a physician's work.

American Nurses Association (ANA) published a position statement regarding euthanasia, assisted suicide, and aid in dying in 2013 (Position statement 2013). The purpose of the statement is to provide information about nurse's ethical obligations in responding to requests for assisted suicide and euthanasia. The statement supports the application of palliative care nursing guidelines in practice and it also makes recommendations for education, administration, and research. American nurses association has clearly described nurses' position in aid in dying, whereas the European Federation of Nurses Association (EFN) has not declared a statement regarding euthanasia, assisted suicide or aid in dying. (American nurses association 2013; Ethical Guidelines of Nursing 2014.)

Finnish Ethical Guidelines of Nursing was published by the Finnish Nurses Association in 2014 (Ethical Guidelines of Nursing 2014). The guidelines cover a wide range of nursing areas but there is no mention of what the role of nursing and the position of a nurse are as far as aid in dying and passive euthanasia are considered

3.2 Physician assisted suicide

The practice of physician assisted suicide (PAS), which has a different status in certain countries, is distinct from voluntary euthanasia. Assisted suicide is giving the patient the information or the medicine which the patient can use to commit suicide. In other words, physician assisted suicide is defined as the physician offering the way or the lethal amount of medicines for the patient to commit suicide. Thus, it is the individual who carries out the final act in a situation that has been arranged by health care practitioners. (Butcher 2007, 206–207; Pappas 2012, 170.) Furthermore, physician assisted suicide, also known as physical assisted death or doctor assisted suicide, can be separated from medical aid in dying (Canadian Medical Association 2014). Canadian Medical Association, for example, defines physician assisted suicide as a situation where a physician offers the information or the means to commit a suicide, or possibly both, to the patient. Counselling of the lethal amount of medicines is provided to the patient as well as prescribing the medicine to him or her. However, medical aid in dying is described as the physician participating in administrating the drug that causes the death of the patient. The definition includes that the fatal medicines are delivered by the physician but the actual administration is done by the patient. (Canadian Medical Association Policy 2014, 1–2.)

Physician assisted suicide is often confused with assisted suicide. The main difference is that in assisted suicide the patient performs the act of death him or herself, whereas in physician assisted suicide, a physician performs the act on behalf of the patient, for example if the patient is paralyzed (Darji et al. 2011, 94–95). According to van der Arend (1998), the request of euthanasia or physician assisted suicide must come from the patient, otherwise it is not defined as euthanasia or physician assisted suicide. For instance, cases such as ending a life of a coma patient or a new born cannot be included in these definitions. (van der Arend 1998, 308.)

3.3 Decision making process

Nurses are often in a situation where they discuss the possibility of discontinuing the treatment with patients and their relatives. These discussions often require the nurses' decisions on how to react to the patients' and relatives' opinions about the matter and how to handle the situation overall. Discussing death can make nurses conscious of their own mortality and it can cause anxiety and discomfort. Peters, Cant, Payne, O'Connor, McDermott, Hood, Morphet and Shimoinaba (2013) found that younger nurses consistently reported stronger fear of death and more negative attitudes towards caring for dying patients than older nurses (Peters et al. 2013, 14). It can therefore be assumed that decision making in nursing is often associated with uncertainty.

Decision making in nursing is a continuous process which includes the best available evidence to provide care by using evidence-based practice. The emphasis is on identifying the best research evidence and integrating it with other factors such as the patient's preferences, the nurse's clinical expertise, and available resources when making clinical decisions. (Polit & Beck 2014, 20–21.) Furthermore, decisions in nursing are not made in isolation from the context in which they are made. Koubel (2013, 124–125) emphasizes that nurses should be aware of the guidelines, processes and protocols that are utilized when making decisions and professional judgements in practice. Further (Koubel 2013, 124–125) states that the factors influencing professional judgement in nursing depend on a wide range of elements such as legal guidelines, ethical codes of conduct, expertise and experience in nursing, the views of other colleagues. In addition, he highlights the importance of utilizing available resources, available evidence of best practice, the choices

and capacity of the patient and his or her relatives, and decisions made in similar situations (Koubel 2013, 124–125).

It is important for nurses to involve patients, even if it is challenging, in the decision making to choose the best solution for them. This may often involve nurses to walk the line between autonomy and paternalism (Koubel 2013, 125). When caring for end-of-life patients, nurses have to acknowledge the complexity of decision making. Ethical decision making can vary from allowing the patient to make his or her own decisions even though others may perceive this as irresponsible to protecting the patient from the right to her or his independent choices. This is because you as a professional believe you know what is best for her or him. (Newham & Hawley 2007, 79.) Although nurses think ethically in their work most of the time, ethical issues in decision making are quite personal and intimate (Bennet 2015, xi–xii). Discussions often involve ethical aspects, which do not have right or wrong answers. Thus, exploring ethical decision making process in euthanasia and physician assisted from nurses' perspective is highly important. Nevertheless, in the decision making process, it is crucial to achieve the best outcome for an individual patient, promote healthy environment, improve clinical practice and achieve cost-effectiveness in nursing. (Leufer & Cleary-Holdforth 2009, 37–38.)

In comparison with the research on the attitudes towards the decision making process in euthanasia and physician assisted suicide, the nurses' point of view has not been studied as much. The Finnish Medical Association, for example, has regularly conducted surveys on physicians and recent study results revealed that the members of the association are against legalizing euthanasia and physician assisted suicide. (Saarni et al. 2013, 162.) At present, regularly conducted surveys for nurses on euthanasia or physician assisted suicide are not available even though nurses are most likely the ones terminally ill patients come to discuss the subject.

3.4 Nurse-patient relationship

As described above, nurses have a major role at the end of a patient's life. Belcher and Jones (2009, 146) argue that the relationship between a nurse and a patient has to be confidential in order to have efficient communication. To reach this aim, the relationship has to be based on the mutual trust of both sides. According to Arnold and Boggs (2003),

trust is essential to both parties to be sure that the other one is telling the truth. Trust includes communication, understanding, sincerity and dedication. (Arnold & Boggs 2003, According to Belcher & Jones (2009, 142–143.) Patients and their relatives require information and support from nurses and other health care professionals as far as ending the treatment or getting help when dying are considered. Since the matter is sensitive and generates various opinions, nurses have to increase their accountability towards the patients. In short, communication is a vital element of accountability especially in a nurse-patient relationship. (Koubel 2013, 129–130, Canadian Medical Association Policy 2014.)

The nurse-patient relationship is a therapeutic and caring relationship and all facets have to be only about the patient's needs. The relationship cannot be built to be personal and therefore boundaries have to be established. Accepting gifts from patients, sharing personal contact information, discussing nurse's personal relationships with a patient and beginning a relationship during or after the treatment are considered as going beyond the boundaries. Boundaries have to be set due to the patient's vulnerability. (Benbow 2013, 30; Griffith 2013, 1087–1088.)

3.5 Legislation

The legislation of euthanasia and physician assisted suicide varies by country. Although many countries and states have considered the legal status of euthanasia and physician assisted suicide, the subject has been studied mostly in the countries where they are legal such as the Netherlands, Belgium and some states of the United States of America (Saarelma 2011, 750).

There are at least three different approaches to euthanasia and physician assisted suicide. First, they can be considered as murder. Second, they are against the law but the acts are not punishable, and third, euthanasia and physician assisted suicide are legal medical procedures, which are strictly regulated by the law. Punishments alter from lenient to death penalty. (Banović & Turanjanin 2014, 1316.)

In the following chapters, the legislation of euthanasia and physician assisted suicide are explained in further detail. The focus of this literature review is on the legislations of the Netherlands and Belgium since the sample studies were conducted in these countries.

3.5.1 The Netherlands

In the Netherlands, euthanasia and physician assisted suicide are legal and they are not considered as criminal acts if certain criteria of due care are fulfilled. Furthermore, two criteria exist. First, meeting the prerequisites of due care under Termination of Life on Request and Assisted Suicide (Review Procedures) Act (1.4.2002). Second the physician has to report the act of euthanasia or physician assisted dying to The Regional Committee for Termination of Life on Request and Assisted Suicide. The committee then decides if the act of euthanasia or physician assisted suicide has been done according to the law. Physician has to consult another physician who has met the patient according to the law but consulting other health care professionals is not required. Physicians, nurses, and other healthcare professionals are not obligated to participate in the process of euthanasia and physician assisted suicide against their will. In addition, the physician and the patient have to have a medical relationship, which means that the patient has to be a resident in the Netherlands. (Termination of Life on Request and Assisted Suicide (Review Procedures) Act 1.4.2002.)

3.5.2 Belgium

Euthanasia and physician assisted suicide were legalized in Belgium in 2002. The criteria for euthanasia and assisted suicide are specified in The Belgian Act of Euthanasia. The main difference between the act of Belgium and the act of Netherlands is that, in Belgium, the physician has to consult a nursing team of the euthanasia and physician assisted suicide if the team is involved in the daily care of the patient. In case there is no such team, the consultation has to happen with an advanced directive team. Moreover, the attending physician has to inform the patient's relatives about the decision of the consultation if the patient wishes so. The patient has to have a chance to talk about the request with anyone he or she would like to. (The Belgian Act on Euthanasia 28.5.2002.)

As in the Netherlands, reporting the act of euthanasia and physician assisted suicide is required by the law in Belgium and the report is delivered to the Federal Control and Evaluation Commission. The commission then decides whether the act has been done according to the law. In Belgium, the healthcare professionals cannot be enforced to participate in euthanasia or physician assisted suicide against their will. In case the attending physician refuses to participate, he or she must inform the patient and the team of healthcare professionals involved about the refusal and the reason for it. (The Belgian Act on Euthanasia 28.5.2002.)

4 METHODOLOGY

This Bachelor's thesis uses the literature review method based on Polit's and Beck's (2012, 96) description of the method. In the following chapters, the instructions and how they were followed when conducting this thesis are explained.

4.1 Literature review

According to Polit and Beck (2012, 96), a literature review gathers data from a certain topic. When a researcher collects all the data from a certain area, he or she can see if there are any information gaps that require further research. In a literature review it is important to use primary sources in order to get as much information, and, more specifically, as objective information as available. Polit and Beck (2012) divide the writing of a literature review into nine different parts. The stages are: 1) formulating the research questions, 2) making a search strategy which includes selecting databases and search words, 3) searching primary sources, 4) using exclusion and inclusion criteria to limit the sources, 5) reading the sources, 6) obtaining the main information from the studies, 7) critiquing the studies, 8) analysing the information and 9) preparing the report. They emphasize that the written outcome of the review should be up-to-date, understandable and thorough. (Polit & Beck 2012, 96.) In this thesis, the instructions mentioned above were followed. Due to the nature of a literature review, no ethical approval was needed from ethical committees.

4.2 Inclusion and exclusion criteria

After the research questions were formulated, the research strategy was made. The keywords were "ethic*", "decision making process", "nurs*", "euthanasia", "physician assisted suicide", "palliative care", and "end of life". Combinations of these words were used by both applying Boolean operators, which allows to expand or limit the searches, and truncation symbol (*), which contains the root of the word in the search with different end variations (Polit & Beck 2012, 99).

Inclusion and exclusion criteria, presented in table 1, were carefully chosen to gather high quality evidence, which would answer to the research questions. The evidence was chosen according to the published language (English), the availability of full text, the type of the study and its relevancy to nursing. In order to acquire high quality studies for this thesis, only peer-reviewed studies were accepted. The research questions enhanced the focus on the nursing perspective. The questions highlighted the evidence of the decision making process of nurses excluding topics that were not the focus for this review, such as attitudes and beliefs. The capability of answering to the research questions was also carefully analysed. Morse (2012, 137) justifies the redundancy of time limitation since behaviours, concepts and theories remain valid. As mentioned above, Polit and Beck (2012, 96) recommend to use only primary sources, and therefore literature reviews were excluded.

TABLE 1. Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Published language (English)	Literature review
Peer-reviewed article	Not an academic source
Relevancy to nursing	
The availability of full text	

4.3 Literature searches

The chosen databases were Cumulative Index to Nursing and Allied Health Literature (CINAHL), Joanna Briggs Institute, Cochrane Library, Ovid, PubMed and Ebscohost (academic search elite). Searching primary sources was done by finding the original sources which were referenced in the analysed studies. New studies were not found in this stage.

The databases of Joanna Briggs Institute and Cochrane Library did not reveal any results with the keywords "ethic", "nurse" and "euthanasia". Search limitations were not used. Keywords in Ovid were the same as above and 115 Results were shown. Since all the articles were not accessible, "Original articles" and "Ovid full text available" limitations were used. This search returned nine articles. After reviewing the abstracts of the articles it was apparent that they were irrelevant to the thesis.

Keywords used in PubMed were "ethic", "nurs*" and "euthanasia" and they produced 784 search results. As in Ovid, all of the articles' full texts were not available, so the limitation "Free full text" was used, and, as a result, forty results were left. After carefully assessing the titles and abstracts, none of the results were relevant to the nurses' involvement in the decision making process in euthanasia and physician assisted suicide.

The same keywords, "ethic", "euthanasia" and "nurs*", were used when searching on Ebscohost (academic search elite). The number of results was 168. As before, all of the articles were not available, and therefore the limitation of "full text" was chosen. Also, limitations of scholarly (peer reviewed) journals was also chosen in order to get only high quality articles. As a result, 105 results returned, which are included in the literature retrieval process.

In order to get all possible data of the matter from CINAHL, different combinations of the keywords, which are presented in the following table (table 2), were used. In total, 900 studies were found.

TABLE 2. Searches in CHINAL

Searches	**Results**
Decision making process AND nurs* AND euthanasia	20
Ethic* AND decision making process	162
Ethic* AND decision making process AND nurs*	78
Ethic* AND decision making process AND nurs* AND euthanasia	12
Ethic* AND decision making process AND nurs* NOT attitude	70
Ethic* AND decision making process NOT attitude	144
Ethic* AND decision making process AND physician assisted	2
Ethic* AND decision making process AND palliative care	16
Euthanasia AND nurs* NOT attitude*	374
Ethic* AND decision making process AND end of life	22

The literature retrieval process is seen in figure 1. The total number of results was 1005, which was gathered from Ebscohost (academic search elite) and CINAHL. The first criterion for exclusion was to exclude literature reviews and articles by their titles' relevance. Next, the title's relevance from the nursing point of view, ethics, euthanasia and physician assisted suicide was analysed. Some duplicates appeared and they were ignored in the process. These exclusion criteria remained the same when assessing the articles more profoundly in the literature retrieval process. The criteria excluded 924 studies leaving 81 studies into consideration. All of the remaining abstracts were carefully read and as a result, 43 more studies were excluded leaving 38 studies for further inspection. Finally, all the studies were thoroughly assessed and based on the articles' whole study, 31 studies were excluded due to their irrelevancy to the nursing point of view, ethics, euthanasia and physician assisted suicide. The remaining articles were confirmed to answer the research questions. As a result, seven studies were chosen for this literature review. The studies were published in 1997, 1998, 2004, 2006, 2007 and 2008. Five of the studies were conducted in The Netherlands, and two of them in Belgium.

Database: CINAHL
Keywords: "Decision making process AND nurs* AND euthanasia", "Ethic* AND decision making process", "Ethic* AND decision making process AND nurs*", "Ethic* AND decision making process AND nurs* AND euthanasia", "Ethic* AND decision making process AND nurs* NOT attitude", "Ethic* AND decision making process NOT attitude", "Ethic* AND decision making process AND physician assisted", "Ethic* AND decision making process AND palliative care", "Euthanasia AND nurs* NOT attitude*" and "Ethic* AND decision making process AND end of life"
Limitations: Full text, peer-reviewed
Results: 900

Database: Ebscohost (academic search elite)
Keywords: "ethic, euthanasia AND nurs*"
Limitations: full text, scholarly (peer reviewed) journals
Results: 105

Total number of results: 1005

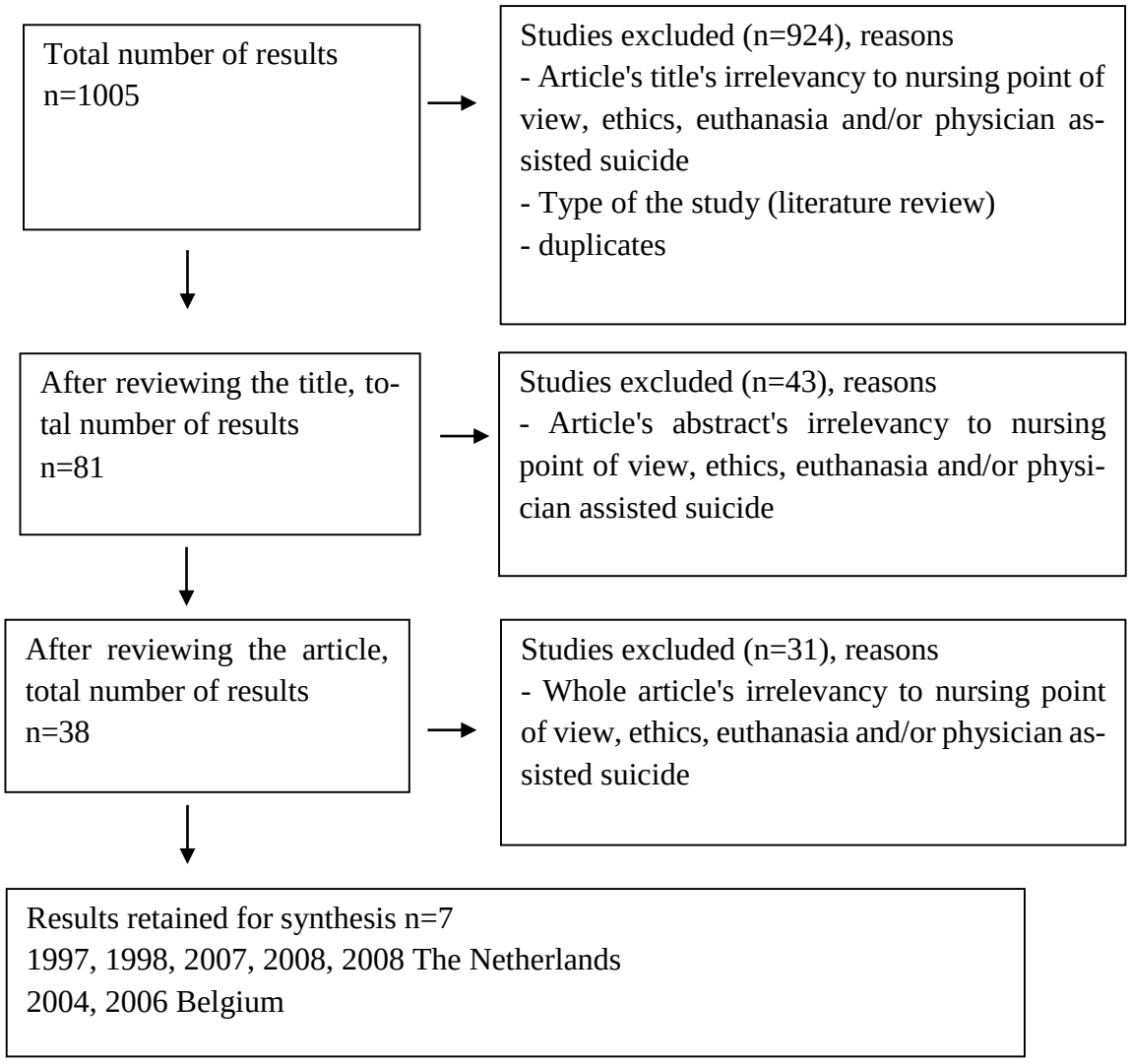

FIGURE 1. Literature retrieval process

4.4 Data analysis

When the data has been collected and read thoroughly, data analysis can begin. Data analysis consists of finding the main themes, similarities and differences between the data. (Polit & Beck 2012, 119.) The studies chosen for the literature review are investigated in methodological matrix (appendix 1). To detect the main themes of the data, a result matrix was made (table 3). (Polit & Beck 2012, 108.)

In the result matrix (table 3), the main themes described are: the quantity of nurses who are taking part in the decision making process of euthanasia and physician assisted suicide, nurses' consultation roles, the ways of consultation, how nurses are taking the initiative, and the reasons for not consulting the nurses. It is also marked which research question (question 1 or 2) the particular theme answers to.

TABLE 3. The matrix of the main themes.

Author(s), year	**The quantity of nurses taking part in decision making process Q 1***	**Nurses' consultation roles Q 1***	**The ways of consultation Q 1**	**Taking the initiative Q2**	**Reasons for not consulting Q2**
van Bruchem-van de Scheur et al., 2007	x			x	x
Muller et al. 1997	x	x			x
van de Scheur et al., 1998		x	x		
Bilsen et al., 2004	x				x
De Bal et al., 2006		x	x	x	x
van Bruchem-van de Scheur et al., 2008	x		x	x	x

de Veer et al., 2008	x				

Q1* = How are nurses involved in the decision making process regarding euthanasia and physician assisted suicide?

Q2* = What are the factors affecting nurses' involvement in ethical decision making in euthanasia and physician assisted suicide?

5 FINDINGS

The findings are divided under each research question to clarify the main findings for the reader.

5.1 Research question 1: nurses' involvement

The first research question was about nurses' involvement in the decision making process regarding euthanasia and physician assisted suicide. Three main themes were found to cover this research question: the quantity of nurses taking part in the decision making process of euthanasia and physician assisted suicide, nurses' consultation roles and the ways of consultation.

5.1.1 Nurses' participation

An individual study by Bilsen, Vander Stichele, Mortier and Deliens separated the level of participation into two different environments: the patients' homes and institutions (Bilsen et al. 2004, 586). In homecare, consultation between a physician and a nurse occurred in 20% of the cases. The physicians consulted the families equal amount of times (20%) as they consulted the nurses whereas in an institution the consultation percentage of nurses was 83.3%. According to Bilsen's et al. (2004) study results, the physicians consulted the nurses in the decision making of euthanasia in three out of four cases. A healthcare worker (excluding a nurse), with or without the patient's family, participated in the discussion in half of the cases (50%), in home environment. The decision making process with a healthcare worker (excluding a nurse), with or without family or with family only, took place in 8.3% of the cases studied. There was no clarification provided for the definition of the healthcare worker. In the study of Bilsen et al. (2004), the data were collected in retrospect from death certificates in Belgium, and the information was provided by the physicians who had signed the death certificate. (Bilsen et al. 2004, 586–587.)

The study by van Bruchem-van de Scheur, van der Arend, Abu-Saad, van Wijmen, Spreeuwenberg and ter Meulen (2008, 1622) revealed that nurses were involved in the decision making process regarding euthanasia and physician assisted suicide in more than three out of four (78.8%) cases. In contrast, de Veer, Francke and Poortvliet (2008, 225) stated that nurses were involved in the decision making process of euthanasia in 19% of the cases and in the decision making process of physician assisted suicide 1% of the cases. When the nurses were involved in the decision making process, the nurses discussed the request with the patient (87%), with the patient's family (83%) and with the physician in charge (74%). (de Veer et al. 2008, 226.) On the other hand, van Bruchem-van de Scheur, van der Arend, Spreeuwenberg, Abu-Saad and ter Meuler (2007, 48) reported that nurses participated in the decision making process less than half of the times (41.2%). It is necessary to point out that van Bruchem-van de Scheur et al. excluded the cases where the end of life request was so clear that nurses did not feel the need for consultation. Only one study by Muller, Pijnenborg, Onwuteaka-Philipsen, van der Wal and van Eijk (1997, 428) demonstrated the differences between the consultation levels according to the content of consultation. For instance, Muller et al. (1997, 427–428) described the patient's request and the actual administration as the levels of consultation. No further information was provided concerning the above mentioned levels.

5.1.2 Consultation roles

According to the selected studies, a nurse's role was to provide information about the patient's needs, feelings, request and whether to fulfil the request or not (Muller et al. 1997, 428; van de Scheur & van der Arend 1998, 502; De Bal, de Casterlé, De Beer & Gastmans 2006, 595).

Muller et al. (1997, 428) conducted a three-part study (I, II, II) with three different samples. Data were collected from clinical specialists, general practitioners and nursing home physicians. In the study I, almost every clinical specialist (95%) consulted the nurses concerning the content such as the request and the actual administration, and the request and the intention. Muller et al. (1997, 428) indicated in the study II that general practitioners consulted the nurses in 55% of the cases. The most common areas of consultation were the request, intention and actual administration. In the study III, where the sample consisted of nursing home physicians, it was discovered that almost all of the nursing home

physicians (95%) consulted the nurses in various areas of consultation. As stated previously, the issue in Muller's et al. study was that the researchers did not clarify the levels of consultation more profoundly. (Muller et al. 1997, 428.)

All nurses in the study by De Bal et al. (2006, 595) felt that the consultation was important in the decision making process of euthanasia. They thought that they were obligated to inform the patient's feeling of suffering to the members of the nursing team. Thus, the nurses wanted to act as advocates of the patients due to their close and caring relationship. The nurse-participants showed the need for support in their caring for end of life patients. (De Bal et al. 2006, 590, 595.)

5.1.3 The ways of consultation.

Consultations in the decision making process took place in several ways. The consultation method varied from informal meetings in hallways to formal, scheduled meetings between health care providers and the patients and their families. (van de Scheur et al. 1998, 502; van Bruchem-van de Scheur et al. 2008, 1622–1623.) In informal consultation meetings, a physician and a nurse changed a few words when they met in a corridor in a health care unit (van de Scheur et al. 1998, 502). In one study out of seven, nurses organized a multidisciplinary team to resolve which professionals should be involved in the decision making process (De Bal et al. 2006, 595–596). Similarly, nurses and physicians held formal meetings arranged beforehand to discuss the patient's request of dying (van Bruchem-van de Scheur et al. 1008, 1622–1623).

5.2 Research question 2: factors affecting involvement

The second research question was aimed to describe the factors affecting nurses' involvement are in the decision making process in euthanasia and physician assisted suicide. Two themes were discovered to answer the question: taking the initiative and the reasons for not consulting the nurses.

5.2.1 Taking the initiative

van Bruchem-van de Scheur et al. (2007, 48) and van Bruchem-van de Scheur et al. (2008, 1622) observed that physicians took the initiative in raising the discussion on the patient's request for assistance in dying with nurses more often than the nurses themselves did. In both studies, nurses took the initiative to be involved in the decision making process in approximately 30% of the cases. However, van Bruchem-van de Scheur et al. (2008, 1622) discovered that the nurses took the initiative almost as often as physicians when the request of euthanasia or physician assisted suicide was not accepted by the physician. When the request of euthanasia or physician assisted suicide was accepted, the physicians took initiative more often than the nurses. (van Bruchem-van de Scheur et al. 2008, 1622.)

5.2.2 Reasons for not consulting

Five studies out of seven reported several reasons why physicians did not include nurses in the decision making process of euthanasia and physician assisted suicide. The main reason was that the patient did not want nurses to be included in the decision making process of euthanasia and physician assisted suicide. The second reason was that physicians thought they did not need the nurses' professional expertise because the patient's request was so obvious and clear. In addition, a great number of physicians mentioned that they cannot disclose the patient's request because they considered it as a matter of doctor-patient confidentiality. (Muller et al. 1997, 428; van Bruchem-van de Scheur et al. 2007, 48; van Bruchem-van de Scheur et al. 2008, 1622.) In their study, Muller et al. (1997, 428) and Bilsen et al. (2004, 586) showed that physicians had long and personal relationships with the patients whereas nurses were not equally involved in the caring process. This was the case especially in homecare settings where nurses did not provide nursing care at all or it was restricted to a few minutes per day (Muller et al. 1997, 428; Bilsen et al. 2004, 586).

The study of De Bal et al. (2006, 595) was conducted in 2006 when euthanasia and physician assisted suicide were illegal in the Netherlands. Therefore no common practice for the decision making process existed (De Bal et al. 2006, 595). In the Netherlands, unlike in Belgium, including nurses in the decision making process of euthanasia and physician assisted suicide is not stated in the law although it is advisable (van Bruchem-van de

Scheur et al. 2008, 1622). De Bal et al. (2006, 595) stated that the setting (palliative/regular care), the specialty of the physician and the nursing care context also had an effect on the nurses' involvement level. De Bal and her colleagues were the only researchers out of the seven studies selected for this review, to point out that the hierarchical doctor-nurse relationship was one of the reasons for the lack of consultation between the nurses and the doctors (De Bal et al. 2006, 595). van de Scheur et al. (1998, 502) noted that while the majority of the nurses felt that the informal consultation was enough, some nurses did not count the informal consultation as their involvement in the decision making process at all (van de Scheur et al. 1998, 502).

6 DISCUSSION

The primary purpose of this literature review was to describe nurses' role and the factors affecting nurses' involvement in the ethical decision making process in euthanasia and physician assisted suicide. The objective was to provide a synthesis of research results of ethical decision making process in euthanasia and physician assisted suicide to benefit the nurses who are taking care of dying patients.

Nurses' involvement in the ethical decision making process of euthanasia and physician assisted suicide has not been studied greatly. This was noticeable when the literature search was made. Moreover, the search questions had to be changed since the searches did not reveal any studies answering to the original questions. The original research questions were: 1) What are the elements affecting nurses' ethical decision making process in euthanasia and physician assisted suicide? 2) How these elements affect nurses' ethical decision making process in euthanasia and physician assisted suicide? Nevertheless, even after changing the research questions, the data collection was limited and no clear ethical perspective of the decision making process of nurses was found. Consequently, it was necessary to shift the focus of this literature review more towards the decision making process of euthanasia and physician assisted suicide from nurses' perspective.

This literature review raises several issues regarding nurses' role and position in the decision making process of euthanasia and physician assisted suicide. The main issue is that the topic has not been studied a great deal from the nurses' standpoint. Although seven articles were found, the academic databases used in this thesis did not reveal any studies made from the ethical point of view described above. This is somewhat surprising even though it is known that physicians are the ones responsible for the decision whether to fulfil a patient's request of euthanasia or physician assisted suicide or not. In spite of this fact, nurses play a major role in the patients' lives due to their constant care and, therefore, nurses will likely have an advantage over physicians as far as the patients' feelings and needs are concerned.

Currently, the importance of multiprofessional teamwork is emphasised in health care work (Thylefors 2012, 273–273; Lancaster, Kolkowsky-Hayner, Kovacich & Greer-Williams 2015, 280). However, in the studies of Muller et al. (1997, 428), van Bruchem-van de Scheur et al. (2008, 162) and van Bruchem-van de Scheur et al. (2007, 48), physicians

considered euthanasia and physician assisted suicide as matters to be discussed between them and the patient. van Bruchem-van de Scheur et al. (2008, 1623) remarked that "the physicians considered euthanasia as their exclusive domain". However, as indicated in the above-mentioned study (Lancaster et al. 2015, 280), sharing information about the patient's requests, wishes and needs among healthcare professionals would most likely increase the quality of the care. Thus, it was quite surprising that this was one of the main reasons mentioned in the study for not consulting the nurses. In fact, inefficient communication and collaboration among healthcare professionals are associated with the negative effects, whereas productive communication and collaboration are shown to improve patient safety (Aston, Shi, Bullot, Galway & Crisp 2005, 210–211). Naturally, the patient's wish for not including nurses in the decision making process has to be respected. When the patient is asked the permission to consult the nurses by the physician, it should be asked neutrally regardless of the physician's personal opinion.

In their study, Muller et al. (1997, 428) itemized the issues the nurses consulted with the attending physician. For instance, issues such as the request of the patient, the request and intention and the request and the administration were specified. One challenge of this review was that the consultation levels were not defined precisely. This is quite concerning given the fact that consultation in health care can appear in different levels and the content may vary greatly depending on the people involved. Consultation in nursing is situation-specific and it would be highly important to define the levels of consultations in the studies which will be conducted in the future.

De Bal et al. (2006, 595) pointed out that a hierarchical doctor-nurse relationships was one of the reasons for the lack of consultation. They were the only ones who exposed this phenomenon, however, the same conclusion could be deduced from the other studies selected for this literature review. van Bruchem-van de Scheur et al. (2007, 48) discovered that one of the reasons for not consulting the nurses was the lack of collaboration between the physicians and the nurses. Reasons for the poor collaboration were not mentioned but it could be concluded that a hierarchical doctor-nurse relationships would had an effect on the teamwork. Furthermore, the lack of functional teamwork could lead to emotional stress of the nurses. As Butcher (2007, 211) indicates, the professionals caring for the dying patients have the right to support. He further states that this is particularly the case when professionals are exposed to the daily stress caused by caring for the patients, who

would be described as burdensome. In addition, the nurses have to continue to do their other daily tasks at the same time.

Contrary to what might be expected, nurses had a limited participation in the decision making process of euthanasia and physician assisted suicide based on the findings of this review. In contrast, this might seem surprising since nurses spend a great deal of time with the patients and relatives. In almost half of the cases (45.1%) in the study of van Bruchem-van de Scheur et al. (2008, 1622) nurses were the ones with whom the patients started talking about euthanasia or physician assisted suicide. In fact, De Bal et al. (2006, 596) reported that nurses were always the first professionals who received the request from the patient. To sum up, concerning the above-mentioned cases, the nurses were always involved in some level in the decision making process (De Bal et al. 2006, 595).

Three studies out of seven revealed that the nurses did not take the initiative to involve in the decision making process as many times as the physicians did. This is somewhat concerning, because according to Dreher, Barginere, Clark and Wright (2013, 140) nurses need to act powerfully on behalf of the patients and their families regardless of the practice setting. They further claim (Dreher et al. 2013, 140) that acting powerfully demonstrates professional expertise which, as a result, will influence capturing the attention of other healthcare professionals.

6.1 Limitations of the review

This literature review has a few limitations which may affect the findings. Even though many databases were used, only CINAHL provided the usable data. Although CINAHL is the most well-known and commonly used database in nursing, including more databases to this review might have increased the number of selected studies in the final sample. Another limitation is that the search strategies used in this review would have underrepresented studies in other languages such as French and Dutch. In fact, there were particularly many studies concerning nurses' role in euthanasia and physician assisted suicide, which were published in Dutch. Some selected studies had physicians as their sample. The physicians were asked to describe nurses' role and their position in the process of euthanasia or physician assisted suicide. This was taken into consideration when drawing conclusions and recommendations about the data. Moreover, the selection process of

the studies was carried out carefully but only by the reviewer. In addition to that, the quality appraisal of the individual studies included was not performed. The reason for this is that the CINAHL database utilised in this review provides mainly nursing and other health literature from various allied health disciplines.

The findings of this review vary a little due to several reasons. In the study of Bilsen et al. (2004), physicians answered questionnaires about nurses' involvement but the results may have become distorted since nurses did not provide care for all patients during the time the study was conducted. (Bilsen et al. 2004, 585–586.) The variation within the results may be due to the fact that in some studies the sample included only either physicians or nurses. The physicians and nurses were asked about nurses' participation in the decision making process of euthanasia and physician assisted suicide. The physicians may have been able to answer why consultation was lacking but it can be questioned if they were the right persons to comment on the nurses' involvement in the decision making.

6.2 Conclusion and recommendations

The findings of this review suggest that nurses' role and position is quite unclear in the decision making process of euthanasia and physician assisted suicide. Although euthanasia and physician assisted suicide are not legal in most of the countries, the nurses play an important role in the care of dying patients. Given this fact, a surprisingly small number of researchers have studied the subject.

The findings could indicate that nurses need support for taking more actively part in the decision making process when caring for end of life patients. Moreover, support and encouragement given by their superiors and colleagues may be beneficial for them. In addition, they might benefit from the professional guidance given by other health care professionals outside their work place. Regular multiprofessional meetings would also be useful for the nurses to strengthen their position and role in the decision making process of euthanasia and physician assisted suicide (Lancaster et al. 2015, 280). Based on the findings of this review, providing common guidelines for the nurses taking care of dying patients is recommended.

Given the different legislations between Belgium and the Netherlands, a few issues should be taken into consideration when drawing the conclusions of the findings of this review. According to the law in Belgium, nurses are not required to ask the patient's permission to inform other healthcare professionals of his or her wish to die (De Bal et al. 2006, 597). In the Netherlands, on the other hand, the permission is required. Although the communication between nurses and physicians is a legal requirement in Belgium, this requirement was not always met (Bilsen et al. 2004, 586, 588). As a result, this could lead to contradictions in nursing care.

Although the evidence was based on a small sample, these findings suggest that more research needs to be done on the decision making process of euthanasia and physician assisted suicide. New study results are needed especially from the ethical point of view regarding nurses' involvement. Furthermore, more attention should be paid to nurses' independent position as professionals who are able to make decisions and provide expert opinions based on their knowledge skills and education.

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APPENDICES

Appendix 1. Methodological matrix

Title of the article	author(s)	Country of the study	Published journal, year
The role of the nurse in active euthanasia and physician-assisted suicide	Muller, M., Pijnenborg, L., Onwuteaka-Philipsen, B., van der Wal, G. & van Eijk, J.	the Netherlands	Journal of Advanced Nursing 26 (2), 424–430. 1997
The role of nurses in euthanasia: a Dutch study	van de Scheur, A. & van der Arend, A.	the Netherlands	Nursing Ethics 5 (6), 497–508. 1998
Involvement of nurses in physician-assisted dying	Bilsen, J., Vander Stichele, R., Mortier, F. & Deliens, L.	Belgium	Journal of Advanced Nursing, 47(6), 583–591. 2004
Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): a qualitative study	De Bal, N., de Casterlé, B., De Beer, T. & Gastmans, C.	Belgium	International Journal of Nursing Studies 43 (5) 589–599. 2006
Euthanasia and physician-assisted suicide in the Dutch homecare sector: the role of the district nurse	van Bruchem-van de Scheur G., van der Arend, A., Spreeuwenberg, C., Abu-Saad H. & ter Meuler, R.	the Netherlands	Journal of Advanced Nursing 58(1), 44–52. 2007
Euthanasia and assisted suicide in Dutch hospitals: the role of nurses	van Bruchem-van de Scheur G., van der Arend A., Abu-Saad H., van Wijmen F., Spreeuwenberg C. & ter Meulen R.	the Netherlands	Journal of Clinical Nursing 17, 1618–1626. 2008
Nurses' involvement in end-of-life decisions	de Veer, A., Francke, A. & Poortvliet, E-P.	the Netherlands	Cancer Nursing 33 (3), 222–228. 2008