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**ANJA TERKAMO-MOISIO**

**COMPLEXITY OF ATTITUDES TOWARDS  
DEATH AND EUTHANASIA**



*Complexity of attitudes towards death and  
euthanasia*



ANJA TERKAMO-MOISIO

*Complexity of attitudes towards death and  
euthanasia*

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## ABSTRACT:

The studies this thesis are based upon had the following objectives. First, to reveal and describe attitudes towards death and euthanasia among the general public and nurses in Finland. Then, to explore the factors related to the attitudes and analyse connections between individuals' death- and euthanasia-related attitudes in both target groups. Finally, to construct an empirical model of factors associated with individuals' attitudes towards euthanasia.

These objectives were addressed in a qualitative interview-based study and a quantitative web-based survey. Interviewees in the first study were 17 registered nurses who worked in two primary care hospitals in southern Finland. The collected data were analysed with inductive content analysis. Participants in the survey were representatives of the general public (n=2796) and nurses (n=1003), who were recruited via social media and the Finnish Nurses Association members' bulletin. Data were collected online with a designed electronic questionnaire then analysed using statistical methods and Bayesian network modelling.

Participating nurses and members of the general public in Finland generally had neutral attitudes towards death. The level of fear of death was low in both groups. Furthermore, participants in both groups reported low levels of death avoidance, and more of both groups believed that death could provide welcome escape from a life filled with suffering than in a happy afterlife. Both groups expressed attitudes indicating general approval of euthanasia. Most of the nurses (74.4%) and members of the general public (85.2%) expressed their acceptance of euthanasia as part of Finnish health care. In addition, more than half of the participants in both groups (62.1 and 67.0% respectively) thought that Finland would benefit from a law permitting euthanasia. However, the interviews revealed that nurses had concerns about possible misuse of euthanasia, and that a nurses' right of conscientious objection to participation in euthanasia was crucial. The empirical model of factors associated with individuals' attitudes towards euthanasia revealed that profession, religiosity and attitudes towards death were predictors of individuals' attitudes towards euthanasia. However, religiosity was only a predictor when its component dimensions were separately assessed.

The studies have provided new knowledge about attitudes towards death and euthanasia of nurses and the general public in Finland, and presented a new empirical model that could be employed in future research and education. The studies have several implications. An open dialogue about death and euthanasia at all levels of Finnish society is crucial. More information and death-related education is needed in the nursing profession to improve the quality of end-of-life care. Additional research is needed for further characterization of attitudes towards death and euthanasia.

National Library of Medicine Classification: W 62, WB 65, W 85.5, WA 900, WY 20.5, WY 85

Medical Subject Headings: Attitude; Attitude to Death; Bayes Theorem; Death; Euthanasia; Nurses; Public Opinion; Social Media; Surveys and Questionnaires; Finland



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## TIIVISTELMÄ:

Tämän tutkimuksen tarkoituksena oli selittää kansalaisten sekä sairaanhoitajien kuolemaan ja eutanasiaan kohdistuvia asenteita. Lisäksi tarkoituksena oli kuvata asenteisiin vaikuttavia taustatekijöitä sekä analysoida niiden välisiä suhteita molemmissa kohderyhmissä. Tutkimuksen päämääränä oli tuottaa empiirinen malli ihmisen eutanasiaan kohdistuvien asenteiden taustatekijöistä.

Tämä tutkimus koostuu laadullisesta haastattelututkimuksesta sekä määrällisestä elektronisesta kyselytutkimuksesta. Haastattelututkimukseen osallistui 17 sairaanhoitajaa, jotka työskentelivät kahdessa perusterveydenhuollon sairaalassa Etelä-Suomen alueella. Kerätty aineisto analysoitiin induktiivisen sisällönanalyysin avulla. Kyselytutkimukseen osallistui 2796 kansalaista sekä 1003 sairaanhoitajaa, joita tiedotettiin tutkimuksesta sosiaalisen median sekä Sairaanhoitajaliiton jäsentiedotteen välityksellä. Määrällisen tutkimuksen aineisto analysoitiin tilastotieteellisin menetelmin. Tutkimuksessa tuotetun empiirisen mallin toteutuksessa hyödynnettiin Bayesverkkoa.

Tutkimukseen osallistuneiden kansalaisten sekä sairaanhoitajien asenne kuolemaan oli neutraali. Kuoleman pelko sekä sen välttely olivat alhaisella tasolla molemmissa ryhmissä. Sekä kansalaisten että sairaanhoitajien asenteissa kuolema näyttäytyi voimakkaammin pakomahdollisuutena kärsimyksen täyhteisestä elämästä kuin porttina kuolemanjälkeiseen elämään. Osallistujien eutanasiaan kohdistuvat asenteet olivat myönteisiä kummassakin ryhmässä. Suurin osa sairaanhoitajista (74.4%) sekä kansalaisista (85.2%) ilmoitti hyväksyvänsä eutanasian osana suomalaista terveydenhuoltoa. Samoin 62.1% sairaanhoitajista ja 67.0% kansalaisista ajatteli Suomen hyötävän eutanasian sallivasta laista. Haastattelututkimuksen tuloksissa nousi esiin sairaanhoitajien huoli eutanasian mahdollisesta väärinkäytöstä. Lisäksi sairaanhoitajat pitivät mahdollisuuttaan kieltäytyä osallistumasta eutanasiaprosessiin tärkeänä. Tutkimuksessa tuotettu empiirinen malli osoittaa ammatin, ihmisen uskonnollisuuden sekä kuolemaan kohdistuvien asenteiden vaikuttavan henkilön eutanasia-asenteisiin. Uskonnollisuuden vaikutus ilmenee kuitenkin ainoastaan tilanteessa, jossa sen eri dimensiot on huomioitu sekä arvioitu toisistaan erillisinä.

Tämä tutkimus on tuottanut uutta tietoa kansalaisten sekä sairaanhoitajien kuolemaan sekä eutanasiaan kohdistuvista asenteista Suomessa. Tuotettua empiiristä mallia voidaan hyödyntää sekä tulevaisuuden tutkimuksissa että sairaanhoitajien koulutuksessa. Johtopäätöksenä voidaan todeta avoimen eutanasia keskustelun olevan ensiarvoisen tärkeää yhteiskunnan kaikilla tasoilla. Elämän loppuvaiheen hoidon laadun parantamiseksi hoitohenkilöstön koulutusta on tehostettava sekä heille on tarjottava nykyistä enemmän tietoa aiheesta. Tutkimusten tulokset osoittivat kuolemaan ja eutanasiaan kohdistuviin asenteisiin liittyvän jatkotutkimuksen merkityksen molempiin ilmiöihin liittyvän tiedon sekä ymmärryksen lisäämiseksi.

Luokitus: W 62, WB 65, W 85.5, WA 900, WY 20.5, WY 85

Yleinen Suomalainen asiasanasto: asenteet; bayesilainen menetelmä; eutanasia; haastattelututkimus; kyselytutkimus; kansalaiset; kuolema; sairaanhoitajat; sosiaalinen media; Suomi; taustatekijät



*“Many that live deserve death. And some die that deserve life. Can you give it to them? Then be not too eager to deal out death in the name of justice, fearing for your own safety. Even the wise cannot see all ends.”*

*J.R.R. Tolkien*



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Lappeenranta, July 2016

*Anja Terkamo-Moisio*





# List of the original publications

This dissertation is based on the following original publications:

- I   Terkamo-Moisio A, Kvist T & Pietilä A-M. Multifaceted nature of euthanasia: perceptions of Finnish registered nurses. *The Journal of Hospice and Palliative Nursing* 17: 105-112, 2015.
- II   Terkamo-Moisio A, Kvist T, Laitila T, Kangasniemi M, Ryyänänen O-P & Pietilä A-M. The traditional model does not explain attitudes towards euthanasia: a web-based survey of the general public in Finland. *Omega – Journal of Death and Dying*. doi 10.1177/0030222816652804
- III   Terkamo-Moisio A, Kvist T, Kangasniemi M, Laitila T, Ryyänänen O-P & Pietilä A-M. Nurses' attitudes towards euthanasia in conflict with professional ethical guidelines. *Nursing Ethics*. 2016. doi 10.1177/0969733016643861
- IV   Terkamo-Moisio A, Kvist T, Ryyänänen O-P & Pietilä A-M. What do nurses and general public think about death? A Web-based survey. Submitted.

The publications were adapted with the permission of the copyright owners.

In addition, this summary includes previously unpublished material.



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## ORIGINAL PUBLICATIONS (I-IV)

## APPENDICES

# Abbreviations

ACP	Advanced care planning
ANA	American Nurses Association
AoIR	Association of Internet Researchers
BN	Bayesian Network
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CRS	The Centrality of Religiosity Scale
DAP-R	The Death Attitude Profile – Revised
EBSCO	EBSCOhost Academic Search Premier
ETENE	The National Advisory Board on Social Welfare and Health Care Ethics
EOL	End-of-life
EVS	The European Values Study
ICN	International Council of Nurses
ISCED	International Standard Classification of Education
NDE	Near-death experience
PAD	Physician-assisted dying
PAS	Physician-assisted suicide
PCA	Principal Component Analysis
TENK	Finnish Advisory Board on Research Integrity



# 1 Introduction

Mortality is an inevitable part of human life. Every year more than 50 000 individuals die in Finland, 65% of whom face their death in a health care facility (Official Statistics of Finland 2015a), where nurses care for them and support their close ones.

Death arouses many, sometimes conflicting, thoughts and emotions in every individual, and thus influences how s/he engages with life. For example, love and other commitments may be rejected in order to avoid the unavoidable pain of separation, caused at the latest by death. (Wong & Tomer 2011.) An individual's positive or negative predispositions towards death can be regarded as part of a set of enduring characteristics, or *attitudes*, that can be used to understand and predict human behaviour (Peters et al. 2013b, Riemer et al. 2014). Nurses play a crucial role in end-of-life (EOL) care, as emphasized in various studies (Peters et al. 2013b). However, nurses' attitudes towards death have a significant impact on their willingness to participate in EOL care, the quality of the care they provide, and their professional wellbeing (Khader, Jarrah & Alasad 2010, Peters et al. 2013b). Although death is commonly associated with negative attitudes, a death that represents the end of suffering may be regarded positively (Hinderer 2012, Mak 2012).

Euthanasia, defined as a deliberate act intended to terminate a person's life at his/her own explicit request, has been a topic of ongoing debate in several countries in Europe, including Finland. The Finnish National Advisory Board on Social Welfare and Health Care Ethics (ETENE) stated in 2012 that in some occasional situations the possible use of euthanasia may not be completely excluded on ethical grounds. (ETENE 2012.) This statement reignited debate about euthanasia and its possible legalization in Finland. The topic has been discussed mainly from political, theological and medical perspectives, although possible changes in this regard would have repercussions for more than 100 000 nurses in Finland (Ailasmaa 2014). However, nurses' voices have remained unheard in the Finnish euthanasia debate. This may be partly due to lack of current knowledge about attitudes of nurses and the general public towards death and euthanasia.

A literature review yielded no Finnish studies regarding death-related attitudes, and the last study reporting attitudes of Finnish nurses and the general public towards euthanasia was published in 2002 (Ryynänen et al. 2002). Furthermore, connections between death- and euthanasia-related attitudes have not been specifically explored by researchers either in Finland or internationally (Gielen et al. 2009).

Attempts have been made to explain individuals' attitudes towards death and euthanasia in terms of various factors such as age, gender, death exposure, ethical aspects and religiosity. However, previous studies have reported conflicting results, attributed to differences in definitions of euthanasia, cultural aspects and phrasing of questions (Gamliel 2013, Holt 2008). Furthermore, previous studies have been criticized for weaknesses in the operationalisation of religiosity (Gielen, Van den Branden & Broeckaert 2009a) and statistical analysis methods used (Vézina-Im et al. 2014). All these discrepancies and criticisms were taken into consideration in the studies this thesis is based upon, and addressed by adjusting definitions and the methodology in ways that seemed appropriate for reasons outlined in the thesis and appended original publications.

The studies had the following objectives. First, to reveal and describe attitudes towards death and euthanasia among the general public and nurses in Finland. Then, to explore the factors related to the attitudes and analyse connections between individuals' death- and euthanasia-related attitudes in both target groups. Finally, to construct an empirical model of factors associated with individuals' attitudes towards euthanasia.

## 2 Death, euthanasia and society

### 2.1 INEVITABLE DEATH

At some point in life every individual will face death in one form or another. Death arouses various feelings, which may sometimes be conflicting. A person may be terrified of death but at the same time drawn by its mysterious nature. (Wong & Tomer 2011.) It has been suggested that individuals would deny death completely, if possible (Cozzolino, Blackie & Meyers 2014). However, realization of the finitude of life as well as one's own mortality are essential parts of humanity, therefore death-related thoughts are as inevitable as death itself. Furthermore, this understanding underlies much art and the ways individuals handle existential questions regarding, for example, the purpose of life. (Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004, Wong & Tomer 2011.)

The multifaceted nature of death is manifested in humans' diverse responses to it. People think and feel about death in different ways, which may include stark fear, neutral acceptance and approaches, or even a combination of all those feelings (Cozzolino, Blackie & Meyers 2014, Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004, Tassell-Matamua & Lindsay 2016). Due to the unique meaning death has for every human, it also influences how we live our lives (Wong & Tomer 2011). A negative obsession with death can be an obstacle to a fulfilled life, potentially leading, for example (as mentioned above), to avoidance of love or other commitments to avoid the pain of inevitable separation at some point in the future (Wong & Tomer 2011). In contrast, greater life satisfaction has been associated with a neutral acceptance of death (Neimeyer, Wittkowski & Moser 2004). It has been argued that putting death into an overarching context could give it a meaning (e.g. the present generation must give way to our children's and grandchildren's generations) that results in less negative feelings when thinking about one's own or others' deaths. Moreover, neutral acceptance has been found to reduce grief after the loss of a loved one and thus ease the mourning process. (Boyratz, Waits & Horne 2015, Neimeyer, Wittkowski & Moser 2004.)

Despite the multidimensionality of death-related attitudes, most previous research has focused, implicitly or explicitly, on negative aspects, such as death anxiety or fear of death, while positive attitudes have received much less research attention (Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004, Wong, Reker & Gesser 1994). Despite slight differences in nuances, *death anxiety* and *fear of death* have been used interchangeably in previous literature (Wong, Reker & Gesser 1994). *Death anxiety* can be described as a multifactorial phenomenon, consisting of individuals' anxieties related to death (Brisley & Wood 2004). It has been argued that death anxiety is more general and subconscious than *fear of death*, which is regarded as a conscious feeling focused on one or more particular aspects related to death (Figure 1), the bearing of which may vary over time, age and ethnicity of an individual (Neimeyer, Wittkowski & Moser 2004, Wong, Reker & Gesser 1994). Both death anxiety and fear of death manifest as feelings that can affect a person psychologically, physically, socially and spiritually. They are also seen as the most profound anxieties, and thus highly resistant to reshaping. (Brisley & Wood 2004, Tassell-Matamua & Lindsay 2016.) A related phenomenon, *death avoidance*, may be seen as a kind of defence mechanism that prevents consciousness of death, by avoiding any thoughts, conversation or activities related to death (Wong, Reker & Gesser 1994).

Positive attitudes towards death can be classed as *neutral*-, *approach*- or *escape acceptance* (Wong, Reker & Gesser 1994). Neutral acceptance concerns death as an integral part of life; neither denying nor welcoming it but accepting it as a fact, an inherent part of life (Neimeyer, Wittkowski & Moser 2004, Wong, Reker & Gesser 1994). In approach acceptance death is regarded as a passageway to a happy afterlife, and thus indicates confidence in the existence



of an afterlife. By contrast, in escape acceptance death is seen as a way out of life that is full of pain and misery, so death is not regarded as good *per se*, but life is seen as bad (Neimeyer, Wittkowski & Moser 2004, Wong, Reker & Gesser 1994).



Figure 1. Examples of aspects associated with fear of death.

The major correlates of death attitudes presented in previous literature are age, gender, physical health, religion and culture. Additional associations have been found between the quality of life, positive components of the self, social support, previous death experiences and individual's attitudes towards death. (Cozzolino, Blackie & Meyers 2014, Mak 2012, Neimeyer, Wittkowski & Moser 2004, Suhail & Akram 2002, Wong & Tomer 2011.) These factors are all interrelated and influence each other. It should be noted that cumulative experiences in life influence the development of an individual's death-related attitudes throughout his/her entire lifespan (Neimeyer, Wittkowski & Moser 2004), highlighting the individual and dynamic nature of one's attitudes towards death.

### 2.1.1 Death, culture and religion

Despite recently increasing openness towards death, particularly in the USA, death is still a taboo theme in most cultures of the world (Chan et al. 2006, Cox et al. 2013, Ho et al. 2010, Mak 2012, Zimmermann 2012). This can be partly seen in actions intended to hide death from the public eye (Ogiwara & Matsubara 2007) and partly in a general tendency to regard death as an inappropriate theme of discussion. Discussions about death and dying in general have been described as rare and hushed. Moreover, diverse myths concerning death in many

cultures may arouse anxiety. For example, thoughts of death may be seen as bringing bad luck and thus ought to be avoided. (Chan et al. 2006, Ogiwara & Matsubara 2007.)

On the other hand, the collectivism in a culture (e.g. Arab culture) is related to individuals' attitudes towards death, which reduces death anxiety (Abdel-Khalek et al. 2009, Nakagi & Tada 2014). Furthermore, making preparations for one's own death has been associated with reduction in the frightening image of death, and regarded as a key feature in death-related discussions (Cox et al. 2013). Although these preparations could be regarded as culture-specific, they are not influenced by cultural taboos according to Chan et al. (2006).

A recent development is that people, especially young people, are seeking answers to death-related questions in mass media such as the internet and television (Mak 2010). In films and computer games death is often portrayed in a violent and unrealistic fashion. In addition, the amount of news about murders and other violent acts is increasing. Therefore, the mass media may ease death acceptance, but may also present a distorted image of death. (Mak 2010, Mak 2012, Ogiwara & Matsubara 2007.)

Religion may be approached and defined in various ways (Cicirelli 2011), for example through individuals' acknowledgement of themselves as a member of a religious organization or community. Another way, relied upon in the studies underlying this thesis, is to regard religion as a multidimensional phenomenon, following Glock and Stark (1968). These authors regarded religion as having five dimensions (Gielen et al. 2011, Huber & Huber 2012, Stark & Glock 1968): intellectual, ideological, private practice, public practice and experience. The dimensions encompass both sociological and psychological elements of religion. The intellectual and ideological dimensions refer to thoughts, public and private practice to action, and experience to emotion and perception. (Huber & Huber 2012.)

A distinction between extrinsic and intrinsic religiosity, based on individual's motivations, has also been made in previous literature (Dezutter et al. 2009, Neimeyer et al. 2011, Pierce Jr. et al. 2007). Intrinsic religiosity reflects the centrality of faith in an individual's life, the degree to which it is a master motive, while extrinsic religiosity has been seen as a way to gain something that is assessed as valuable, such as communality or support from other members in the same religious organization (Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004, Pierce Jr. et al. 2007). However, the appropriateness of this approach for measuring religiosity in secularized contexts has been questioned. Similarly, conflicting findings have been obtained from assessments of associations between death-related attitudes and unidimensional aspects of religiosity. (Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004.)

Regardless of how religion is defined and interpreted, it influences individuals' attitudes towards death (Abdel-Khalek et al. 2009, Cicirelli 2011, Neimeyer, Wittkowski & Moser 2004, Suhail & Akram 2002, Wong, Reker & Gesser 1994). This is partly due to the answers that religions offer to death-related questions, and partly to the meaning of human life that religiosity provides. Moreover, religion may protect people from the frightening aspects of death and ease the fear of death. Sometimes the threat of death triggers a deepening of an individual's spirituality (Neimeyer, Wittkowski & Moser 2004). Accordingly, religious beliefs are commonly, but not always (Ellis, Wahab & Ratnasingan 2013), inversely correlated with levels of death anxiety and positively correlated with levels of neutral acceptance of death among both Christians and Muslims (Cicirelli 2011, Dezutter et al. 2009, Neimeyer, Wittkowski & Moser 2004, Suhail & Akram 2002).

Another aspect that is positively associated with religion and inversely associated with fear of death is an individual's belief in an afterlife, due to the comfort and hope that it offers (Dezutter et al. 2009, Mak 2012). However, the concept of afterlife varies in different religions and cultures, thus the prospect of an afterlife may not ease the fear of death in adherents of all religions (Ho et al. 2010, Hui & Coleman 2012).

### 2.1.2 Individual aspects of death

In addition to culture and religion, loss of a loved one influences individuals' attitudes towards death. The impact of loss depends on the individual's relationship with the deceased (Mak 2012, Missler et al. 2011, Ogiwara & Matsubara 2007.) Important losses at young age mostly exacerbate fear at the interpersonal level, whereas those experienced at more mature age mostly exacerbate concerns regarding the unknown beyond death (Neimeyer, Wittkowski & Moser 2004). Experience of loss arouses a universal emotional reaction, which leads to increased thinking about death and its meaning in life (Mak 2012, Missler et al. 2011, Ogiwara & Matsubara 2007, Wong & Tomer 2011). The thoughts may result in a higher level of death anxiety (Missler et al. 2011), but also increased valuation of life (Brisley & Wood 2004, Mak 2012). By contrast, experience of peaceful deaths is regarded as increasing individuals' death acceptance (Mak 2012).

Similar results have been found among humans who have experienced potentially life-ending situations or near-death experiences (NDEs) (Tassell-Matamua & Lindsay 2016). Such experiences may reduce or even dispel one's fear of death, possibly through a new or bolstered belief in an afterlife. Furthermore, individuals with NDEs have reported a greater appreciation of life. (Cozzolino, Blackie & Meyers 2014, Tassell-Matamua & Lindsay 2016.)

A sense that life has a purpose and is experienced as meaningful and future-oriented reportedly reduces fear of death (Cozzolino, Blackie & Meyers 2014, Missler et al. 2011, Tassell-Matamua & Lindsay 2016), as does acceptance of the lived life, even with its disappointments and possible failures (Nakagi & Tada 2014). Moreover, experiences of social support and good relationships with friends and family enhance individuals' views of life and death (Mak 2012, Missler et al. 2011). Such existential well-being is regarded as a positive component of the self (Cozzolino, Blackie & Meyers 2014), which alleviates individuals' fear of death and its avoidance. Self-esteem is reportedly another component that has a positive influence on attitudes towards death by reducing fear of death and improving its acceptance (Cozzolino, Blackie & Meyers 2014, Tassell-Matamua & Lindsay 2016). However, Neimeyer, Wittkowski & Moser (2004) found that high ego integrity and life satisfaction were associated with high death anxiety.

The level of experienced physical health reportedly has complex relations with humans' attitudes towards death. Good physical health is reportedly associated with low degrees of death anxiety (Dezutter et al. 2009, Missler et al. 2011, Nakagi & Tada 2014, Neimeyer, Wittkowski & Moser 2004). However, high experienced health is particularly associated with fear of one's own death, while poorer experienced health is particularly associated with fear of the death of significant others according to some studies (Missler et al. 2011, Nazarzadeh, Sarokhani & Sayehmiri 2014). Furthermore, although undesirable changes in experienced health may arouse concerns, fear of death is influenced by multiple factors, rather than only by health impairments. For example, hospice patients with an intrinsic religiosity reportedly have greater acceptance of death than some people with better physical health (Neimeyer, Wittkowski & Moser 2004, Neimeyer et al. 2011).

Available indications about relationships between gender and death-related attitudes are somewhat conflicting. No statistically significant relationships between them have been found in some studies (Chan et al. 2006, Nazarzadeh, Sarokhani & Sayehmiri 2014), and in one study men reported greater fear of death and stronger death avoidance than women (Neimeyer et al. 2011). However, most relevant studies have concluded that women are generally more afraid of death than men (Abdel-Khalek et al. 2009, Ellis, Wahab & Ratnasingan 2013, Missler et al. 2011, Pierce Jr. et al. 2007, Suhail & Akram 2002, Wong, Reker & Gesser 1994). Various suggestions have been made in efforts to explain this apparent difference between genders. One is rooted in gender-specific roles in different cultures, holding that women's greater empathy (Khader, Jarrah & Alasad 2010), and nurturing role (Abdel-Khalek et al. 2009, Missler et al. 2011, Pierce Jr. et al. 2007, Russac et al. 2007) could explain their greater concerns about death. Another is rooted in women's reportedly higher levels of intrinsic religiosity, which may be related to comfort or relief (Pierce Jr. et al. 2007).

In line with the social role of women, it has been suggested that they worry more about the interpersonal impact of death than men, which results in more negative attitudes (Missler et al. 2011). Furthermore, women have been described as being more open about their feelings than men, whose unwillingness to admit fears has been seen as one reason for their lower death anxiety (Russac et al. 2007).

Gender differences may also be seen in age-related results of some studies. Death anxiety reportedly peaks during the 20s and then declines, among both women and men, but only women also show another (smaller) peak in their early 50s (Russac et al. 2007). Another study concluded that women in their 20s displayed higher death anxiety than men of the same age (Suhail & Akram 2002). Both studies found the level of death anxiety to be the same among both women and men in their 60s (Russac et al. 2007, Suhail & Akram 2002). However, results regarding the influence of age are generally slightly conflicting. Some studies indicate that death anxiety declines with age (Chan et al. 2006, Missler et al. 2011, Neimeyer, Wittkowski & Moser 2004, Russac et al. 2007), while others suggest that it peaks in mid-adulthood (Neimeyer et al. 2011) or later (Suhail & Akram 2002). The last of these findings was partly attributed to more frequent death-related thoughts among the elderly, due to the increased likelihood of experiencing losses of friends and loved ones. In addition, the probability of one's own impending death may influence attitudes towards death. (Suhail & Akram 2002.) This partly explains findings that increasing age also strengthens belief in an afterlife, and possibly death avoidance, while the level of neutral acceptance may decline with increasing age (Dezutter et al. 2009).

### **2.1.3 Nurses' role in end-of-life care**

Nurses play a significant EOL role in all health care settings by providing care for dying patients and support for their loved ones. Numerous studies have shown that nurses' attitudes towards death influence the quality of care and nurses' willingness to care for dying patients. (Braun, Gordon & Uziely 2010, Dunn, Otten & Stephens 2005, Khader, Jarrah & Alasad 2010, Lange, Thom & Kline 2008, Peters et al. 2013b.) Generally, dealing with death has been seen as one of the risk factors for nurses' professional burn-out. This is partly based on the undesirable emotions (such as sadness, frustration, stress, powerlessness, despair, anxiety and fear) that nurses may feel when they encounter death or care for patients at the EOL. (Hinderer 2012, Khader, Jarrah & Alasad 2010.)

The personal distress described by nurses in such situations results from seeing the reality of death. It may result in a situation where nurses invest less of their emotional selves in the EOL care (Hinderer 2012.) However, deaths do not all affect nurses equally; lack of prior bonds with the deceased may lead to their death being insignificant from the nurses' perspective. Furthermore, nurses may report positive experiences of deaths that represent the end of suffering. (Hinderer 2012.) Nurses describe death experiences changing them as humans, by initiating reflection on their own lives. In addition, exposure to death may increase their positive attitudes towards death. (Gerow et al. 2010, Hinderer 2012.)

In this context, death experiences at the beginning of nurses' careers are particularly significant, because they build foundations for the future EOL care they provide (Gerow et al. 2010). Lack of support from peers, feelings of isolation and helplessness experienced in the early stages of a career may increase nurses' negative attitudes towards death and EOL care. By contrast, experiences of mentoring and support enable the development of positive attitudes towards death. (Gerow et al. 2010.)

Although most previous literature does not indicate that health care professionals have greater death anxiety than other groups (Neimeyer, Wittkowski & Moser 2004), both death anxiety and avoidance are seen as obstacles for EOL care (Brisley & Wood 2004, Peters et al. 2013b, Zimmermann 2012), particularly death-related communication, which is a crucial part of EOL care. For example, nursing home employees who reported higher than average levels of death anxiety were also less willing than average to discuss death and dying, according to Depaola et al. (2003) and Neimeyer, Wittkowski & Moser (2004).

Discussions about death and dying, ethical aspects of EOL and advanced care planning (ACP) are ways to improve the EOL care of seriously ill individuals. Dialogue regarding these themes may be initiated by the patient, his or her relatives, or health care professionals (Dobbs et al. 2012). Nurses' willingness and ability to discuss the EOL themes may be unconsciously influenced by their experiences and individual attitudes towards death (Black 2007). According to the literature, older and experienced nurses are more comfortable having conversations about death-related themes than younger inexperienced colleagues (Khader, Jarrah & Alasad 2010, Peters et al. 2013b). In addition, specific palliative care training and a belief in afterlife increase this confidence (Black 2007, Khader, Jarrah & Alasad 2010, Peters et al. 2013b). However, it has been stated that discussions about death with someone whose death is in sight is challenging even for the most experienced and talented nurses (Khader, Jarrah & Alasad 2010).

The ultimate aim of EOL care is the acceptance of death by patients and their loved ones (Zimmermann 2012). In order to achieve this aim the nurses' acceptance of death is crucial, not only for the philosophy of palliative care but also for the quality of EOL care (Braun, Gordon & Uziely 2010, Brisley & Wood 2004, Cevik & Kav 2013, Dunn, Otten & Stephens 2005, Lange, Thom & Kline 2008, Peters et al. 2013b, Zimmermann 2012). However, nurses' attitudes towards death may be influenced and even changed by death-related education, which has also been seen as a way to alleviate nurses' death anxiety. These effects have been reported particularly among younger nurses. (Brisley & Wood 2004, Khader, Jarrah & Alasad 2010, Zimmermann 2012.)

Individual's attitudes towards death are multidimensional and dynamic. They develop over the whole lifespan of a person and are affected by multiple factors (Figure 2).

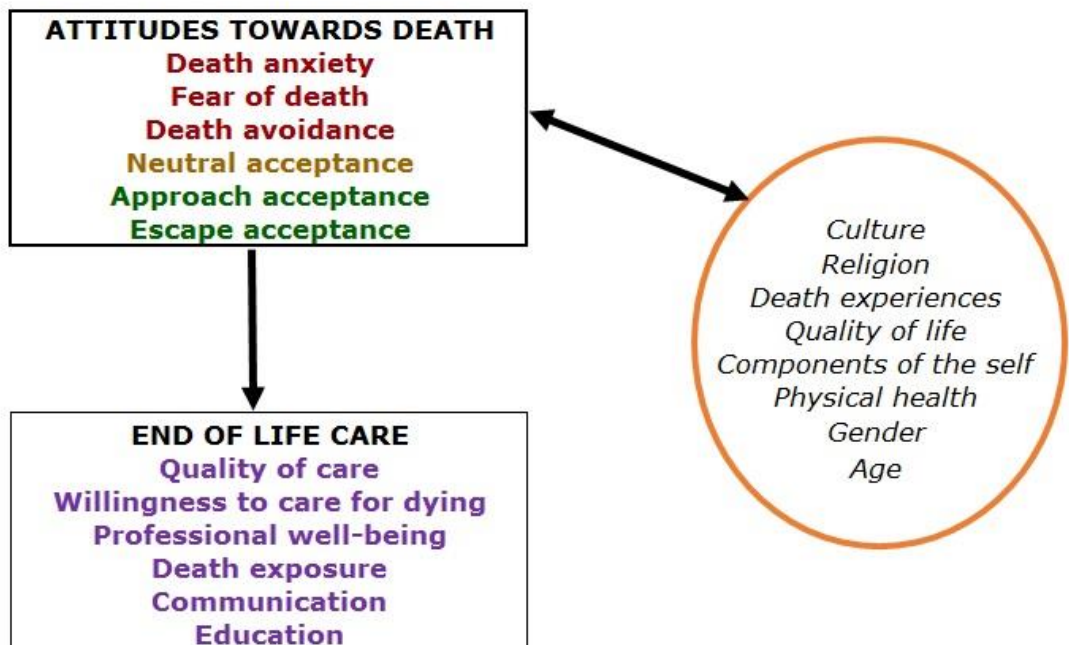


Figure 2. Summary of attitudes towards death and associated factors.

However, none of the single factors alone can explain or predict a human's attitudes towards death. Previous research has focused mainly on the negative death-related attitudes and paid much less attention to the more positive attitudes. Nurses differ from members of the general public because their attitudes towards death influence their professional capacities,

especially in the provision of EOL care, as their attitudes are associated with both quality of EOL care and willingness to care for dying patients. Although death-related attitudes in general are seen as difficult to change, specific training is considered to influence nurses' attitudes.

## 2.2 CONTRADICTIONARY EUTHANASIA

Euthanasia is a controversial phenomenon that is charged with strong, partly conflicting, reactions and feelings (Holt 2008, Ryyänen et al. 2002, Verbakel & Jaspers 2010). Some of the controversy may be attributed to responses to events in World War II (Holt 2008). However, euthanasia originated in classical times and the word literally means "*good death*," a concept that has had various meanings in different eras (Holt 2008, Walters 2004).

Organized advocacy of the legalization of euthanasia in Belgium in the 1980s initiated intensified (and continuing) debate about the issues in Europe (Cohen-Almagor 2009) and subsequently many other parts of the world, such as Australia and the Middle East (Aghababaei 2014, Danyliv & O'Neill 2015, Mullet et al. 2014, Sikora & Lewins 2007, Strongegger et al. 2013, Tamayo-Velazquez, Simon-Lorda & Cruz-Piqueras 2012). In Finland, the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) took a stand on the issues by releasing a position statement entitled "Human Dignity, Hospice Care and Euthanasia" in January 2012. This included acknowledgement of situations where the possible use of euthanasia could not be completely excluded on ethical grounds (ETENE 2012). This prompted further intensification of debate about euthanasia and its legalization by physicians, politicians and the general public. Both the opinions of nurses and their responsibilities if euthanasia would be legalized have received less attention in this discourse.

Interestingly, current trends in Finnish opinion were predicted in 2004, in the preliminary report of the Committee for the Future of the Finnish Parliament (Ryyänen et al. 2004), which forecast that approval of euthanasia and its legalization would strengthen in Finland. Furthermore, the authors assumed that Finland, among other countries, would follow Belgium and The Netherlands by legalizing euthanasia within the next 10-15 years. These predictions were partly fulfilled, as Finnish physicians' approval for euthanasia and its legalization significantly increased between 2003 and 2013 (Louhiala et al. 2015, Ryyänen et al. 2004). Proportions expressing support for its legalization rose from 29.4% to 47.5% in this decade, however proportions who stated that they could sometimes practice euthanasia if it became legal rose from just 20.9% to 22.7% (Louhiala et al. 2015).

The last detailed study concerning euthanasia-related attitudes of the Finnish general public before the studies this thesis is based upon found that half of them responded positively to a general question regarding acceptance of euthanasia (Ryyänen et al. 2002). The assessment indicated that support for euthanasia in various scenarios ranged from 19% (for a patient with severe depression) to 48% (for a patient with severe dementia). In line with attitudes of the general public, half of the surveyed nurses expressed general approval for euthanasia in the study by Ryyänen et al. (2002). However, proportions of nurses who expressed acceptance of euthanasia in the presented scenarios ranged from just 4% to 22% (again for the patients suffering from severe depression and dementia, respectively). Moreover, recent surveys suggest that public opinion in Finland is in favour of euthanasia (Louhiala et al. 2015).

Since March 2012 the Finnish government has offered citizens a new form of state-level online participation, called citizens' initiative, in which citizens may submit initiatives that will be considered by Parliament if they receive at least 50 000 statements of support within six months (Kansalaisaloite.fi 2016). Three initiatives have been submitted regarding the legalization of euthanasia since 2013. The first, which closed on August 2013, attracted 10 016 statements of support (Viholainen 2015). The second ended on April 2014 and was supported

by 4 339 individuals (Ojanne 2014). The most recent is closing in June 2016, and 5 072 people had expressed support by the 18<sup>th</sup> of March 2016 (Viholainen 2016). These numbers indicate that the prediction in the preliminary report regarding the legalization of euthanasia in Finland (Ryynänen et al. 2004) is unlikely to be correct.

### 2.2.1 Definition of euthanasia

Euthanasia is defined here as a deliberate act intended to terminate a person's life at his/her own explicit request. This definition is in accordance with definitions in regulations or laws in the Netherlands, Belgium and Luxembourg (Berghs, Dierckx de Casterlé & Gastmans 2005, Van Bruchem-Van De Scheur et al. 2008c, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016, The Grand Duchy of Luxembourg 2015). Based on this definition, four core characteristics (Figure 3) of euthanasia can be identified: explicit request of a person, intention of the act, aim to terminate life and performance by someone other than the requesting person.

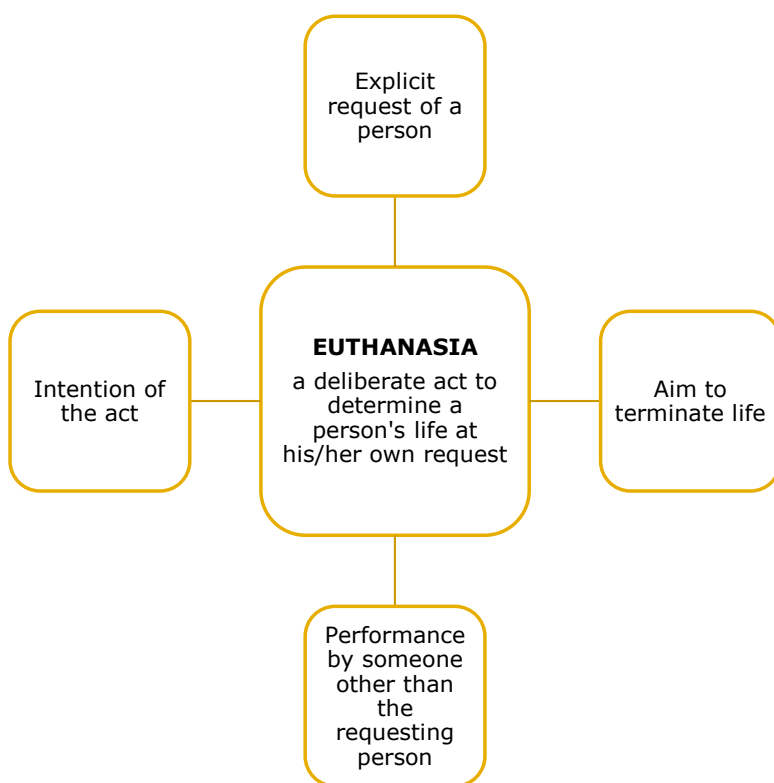


Figure 3. Core characteristics of euthanasia.

However, various definitions and categories of euthanasia have been presented and considered in previous literature that conflict with at least one of these four core characteristics. Moreover, the diversity of definitions and categories used in prior studies complicates the interpretation and comparison of their findings. (Hagelin et al. 2004, Holt 2008, Johansen et al. 2005.)

One form of categorization recognizes *voluntary*, *involuntary* and *non-voluntary* euthanasia. These terms respectively refer to cases where the individual has requested euthanasia, has not requested it, and is incapable of expressing his/her will because (for instance) of a medical condition (Broeckaert et al. 2010, Holt 2008, Kuuppelomäki 2000, Parpa et al. 2010, Tanida et al. 2002). It has also been argued that euthanasia should not necessarily include consent of a dying individual (Gesundheit et al. 2006), and in some studies, e.g. the European Values

Study (EVS), the explicit request of an individual is not included in its definition (Cohen et al. 2006, Cohen et al. 2013, Mousavi et al. 2011).

Further categorization of euthanasia has been based on the nature of the performance: termination of a patient's life by a deliberate act and by the withdrawal or withholding of treatment have been called *active* and *passive* euthanasia, respectively (Aghababaei 2014, Holt 2008, Yousuf & Mohammed Fauzi 2012). The concept of active euthanasia has also been applied to an act that shortens the life of an individual (Gamliel 2013).

A third form of categorization is based on the person who performs the act. Notably, *physician-assisted suicide* (PAS) has sometimes been classed as a type of euthanasia (Stolz et al. 2015). However, in PAS an individual commits suicide, usually by taking medication that a physician has provided or prescribed for him/her for this purpose (Hendry et al. 2013, Tomlinson & Stott 2015). So, the act is performed by the individual who wishes to die, rather than by someone other than the requesting person. Thus, PAS has been classified in various ways. In some previous literature it has been included in the term euthanasia (Boudreau & Somerville 2013, Sikora & Lewins 2007), treated as a parallel concept (Johansen et al. 2005) or regarded as a type of another concept that encompasses both. An example of the latter is *physician-assisted dying* (PAD), as defined by the European Association of Palliative Care (EACP) (DeKeyser Ganz & Musgrave 2006, Tomlinson & Stott 2015).

To avoid ambiguity, in this thesis the term euthanasia always refers to the phenomenon with the core characteristics described above (and shown in Figure 3), as defined at the beginning of this section.

### 2.2.2 The legal status and practice of euthanasia

In all countries globally, except Columbia, Belgium, Luxembourg and The Netherlands, euthanasia is an unlawful act (Dyer, White & García Rada 2015, ETENE 2012, The Grand Duchy of Luxembourg 2015, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016). However, its legalization has been discussed in several other nations e.g. Australia, France and Spain, as well as Finland (ETENE 2012).

There is no reference to euthanasia, or any concept that could be regarded as equivalent to it, in the Criminal Code of Finland. The most relevant chapter of the code, Chapter 21 concerning homicide and bodily injury, categorizes all homicide as manslaughter, murder or killing (Louhiala et al. 2015, Ministry of Justice 2016). The third section of this chapter 21 states that:

*"If the manslaughter, in view of the exceptional circumstances of the offence, the motives of the offender or other related circumstances, when assessed as a whole, is to be deemed committed under mitigating circumstances, the offender shall be sentenced for killing to imprisonment for at least four and at most ten years."* (Ministry of Justice 2016).

Therefore, the performance of euthanasia in Finland could result in imprisonment for four to ten years. Attempted euthanasia is also regarded as punishable in the Criminal Code of Finland. (Ministry of Justice 2016.)

The laws on euthanasia entered into force in 2002 in The Netherlands and Belgium, 2009 in Luxembourg, and 2015 in Columbia (Dyer, White & García Rada 2015, ETENE 2012, The Grand Duchy of Luxembourg 2015, Kouwenhoven et al. 2013, Nys 2002). In every country where it has been legalized euthanasia must be performed by a physician (Dyer, White & García Rada 2015, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016). A further requirement in the European countries is a close physician-patient relationship, in which the physician can assess the expressed euthanasia request. Therefore, the potential candidate must have permanent residence in the country where the request is expressed (Cohen-Almagor 2009, Dyer, White & García Rada 2015, Regionale Toetsingcommissies Euthanasie 2016.)



According to legislation in The Netherlands, a person aged 12 or older may express the euthanasia request. The agreement of parents or guardians to the request is required for individuals who are 12 – 15 years old. Older minors do not need their parents' permission to make a request, but they must be involved in the discussions concerning euthanasia. (Regionale Toetsingcommissies Euthanasie 2016, Nys 2002.) By contrast, the original euthanasia act in Belgium stated that the requesting person needs to be at least 18 years old, or an "emancipated minor" (Cohen-Almagor 2009, Nys 2002). In 2014 the age restriction was withdrawn from the Belgian euthanasia act, resulting in Belgium becoming the only country in the world where euthanasia has been legalized for individuals of all ages if all other criteria are met (Dyer, White & García Rada 2015, Raus 2016). However, consent of a minors' parents or legal representatives is required to perform euthanasia according to a new amendment of the Belgian euthanasia act (Raus 2016). In Luxembourg only mentally competent adults can make a euthanasia request (Dyer, White & García Rada 2015, Ministry of Health & Ministry of Social Security 2010).

In all countries where it is legal, a request for euthanasia may be revoked at any time. It must be in written form in Belgium and Luxembourg. If the patient cannot write a request may be written by an adult that the patient has chosen and who gains no financial benefit from the death of the requesting person. (Cohen-Almagor 2009, Ministry of Health & Ministry of Social Security 2010, Nys 2002.) By contrast, in The Netherlands a request may be expressed orally or in written form (Regionale Toetsingcommissies Euthanasie 2016). A request may also be made in advance directives, in Belgium a euthanasia request in this form is valid for five years and in Luxembourg the request must be confirmed every five years (Ministry of Health & Ministry of Social Security 2010, Nys 2002). No timeframe for validity has been set in The Netherlands (Regionale Toetsingcommissies Euthanasie 2016). In all mentioned countries the request must be repeated, voluntary and well considered. In The Netherlands a request must also be well informed, a requirement that is not included in Belgian law. (Cohen-Almagor 2009, Ministry of Health & Ministry of Social Security 2010, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016.)

A prerequisite for euthanasia in all countries where it is legal is unbearable suffering that cannot be alleviated. An additional stipulation is the lack of prospect of improvement. (Dyer, White & García Rada 2015, Ministry of Health & Ministry of Social Security 2010, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016.) The suffering may be physical or mental and result from an incurable disease or accident. The unbearability of suffering is evaluated by the requesting person, whereas the prospects of improvement are assessed by a physician based on current medical knowledge. A further evaluation from at least one physician, who is impartial towards both the patient and the treating physician, is a further requirement for permissible euthanasia. (Ministry of Health & Ministry of Social Security 2010, Nys 2002, Regionale Toetsingcommissies Euthanasie 2016.) Any euthanasia performed must be documented and reported to a specific commission, which evaluates the accordance of the process with the law (Cohen-Almagor 2009, Ministry of Health & Ministry of Social Security 2010, Regionale Toetsingcommissies Euthanasie 2016).

### **2.2.3 Nurses' role in a euthanasia process**

Nurses have an important, multifaceted role to play in euthanasia processes, as acknowledged and described in a large body of literature (De Bal, Gastmans & Dierckx de Casterlè 2008, De Beer, Gastmans & Dierckx de Casterlè 2004, Dierckx de Casterlè et al. 2010, Francke et al. 2015, Inghelbrecht et al. 2009a). Regardless of the legal status of euthanasia, nurses receive patients' requests regarding it; indeed the first person in health care settings to whom a patient expresses a wish for euthanasia is often a nurse (De Bal, Gastmans & Dierckx de Casterlè 2008, Kranidiotis et al. 2015, Tanida et al. 2002, Van Bruchem-Van De Scheur et al. 2008b). In addition to the continuous presence and resulting accessibility of nurses, this is attributed to the confidential relationship between nurses and patients, and patients' wishes to clarify euthanasia-related matters for themselves (Dierckx de Casterlè et

al. 2010, Van Bruchem-Van De Scheur et al. 2008b). Although nurses do not always interpret a euthanasia request as a patient intends (De Beer, Gastmans & Dierckx de Casterlé 2004), each request must be taken seriously. At this stage nurses try to understand the rationale underlying the request by communicating repeatedly with the patient. A further aim of such communication is to gain certainty that euthanasia is what the patient really wishes. (Denier et al. 2010, Dierckx de Casterlé et al. 2010.) The communication may have several forms, of which active listening has been regarded as crucial (Denier et al. 2010). Furthermore, nurses provide the patient and his/her relatives information, and relay the expressed request to other members of the caring team (Denier et al. 2010, Dierckx de Casterlé et al. 2010).

In Belgium and The Netherlands, nurses may or may not be included in decision-making discussions about a patient's euthanasia request, depending on the context (Bilsen et al. 2014, De Beer, Gastmans & Dierckx de Casterlé 2004, Dierckx de Casterlé et al. 2010, Inghelbrecht et al. 2010, Van Bruchem-Van De Scheur et al. 2008c). By contrast to Belgium, in The Netherlands involvement of nurses in the decision-making is not stipulated in the euthanasia law (Inghelbrecht et al. 2010, Van Bruchem-Van De Scheur et al. 2008a). Nurses may also be excluded from the decision-making based on the patient's wishes, or when the physician regards a consultation as unnecessary. A further reason for excluding nurses is the consideration of euthanasia as an affair between the physician and patient. (Van Bruchem-Van De Scheur et al. 2008a.) However, nurses' involvement in the decision-making has been seen as significant due to the essential information that they can provide about the patient (De Bal, Gastmans & Dierckx de Casterlé 2008, Dierckx de Casterlé et al. 2010, Francke et al. 2015, Van Bruchem-Van De Scheur et al. 2008c). During the decision-making process nurses are the informants for the patient and the relatives, providing answers for their open questions and discussing euthanasia-related themes with them. They may also support physicians in communication with the patient and relatives. (Denier et al. 2010, Dierckx de Casterlé et al. 2010.)

Once an affirmative decision has been made the nurses' role becomes more supportive. In addition to the best possible palliative care, realizing the last wishes of the patient is a central element of the care. Moreover, communication within the caring team is crucial for emotional and psychological preparation for impending performance of euthanasia. (Dierckx de Casterlé et al. 2010.)

If nurses are present at the moment when euthanasia is carried out, their primary role is to support the patient and relatives (De Bal, Gastmans & Dierckx de Casterlé 2008, Dierckx de Casterlé et al. 2010, Van Bruchem-Van De Scheur et al. 2008b). Most nurses do not consider preparatory activity, e.g. inserting an infusion needle or preparing euthanatics, as part of their professional responsibilities (Francke et al. 2015, Van Bruchem-Van De Scheur et al. 2008c). However, sometimes these tasks are performed by the nurses, which is occasionally justified by inexperience of the physician (De Beer, Gastmans & Dierckx de Casterlé 2004, Van Bruchem-Van De Scheur et al. 2008b). Although existing legislation unambiguously states euthanasia to be a task of a physician, various cases of euthanatics being administered by nurses, with or without attendance of a physician, have also been described (De Bal, Gastmans & Dierckx de Casterlé 2008, De Beer, Gastmans & Dierckx de Casterlé 2004, Inghelbrecht et al. 2010, Van Bruchem-Van De Scheur et al. 2008a). By doing so nurses risk criminal prosecution as well as disciplinary measures (Francke et al. 2015, Van Bruchem-Van De Scheur et al. 2008b).

After the patient has died, nurses support the family and provide them care that is regarded as similar to standard aftercare (Dierckx de Casterlé et al. 2010). Further contact with the family of the deceased after a certain period of time is seen as an important part of their care. In addition to the relatives, the physician who has performed the euthanasia and members of the nursing team may also require support. Therefore, a formal debriefing is a significant component of the support of health care professionals who have participated in the euthanasia process. (Dierckx de Casterlé et al. 2010.)

#### 2.2.4 Factors associated with euthanasia-related attitudes

Individuals' attitudes towards euthanasia are associated with multiple factors, such as age, gender, educational level, family-related aspects, religion and (for nurses) nursing speciality (Berghs, Dierckx de Casterlé & Gastmans 2005, Cohen et al. 2006, Cox et al. 2013, Danyliv & O'Neill 2015). A positive association has been found between age and rejection of euthanasia among both the general public and nurses (Berghs, Dierckx de Casterlé & Gastmans 2005, Cohen et al. 2006, Cohen et al. 2014, Holt 2008, Köneke 2014, Verpoort et al. 2004). It has been argued that this is connected with the aging process itself, but it may also be associated with cultural influences. Today's young generations grew up in more liberal societies, which may have influenced their attitudes towards euthanasia. (Cohen et al. 2006.)

Among lay populations males reportedly have more permissive attitudes towards euthanasia than women, according to several studies (Cohen et al. 2006, Poma et al. 2015, Stolz et al. 2015), but not all (Köneke 2014). Nursing is a female-dominated profession, so the gender effect has seldom been studied among nurses (Holt 2008). However, male health personnel are reportedly more willing to practice euthanasia than female nurses (Vézina-Im et al. 2014).

A positive association between acceptance of euthanasia and educational level has also been detected (Cohen et al. 2006, Köneke 2014), although contrary findings are also reported (Stronegger et al. 2013), possibly because highly educated individuals value personal autonomy and individualism (Cohen et al. 2006, Verbakel & Jaspers 2010). By contrast, a non-significant relationship between educational level and euthanasia-related attitudes has been found among nurses (Verpoort et al. 2004), although a higher level of education has been associated with nurses' greater readiness to administer drugs in cases of euthanasia (Inghelbrecht et al. 2009b, Vézina-Im et al. 2014).

Having a single-household or being unmarried are indicative of support for euthanasia according to several studies (Rietjens et al. 2005, Stronegger et al. 2013, Televantos et al. 2013), possibly because individuals who live alone fear loneliness and uncontrolled death, which could be avoided by euthanasia (Stronegger et al. 2013). In addition, it has been suggested that strong family bonds influence individuals' attitudes, *inter alia* increasing valuation of the length of life (Rietjens et al. 2005, Televantos et al. 2013). This hypothesis is supported by a reported tendency of people who live in households that include two or more children to reject euthanasia (Stronegger et al. 2013).

However, religion has been claimed to be the strongest predictor of individuals' attitudes towards euthanasia (Danyliv & O'Neill 2015), and a large body of literature indicates that there is a strong correlation between a person's religious views and his/her rejection of euthanasia (Berghs, Dierckx de Casterlé & Gastmans 2005, Cohen et al. 2006, Cox et al. 2013, Gielen et al. 2011, Holt 2008, Inghelbrecht et al. 2009b, Stolz et al. 2015, Verbakel & Jaspers 2010, Verpoort et al. 2004). However, the role of religion as a predictor of euthanasia-related attitudes has also been questioned (Vézina-Im et al. 2014, Gielen, Van den Branden & Broeckaert 2009b). Individuals' religiosity has been measured in various ways, some of which are claimed to be too simplistic or vague to capture the complexity of religion (Gielen, Van den Branden & Broeckaert 2009a, Vézina-Im et al. 2014). One method of measuring it has been simply to ask participants to state which religion or denomination they belong to or the strength of their religiosity (Gielen, Van den Branden & Broeckaert 2009a). The validity of these measures may be questioned due to the ambiguity of the criteria used to evaluate the responses (Gielen, Van den Branden & Broeckaert 2009a, Huber & Huber 2012). Due to differences in measurements the findings are not fully comparable, which may partly explain why no connection between religion and euthanasia-related attitudes have been detected in some studies (Gielen, Van den Branden & Broeckaert 2009b, Karadeniz et al. 2008, Naseh, Rafiei & Heidari 2015, Vézina-Im et al. 2014).

Frequent contact with terminally ill patients has been found to decrease nurses' acceptance of euthanasia. Accordingly, nurses working in oncology or palliative care contexts are reportedly the likeliest to reject euthanasia. (Berghs, Dierckx de Casterlé & Gastmans 2005,

Holt 2008, Verpoort et al. 2004.) A similar correlation has been reported among lay persons who have experienced suffering in their personal environment or have experience of caring for dying persons, but it lacked statistical significance (Stolz et al. 2015, Verbakel & Jaspers 2010).

The acceptability of euthanasia is also connected to the nature of the condition and suffering of the requesting person. It has been argued that euthanasia is more often rejected for people with psychological conditions and mental misery than for people with incurable physical diseases. (Cox et al. 2013, Rietjens et al. 2005, Ryyänen et al. 2002, Vézina-Im et al. 2014.) This may be related to hope that if mental suffering is a symptom of a psychiatric disease there may be an effective treatment, or the patient's mood may simply improve with time (De Hert et al. 2015). It has further been argued that the nature of suffering is unrelated to the attitudes of nurses and other people in countries that have legalized euthanasia (De Hert et al. 2015, Vézina-Im et al. 2014). However, it should be noted that euthanasia based on psychiatric disorder is generally rare, for example it accounted for less than 1% of all approved cases in The Netherlands in 2014 (Kim, De Vries & Peteet 2016).

No previous evaluation of the relationships between individuals' death- and euthanasia-related attitudes were found in the literature review. However, two prior studies have assessed associations between death anxiety and withdrawing or withholding of medical treatment. One found a significant, but unclear association between the attitudes among elderly individuals (Devins 1979), but the other found no statistical significant relationship between them among nurses in India (Ray & Raju 2006).

### 2.2.5 Ethical arguments for and against euthanasia

When rationalizing their attitudes towards euthanasia, individuals often refer to the four principles of medical ethics: *respect for autonomy*, *non-maleficence*, *beneficence* and *justice* (Beauchamp & Childress 2012, Berghs, Dierckx de Casterlé & Gastmans 2005, Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010). Proponents of euthanasia emphasize *the respect for individuals' autonomy*, stating that people should have the right to decide about their own lives (Hendry et al. 2013, Kranidiotis et al. 2015, Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010, White et al. 2008). In addition, respect for a patient's autonomy influences evaluation of the acceptability of ending his/her life. For example, Mullet et al. (2014) found that even unlawful acts may be considered acceptable in situations where patients' autonomy is respected.

Moreover, respect for autonomy has been linked with individualism and Western culture (Cohen et al. 2014, Sikora & Lewins 2007). However, it has been argued that respect for autonomy should not be excessively individualistic, nor be given moral priority over other principles (Beauchamp & Childress 2012). So, the justification of euthanasia on these grounds has been criticized and regarded as having too little respect for the autonomy of others. Notably, the autonomy of the health care personnel may be violated by the performance of euthanasia based on a patient's own autonomy. (Quaghebeur, Dierckx de Casterlé & Gastmans 2009.) Furthermore, critics hold dying to be a social practice, like life itself, so the patient's community should also be considered. In addition, the concept of autonomy becomes irrelevant for the patient, because s/he is no longer able to enjoy it after euthanasia. (Quaghebeur, Dierckx de Casterlé & Gastmans 2009.)

Objection to euthanasia is commonly justified by the principle of *non-maleficence*, which obligates intentional avoidance of actions that cause harm (Beauchamp & Childress 2012, Quaghebeur, Dierckx de Casterlé & Gastmans 2009), as euthanasia may be seen as causing irreversible harm to the value of life (Quaghebeur, Dierckx de Casterlé & Gastmans 2009). Furthermore, euthanasia violates the first rule of non-maleficence: "do not kill" (Beauchamp & Childress 2012). It has also been argued that euthanasia can seriously harm the integrity of the nursing profession and the mutual trust between the patient and health care personnel. However, in order to judge an action in such cases, additional information is required about

the context, the motives of the participating individuals and the patient's preferences. (Beauchamp & Childress 2012, Quaghebeur, Dierckx de Casterlé & Gastmans 2009.)

Another objection to any form of euthanasia is that it could mark the beginning of a slippery slope, i.e. extension of permission for euthanasia for competent and terminally ill patients with unbearable suffering to incompetent or vulnerable people (Köneke 2014, Ryyänen et al. 2002, Verbakel & Jaspers 2010). This argument bolsters opposition to euthanasia on grounds of the precautionary principle that it is better to be safe than sorry (Beauchamp & Childress 2012, Hendry et al. 2013, Köneke 2014). In attempts to avoid possible misuse of euthanasia (and thus being sorry in this respect), countries that have legalized euthanasia have also established safeguards, such as evaluation by an independent physician and an obligation to report to a euthanasia committee (Köneke 2014, Ministry of Health & Ministry of Social Security 2010, Regionale Toetsingcommissies Euthanasie 2016).

The principle of *beneficence* obligates individuals to protect and defend the rights of others, and to prevent harm and remove things that cause harm to others. Beneficence has been seen as an implicit assumption in all health care professions. (Beauchamp & Childress 2012.) Clearly, it could be argued that euthanasia breaches this principle (Quaghebeur, Dierckx de Casterlé & Gastmans 2009). However, proponents of euthanasia argue that an individual's dignity and quality of life are more worth than its length (Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010). It has also been argued that experiences of suffering and the difficult death of a loved one will influence individuals' attitudes towards euthanasia, and the meaning of beneficence in this context (Hendry et al. 2013). On the other hand, it may be questioned if the interests of a human are served by causing his or her death (Quaghebeur, Dierckx de Casterlé & Gastmans 2009).

Generally, the formal principle of *justice* states that individuals in similar situations should be treated equally (Beauchamp & Childress 2012). In the context of euthanasia, this implies that care should be adjusted to suit individual patients' needs and possibilities, but there is a risk that justifications of euthanasia may be tailored to suit others rather than the patients (Quaghebeur, Dierckx de Casterlé & Gastmans 2009).

Various national and international bodies publish guidelines regarding the professional ethics of nurses (e.g. American Nurses Association 2011, International Council of Nurses 2012, The Finnish Nurses Association 1996). The guidelines vary to some degree (partly due to variations in national laws), but are largely consistent. They all uphold the principles of beneficence and respect for autonomy, and frame nurses' responsibilities with respect to euthanasia. *Inter alia*, nurses must respect each patient as a person, regardless of whether or not they agree with his or her choices. (Berghs, Dierckx de Casterlé & Gastmans 2005, American Nurses Association 2011, International Council of Nurses 2012, The Finnish Nurses Association 1996.) The proponents of euthanasia refer to nurses' duty (emphasized in the guidelines) to alleviate pain, regarding euthanasia as an extreme remedy. By contrast, opponents highlight nurses' obligation to protect human life and human rights, including individuals' rights to life and security of person. (American Nurses Association 2011, International Council of Nurses 2012, The Finnish Nurses Association 1996.) Accordingly, the ANA unambiguously condemns any intent to end the life of a patient, even when motivated by respect for autonomy, compassion or considerations regarding the quality of the patient's life (American Nurses Association 2011). However, nurses' personal values may influence their euthanasia-related attitudes more strongly than professional codes of ethics (Brzostek et al. 2008).

### *3 Attitudes towards death and euthanasia of nurses and the general public*

Following recommended procedures (Burns & Grove 2009) to deepen understanding of the focal phenomena and acquire an overview of existing knowledge, the literature was searched and reviewed several times during the studies this thesis is based upon. The latest literature search was conducted in December 2015. All searches followed a search strategy developed a priori (Table 1), which aimed to capture as many studies relevant to the research as possible (Burns & Grove 2009, CRD 2009). The pre-defined publication timeframe of the literature search was 2000-2015, in order to include the latest studies conducted in Finland concerning euthanasia.

*Table 1. Search strategy for literature review*

<b>Databases</b>	<b>Search strings</b>	<b>Inclusion criteria</b>
CINAHL	Attitude* AND Death AND Nurse*	Years: 2000-2015
EBSCO	Attitude* AND Death NOT Nurse*	Peer reviewed
PsycInfo	Euthanasia AND Attitude* AND Nurse*	Languages: Finnish, English, German
PubMed	Euthanasia AND Attitude* NOT Nurse*	
Scopus		

The selection of articles was based on two review questions: *“What are the attitudes towards death among nurses and the general public?”* and *“What are the attitudes towards euthanasia among nurses and the general public?”*

In the first stage of selection, the titles of retrieved articles were screened and assessed for relevance to the review questions. Then the abstracts of the chosen articles were inspected and evaluated. Articles that did not address either question were rejected, and duplicates were removed. In the final stage of selection the remaining articles were read and evaluated in their entirety. (Burns & Grove 2009, CRD 2009.) Articles reporting death-related attitudes gauged using the Death Attitude Profile-Revised (DAP-R) (Wong, Reker & Gesser 1994) were particularly favoured as they would have the greatest comparability with results of the empirical research. Furthermore, articles regarding euthanasia explicitly for individuals with limitations or lack of any decisional capacity (e.g. neonates or people with dementia) were excluded to emphasize the significance of the person’s own request. At this stage, after the end of the search process, one article was added to the selection.

The selection process (Figure 4) resulted in total 49 articles that were narratively analysed and the key results were summarized in descriptive tables. Attitudes of nurses and the general publics were the object of 20 articles (Appendix I), and the other 29 concerned their attitudes towards euthanasia (Appendix II).

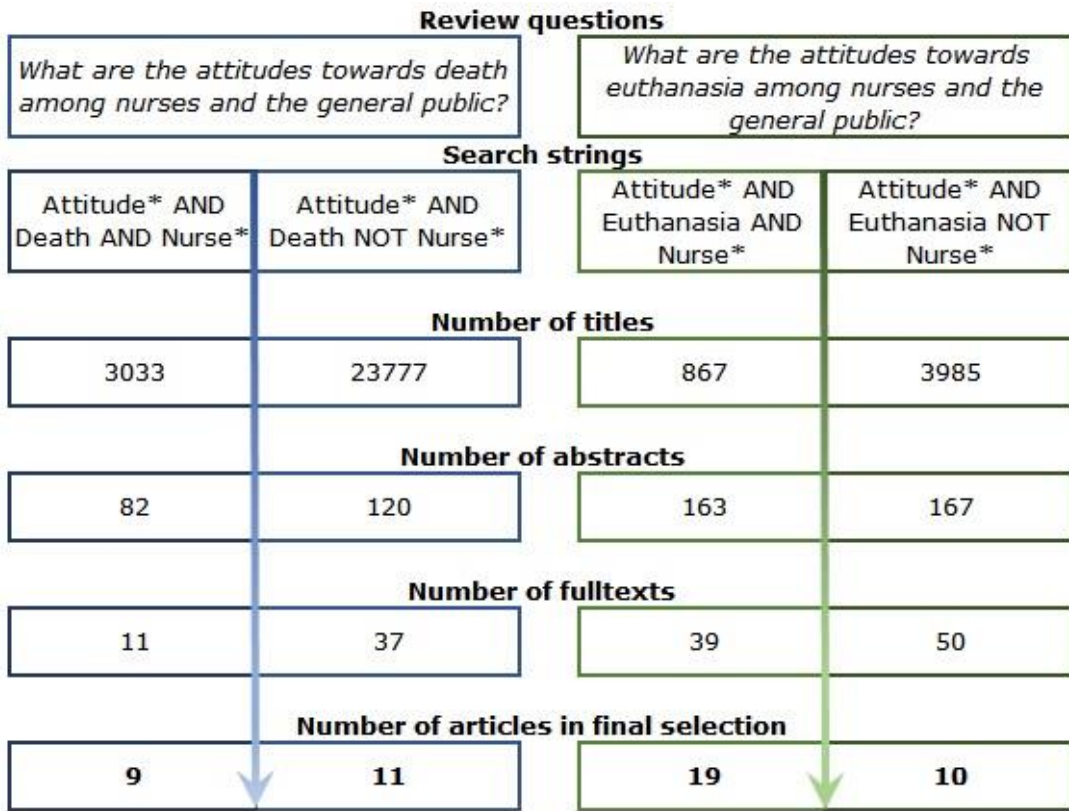


Figure 4. Summary of the selection process of the literature review.

### 3.1 ATTITUDES TOWARDS DEATH

Previous studies, many of which been conducted in the USA, have emphasized the role of death anxiety or fear of death. The participants' attitudes towards death have reportedly ranged from a moderate level of death anxiety (Depaola et al. 2003, Dönmez, Yilmaz & Helvacı 2015, Falkenhain & Handal 2003, Harrawood, White & Benshoff 2008, Tang et al. 2011) to positive attitudes towards death (Makgati & Simbayi 2005).

Results from studies conducted with the DAP-R (Table 2) also indicate that fear of death is generally moderate, except among chronically ill adults (Daaleman & Dobbs 2010), and that an individual may regard death as a natural part of life despite fearing it. Therefore, the fear of death may be associated with death avoidance, but not with the neutral acceptance of death. Apart from a study by Black (2007), these findings also found that participants generally had a moderate to strong belief in a happy afterlife and considerations of death as an escape from a life filled with misery.

Much previous research has focused on the associations between death and demographic factors (Dönmez, Yilmaz & Helvacı 2015, Harrawood, White & Benshoff 2008, Makgati & Simbayi 2005, Malliarou et al. 2011, Nienaber & Goedereis 2015, Peters et al. 2013a, Zyga et al. 2011) or life experience (Bluck et al. 2008). In addition, individuals' attitudes towards death have been examined in connection with grief (Boyras, Waits & Horne 2015), caring for dying patients (Braun, Gordon & Uziely 2010, Cevik & Kav 2013, Dunn, Otten & Stephens 2005, Lange, Thom & Kline 2008) advance directive communication practices (Black 2005, Black 2007) personifications of death (Bassett, McCann & Cate 2008), religiosity (Daaleman & Dobbs 2010, Falkenhain & Handal 2003) and attitudes towards aging and elderly people (Depaola et al. 2003).

Table 2. Overview of mean scores from studies conducted with DAP-R

Study	FoD	DA	NA	AA	EA
Black 2005	4.42	5.13	3.12	3.57	4.16
Black 2007	4.87	5.73	2.16	2.69	4.13
Boyras et al. 2015	-	-	5.34	5.21	4.58
Braun et al. 2010	4.11	2.93	-	3.53	3.60
Cevik & Kav 2013	4.20	4.00	5.50	4.80	3.50
Daaleman & Dobbs 2010	2.87	-	-	5.61	-
Dunn et al. 2005	3.77	2.53	5.69	5.49	4.17
Lange et al. 2008	3.68	2.54	5.59	4.85	3.93
Malliarou et al. 2011	4.90	4.90	5.60	4.20	2.90
Zyga et al. 2011	4.80	3.98	5.63	4.11	3.52

FoD=Fear of death, DA=Death avoidance, NA=Neutral acceptance, AA=Approach acceptance, EA=Escape acceptance

Higher score (1-7) indicates stronger agreement with the dimension.

### 3.1.1 Influence of gender

Previous studies have found conflicting indications of the association between gender and individuals' attitudes towards death. Generally, the fear of death has been found to be greater among women than men (Bassett, McCann & Cate 2008, Dönmez, Yılmaz & Helvacı 2015, Tang et al. 2011), although Malliarou et al. (2011) found the opposite. Accordingly, Daaleman & Dobbs (2010) and Malliarou et al. (2011), but not Basset et al. (2008), found stronger scores for approach acceptance of death (regarding death as a gateway to a happy afterlife) among men than among women. Some studies have found no statistical significant between-gender differences in attitudes towards death manner (Harrawood, White & Benshoff 2008, Makgati & Simbayi 2005, Peters et al. 2013a).

### 3.1.2 Age and individuals' religiosity

Previous literature reveals that relationships between age and death-related attitudes are multifaceted. No significant association has been found in some studies (Black 2005, Makgati & Simbayi 2005, Peters et al. 2013a), but results of others indicate that fear of death or death avoidance increases in old age (Black 2007, Lange, Thom & Kline 2008, Malliarou et al. 2011, Zyga et al. 2011). Similarly, associations have been reported between age and reductions in both neutral and escape acceptance of death (Black 2007). These findings are, however, challenged by findings that younger participants had greater fear of death or lower natural acceptance than older participants (Dunn, Otten & Stephens 2005, Harrawood, White & Benshoff 2008, Zyga et al. 2011). In addition, Lange et al. (2008) found that death was regarded as a natural part of life or an escape from a painful life by higher proportions of nurses who were in their 50s or older than younger nurses.

Increasing religiosity has been linked with decreasing fear of death (Cevik & Kav 2013), although Makgati & Simbayi (2005) found no linkage between religiosity and death-related attitudes. However, the relationship between one's religiosity and believe in afterlife appears to be important, and linked to a positive correlation between religiosity and the approach acceptance of death (Braun, Gordon & Uziely 2010, Daaleman & Dobbs 2010, Falkenhain & Handal 2003).

### 3.1.3 Work experience, education and death exposure

Some studies have found no statistical significant association between work experience in general and death-related attitudes of nurses or social workers (Black 2005, Peters et al. 2013a). However, Zyga et al. (2011) detected a negative association between Greek nurses'



work experience and fear of death. Individuals' experience of caring for dying patients also reportedly reduces fear of death and death anxiety (Bluck et al. 2008, Lange, Thom & Kline 2008). Similarly, higher levels of education and death exposure have been associated with lower fear of death, and the latter has been linked with death avoidance. A negative link between death exposure and avoidance of death has also been reported in several studies (Braun, Gordon & Uziely 2010, Bluck et al. 2008, Harrawood, White & Benshoff 2008, Lange, Thom & Kline 2008, Peters et al. 2013a).

### 3.2 ATTITUDES TOWARDS EUTHANASIA

In total 29 original research articles concerning attitudes towards euthanasia were selected for detailed review: 16, 10 and 3 focused on attitudes of nurses, the general public and both target groups (Table 3). Substantial proportions of these studies were conducted in Belgium and Turkey (five in each country), but in total they covered populations in 18 countries.

*Table 3.* Target groups of reviewed papers concerning euthanasia-related attitudes

<b>Nurses</b>	<b>General public</b>	<b>Both</b>
Asai et al. 2001	Aslan & Cavlak 2007	Kuuppelomäki 2000
Bendiane et al. 2007	Carter et al. 2007	Mickiewicz et al. 2012
Bendiane et al. 2009	Chong & Fok 2009	Ryynänen et al. 2002
Brzostek et al. 2008	Cohen et al. 2014	
De Hert et al. 2015	Karlsson et al. 2012	
Gielen et al. 2009	Marcoux et al. 2007	
Inghelbrecht et al. 2009	Rietjens et al. 2005	
Karadeniz et al. 2008	Roelands et al. 2015	
Kranidiotis et al. 2015	Stronegger et al. 2013	
Kumas et al. 2007	Televantos et al. 2013	
Naseh et al. 2015		
Porredi et al. 2013		
Tamayo-Velazquez et al. 2012		
Tepehan et al. 2009		
Turla et al. 2006		
Zenz et al. 2015		

Within Europe Cohen et al. (2014) found that acceptance of euthanasia was: highest (in 2008) in Denmark, Belgium, France and The Netherlands; and weakest in Kosovo, Cyprus and Turkey (Finland had 8<sup>th</sup> highest ranking of 47 countries for acceptance). They also found that increases in supportive attitudes towards euthanasia since 1999 had been strongest in Spain, Portugal, Great Britain and Germany, while changes in attitudes in the opposite direction had been strongest in the Russian Federation, Ukraine and Greece (Cohen et al. 2014).

Proportions of participants who reportedly accepted euthanasia in the selected studies ranged from 23% (Asai et al. 2001) to 92% (Inghelbrecht et al. 2009a) among nurses and from 23% (Televantos et al. 2013) to 96% (Roelands et al. 2015) among the general public. The reported support for euthanasia was strongest in Belgium among both groups (Inghelbrecht et al. 2009a, Roelands et al. 2015), but weakest among nurses in Japan (Asai et al. 2001) and the general public in Cyprus (Televantos et al. 2013). Several studies have found that the general public tends to have more positive attitudes towards euthanasia than nurses (Kuuppelomäki 2000, Mickiewicz et al. 2012, Ryynänen et al. 2002).

Proportions of nurses who have reportedly accepted legalization of euthanasia have varied between 18% (Kumas, Oztunc & Alparslan 2007) and 65% (Bendiane et al. 2007). The only study in the selected set that gauged this attitude among representatives of the general public found that proportions who accepted its legalization ranged from 26 to 62%, depending on their roles (Mickiewicz et al. 2012).

Among nurses participating in the selected studies, between 6% (Turla et al. 2006) and 53% (Asai et al. 2001) indicated that they had received a request to hasten death from a patient or their relatives. Patients' requests were regarded as rational sometimes by 85% of the nurses in studies addressing this aspect (Asai et al. 2001, Karadeniz et al. 2008). However, a minority (10%-21%) stated that they would practice, or were willing to assist in euthanasia, if it was legal (Asai et al. 2001, Karadeniz et al. 2008, Kranidiotis et al. 2015, Tamayo-Velazquez, Simon-Lorda & Cruz-Piqueras 2012, Turla et al. 2006). However, exceptionally, 66% of nurses surveyed in Poland (Mickiewicz et al. 2012) and 54% in Spain (Tamayo-Velazquez, Simon-Lorda & Cruz-Piqueras 2012) expressed approval for participation in a euthanasia process.

### **3.2.1 Age and gender**

Previous literature indicates that acceptance of euthanasia and its legalization declines with increasing age of individuals, particularly among those aged 50 years or more (Bendiane et al. 2007, Bendiane et al. 2009, Cohen et al. 2014, Mickiewicz et al. 2012, Ryyänänen et al. 2002). Older nurses also tend to believe that good palliative care can avoid the need for euthanasia more strongly than younger colleagues (Inghelbrecht et al. 2009a). However, in several studies the detected association between individuals' age and euthanasia-related attitudes was not statistically significant (Carter et al. 2007, Gielen et al. 2009, Kumas, Oztunc & Alparslan 2007, Naseh, Rafiei & Heidari 2015, Stronegger et al. 2013, Televantos et al. 2013), or the nature of the relation was not reported (Poreddi et al. 2013). Furthermore, in a survey of the general public in China older participants expressed greater agreement with euthanasia than the younger participants (Chong & Fok 2009).

Generally, males are regarded as having more positive attitudes towards euthanasia and its legalization than women (Bendiane et al. 2007, Bendiane et al. 2009, Cohen et al. 2014, Ryyänänen et al. 2002, Televantos et al. 2013, Turla et al. 2006). No results indicating that women are more supportive of euthanasia than men have been presented. However, no statistical significant relationships between gender and euthanasia-related attitudes have been found in some studies (Aslan & Cavlak 2007, Carter et al. 2007, Gielen et al. 2009, Naseh, Rafiei & Heidari 2015, Rietjens et al. 2005, Roelands et al. 2015, Stronegger et al. 2013).

### **3.2.2 The influence of religion**

No statistically significant connection between religion and euthanasia-related attitudes has been found in some studies (Karadeniz et al. 2008, Naseh, Rafiei & Heidari 2015). Nevertheless, religion has been regarded as one of the main factors influencing individuals' attitudes towards euthanasia and its legalization. According to several studies, non-religious people have the most positive attitudes towards euthanasia (Kranidiotis et al. 2015, Rietjens et al. 2005, Ryyänänen et al. 2002). Furthermore, earlier findings indicate a negative correlation between religion and euthanasia-related attitudes, particularly between religiosity and acceptance of euthanasia (Bendiane et al. 2009, Carter et al. 2007, Chong & Fok 2009, Cohen et al. 2014, Inghelbrecht et al. 2009a, Televantos et al. 2013). Even studies, that made no statement regarding the trend of this relationship, emphasized individual's religion or philosophy of life as a significant background factor of one's attitudes towards euthanasia and its legalization (Kumas, Oztunc & Alparslan 2007, Poreddi et al. 2013, Roelands et al. 2015).

### **3.2.3 Family-related factors and income level**

No statistically significant correlation between marital status and individuals' attitudes towards euthanasia has been found in some studies (Carter et al. 2007, Naseh, Rafiei & Heidari 2015), whereas others have found more support for it among singles and unmarried people than among other groups (Rietjens et al. 2005, Stronegger et al. 2013, Televantos et al. 2013). In addition, the number of children has been found to correlate negatively with acceptance of euthanasia, i.e. parents with multiple children are least prone to support euthanasia or its legalization (Stronegger et al. 2013). Positive associations have also been

reported between acceptance of euthanasia and both mothers' educational level (Aslan & Cavlak 2007) and individuals' income (Carter et al. 2007, Cohen et al. 2014, Stronegger et al. 2013).

### **3.2.4 Education and nurses' work-related factors**

There are conflicting indications of links between education and attitudes towards euthanasia and its legalization among nurses and the general public. A positive association between level of education and supportive attitudes has been found in some studies (Cohen et al. 2014, Televantos et al. 2013), while others have found no statistical significant relation between them (Kumas, Oztunc & Nazan Alparslan 2007, Roelands et al. 2015), or have come to the opposite conclusions (Rietjens et al. 2005, Stronegger et al. 2013).

Among the general public, experience in caring for family members has been associated with increases in the tendency to agree with euthanasia (Chong & Fok 2009, Kuuppelomäki 2000). However, no significant associations between attitudes towards euthanasia and either experiences of EOL care or knowledge of EOL actions among the general public have been found in some studies (Roelands et al. 2015, Stronegger et al. 2013).

By contrast, nurses' education and competence in palliative care or pain management is negatively associated with their acceptance of euthanasia and its legalization, according to some studies (Bendiane et al. 2009, Zenz, Tryba & Zenz 2015), but not all (Bendiane et al. 2007). Higher than average acceptance of euthanasia has also been found among nurses working at night or in acute settings (Bendiane et al. 2009, De Hert et al. 2015). Furthermore, some studies have found that nurses' attitudes towards euthanasia and its legalization are positively associated with their confidence in medical science (Kumas, Oztunc & Alparslan 2007) and work experience (Gielen et al. 2009), but others have found no evidence confirming such correlations (Naseh, Rafiei & Heidari 2015, Poreddi et al. 2013).

## **3.3 PRESUMPTIONS OF THE STUDIES**

The previous literature has explained individuals' attitudes towards death and euthanasia with multiple, mainly similar factors. It is to notice, however, that the findings of previous literature are partly contradictory, which may be addressed to the different settings, methods and used definitions. These contradictions should be taken into account by the interpretation of the findings. However, based on the conducted literature review, the tentative presumptions of this study are:

1. Younger individuals have more neutral attitudes towards death and more supportive attitudes towards euthanasia than the older ones.
2. Females report higher levels of fear of death and lower levels of acceptance towards euthanasia than males.
3. Religious individuals have lower level of fear of death and acceptance toward euthanasia than non-religious individuals.
4. Nurses, who assess their expertise higher in EOL care or pain management have more negative attitudes towards euthanasia than nurses with lower assessed expertise.

## *4 Aims of the studies*

The studies this thesis is based upon had the following aims. First, to reveal and describe attitudes towards death and euthanasia among the general public and nurses in Finland. Then, to explore the factors related to the attitudes and analyse connections between individuals' death- and euthanasia-related attitudes in both target groups. Specific research questions addressed were:

1. What kinds of perceptions do nurses have of euthanasia and its legalization?
2. What kinds of attitudes do nurses and the general public have towards death and euthanasia?
3. What factors are related to the attitudes in both target groups?
4. How are individuals' death-related attitudes connected to their attitudes towards euthanasia?

The final aim was to construct a robust empirical model of factors associated with individuals' attitudes towards euthanasia.

## 5 Methods

The empirical research involved two cross-sectional studies: one qualitative (Study 1) and one quantitative (Study 2). In addition to differences in fundamental methodological approach, the studies differed in terms of samples, settings, data collection and data analysis (Table 4). The studies have been presented in four original publications, designated I-IV, I based on data acquired in Study 1 and II-IV based on data acquired in Study 2 (Table 4).

*Table 4.* Description of the empirical studies

Study no.	Original publications	Sample and setting	Data collection	Data analysis
1	I	Registered nurses (n=17) who worked in different units of 2 primary care hospitals in Southern Finland	Individual, semi-structured interviews were conducted between November 2012 and January 2013	Inductive content analysis
2	II-IV	Representatives of the general public (n=2796) and nurses (n=1003) recruited via social media and the members' bulletin of the Finnish Nurses Association	Data were collected over four weeks in October-November 2014, using a web-based questionnaire with five components: demographic characteristics, work-related characteristics, euthanasia-related questions, the Centrality of Religiosity Scale and the Death Attitude Profile-Revised.	Descriptive statistics, Kolmogorov-Smirnov test, Mann-Whitney test, Kruskal-Wallis test, PCA, Bayesian network modelling

### 5.1 QUALITATIVE INTERVIEW STUDY

#### 5.1.1 Interviewees and recruitment

Nurses provide care for a broad range of patients, including the terminally ill, in the primary health care hospitals in Finland. Thus, to acquire a broad sample of nurses the chief nursing officers of three primary care hospitals, to which the researcher had no prior connections, were contacted. All of the hospitals are located in southern Finland: two in towns with similar numbers of inhabitants to an average Finnish city, and one in a town with a substantially smaller population. In all three cases the nearest secondary care hospital was in either the same town or the immediate vicinity. One of the chosen hospitals refused to participate due to ongoing organizational changes, but approval for the research was applied for and obtained from the other two hospitals.

The criteria for including nurses in the interview study were being a registered nurse and having sufficient language skills in Finnish (considered crucial to avoid possible misunderstandings). The loss of a next of kin or close relative / friend during the past year was an exclusion criterion. A total of 17 nurses who met these criteria participated in the study.

Both genders were represented among participating nurses, but the ratio has remained confidential, due to concerns of possible identification expressed by one interviewee. The ages of the interviewees ranged from 28 to 64 years (mean, 47.7 years). The average work experience of participating nurses was 18.7 years, with variation from 4 to 36 years. Twelve of the participating nurses had a nursing diploma of short-cycle tertiary education according

to the ISCED 2011 classification scheme and five had a bachelor's degree in nursing. Four of the nurses reported encountering dying patients daily, four weekly and five monthly. In addition, four nurses stated that they provided care for dying individuals less frequently than monthly.

After research approval had been obtained from the organizations, the researcher contacted all head nurses in the hospitals and made an appointment, in which she informed the head nurses about the study, who subsequently relayed the information to the nurses in their wards. In addition, all nurses received information about the study via e-mails sent by the head nurses.

The nurses were advised about the voluntariness of the participation, possibility to withdraw at any time and confidentiality of their responses. In addition, they were allowed to contact the researcher by e-mail with additional questions regarding the study. The nurses were asked to express their willingness to participate to the researcher by e-mail. However, some of them decided to inform their head nurses, who relayed the information to the researcher. Thereafter the interviewees were contacted by the researcher in order to arrange the interview.

### 5.1.2 Data collection

Data were gathered by individual, semi-structured interviews that included questions regarding four themes: euthanasia, the legalization of euthanasia, physician-assisted suicide and the nurses' role in a euthanasia process. Semi-structured interviews were chosen due to the limited amount of previous knowledge. In addition, the researcher wanted to retain the possibility of asking additional questions during the interview, which this method provides. (Burns & Grove 2009.) Prior to the data collection two preliminary interviews were carried out to ensure that the interview themes and questions were appropriate and provide answers to the research questions (Elo et al. 2014). No changes were made based on the preliminary interviews, which were thus included in the dataset.

The data were collected between November 2012 and January 2013. All interviews were conducted by the researcher once, in a place of the interviewee's choice in order to increase the nurses' wellbeing during the interviews and improve the authenticity of their responses. Each interview was tape-recorded with the permission of the interviewee, who signed an informed consent form at the beginning. Moreover, to avoid ambiguity, the researcher clarified the meaning of euthanasia in this study at the beginning of each interview.

The interviews had a mean duration of 44 minutes. By the 15<sup>th</sup> interview, there was a high degree of repetition in the answers and no new themes emerged. At that point two further interviews were appointed, which were conducted to ensure saturation of the data. Those interviews produced no additional perspectives, therefore the 17 interviews provided data saturation.

### 5.1.3 Data analysis

The data were analysed by inductive content analysis, which was chosen due to the paucity of previous studies and lack of appropriate theory regarding nurses' perceptions of euthanasia (Burns & Grove 2009, Elo & Kyngäs 2008). The analysis focused solely on the manifest content of the interviews (Elo & Kyngäs 2008, Graneheim & Lundman 2004). The researcher transcribed the interviews verbatim, which resulted in a total of 191 pages of text, 94 of which were relevant to the research questions posed and addressed in Original publication I: *"How would you describe your perceptions of euthanasia and its legalization?"* and *"Please describe for me a situation where termination of a human's life by his/her own request would be justified."*

Thereafter the researcher read the transcribed interviews repeatedly in order to familiarize herself with them, get an overview of the whole dataset, then identify and mark the meaning units, the length of which varied from one word to several sentences (Elo & Kyngäs 2008, Graneheim & Lundman 2004, Vaismoradi et al. 2016). Subsequently the marked expressions

were reduced to general statements based on their content. Then the general statements that shared the same meaning were further grouped into subcategories and organized and reorganized according to their contents. Eventually eight categories (Table 1 in Original publication I) were formulated that describe the content of the main categories "*Euthanasia*" and "*Legalization of euthanasia*." (Graneheim & Lundman 2004, Elo & Kyngäs 2008, Vaismoradi et al. 2016.) The data were analysed by the researcher and regularly discussed with other, more experienced researchers in order to increase the trustworthiness of the findings (Elo et al. 2014).

## 5.2 QUANTITATIVE WEB-BASED SURVEY

### 5.2.1 Participants, recruitment and data collection

A total of 1003 nurses and 2796 representatives of the general public participated in the quantitative study (Tables 1 & 2 in Original publication IV). Participants were recruited via social media, employing the researcher's public blog that she had created for the purpose of this research in 2013. Further information channels were Facebook, Twitter and seven discussion forums, five of which were chosen because they had large numbers of users, one because it was oriented towards nurses, and the other because it was oriented towards elderly individuals. To avoid bias no information about the study was posted on social media sites that are based on religious faith or take a public stand for or against euthanasia. The researcher published information about the study in the blog and linked it to the Twitter and Facebook pages that had been created for this study. The blog entry was retweeted and shared by other Twitter and Facebook users. The same information was posted in the chosen discussion forums.

There are more than 100 000 registered nurses in Finland (Ailasmaa 2014). Nearly half are members of the Finnish Nurses Association (The Finnish Nurses Association 2014), and members of the association were informed about the study via its members' bulletin, which had a circulation of 29 484 in October 2014.

Social media are still quite rarely employed for recruiting participants in nursing science studies (Khatri et al. 2015, Otieno & Matoke 2014), but they can provide new, cost-effective recruitment channels that provide access to large demographically diverse populations (Khatri et al. 2015, Kosinski et al. 2015, Otieno & Matoke 2014). For example, 87% of Finns aged 16 to 89 years use the internet. Even in the oldest group (75-89 years old) 31% have used it within the last three months, 13% use it several times a day, and 53% have followed a social network service in the past three months according to recent statistics (Official Statistics of Finland 2015b).

Social media also offer possibilities to reach underrepresented populations (Kosinski et al. 2015), individuals who may not otherwise be engaged with professional bodies such as the Finnish Nurses Association (Khatri et al. 2015, Otieno & Matoke 2014) or are hard to reach by conventional means (Gosling & Mason 2015). It has also been argued that increasing the diversity of sampled populations in this manner may improve the representativeness and generalisability of findings (Gosling & Mason 2015, Otieno & Matoke 2014). Furthermore, recruitment via social media may enhance the participants' voluntariness and anonymity, and thus the authenticity of the responses (Gosling & Mason 2015, Otieno & Matoke 2014). Finally, after submission of each questionnaire, the data were directly entered into a database, which reduced the possibility of human error by processing the data (Otieno & Matoke 2014). The data were collected online over four weeks in October-November 2014. Participants in this study had to be at least 18 years old and have sufficient skills in the Finnish language.

### 5.2.2 The instrument, its validity and reliability

In order to ensure consistency with the definition of euthanasia applied in the studies and this thesis, and take participants' cultural characteristics into account, an electronic questionnaire was developed for this study (Table 5). The developed questionnaire consisted of five components: *demographic characteristics*, *work-related characteristics*, *The Centrality of Religiosity Scale (CRS)* (Huber & Huber 2012), *Death Attitude Profile-Revised (DAP-R)* (Wong, Reker & Gesser 1994) and *attitudes towards euthanasia*.

Table 5. Summary of the developed questionnaire

Component	No. of items	Responses	$\alpha$
Demographic characteristics	8	Diverse options	-
Work-related characteristics	8	Diverse options	-
Centrality of Religiosity Scale (CRS)			
<i>Intellect</i>	3		0.85
<i>Ideology</i>	3		0.93
<i>Public practice</i>	3	5-8 point Likert type scale (diverse options)	0.89
<i>Private practice</i>	3		0.91
<i>Experience</i>	3		0.92
Death Attitude Profile-Revised (DAP-R)			
<i>Fear of death</i>	7		0.85
<i>Death avoidance</i>	5	7-point Likert type scale (strongly disagree - strongly agree)	0.88
<i>Neutral acceptance</i>	5		0.58
<i>Approach acceptance</i>	10		0.95
<i>Escape acceptance</i>	5		0.74
Attitudes towards euthanasia			
<i>Acceptance of euthanasia</i>	4	5-point Likert type scale (strongly disagree - strongly agree)	0.91
<i>Legalization of euthanasia</i>	3		0.67
<i>Euthanasia-related communication</i>	3		0.66

$\alpha$  = Cronbach's  $\alpha$

The *demographic characteristics* covered by the questionnaire included the participant's age, gender, marital status and most recent level of education. In addition, participants were asked if they had children, the region of their primary residence and their religious affiliation. They were also asked to state if they were nurses or not.

The questions on *work-related characteristics* were only presented to those who stated they were nurses, who were asked about their shift patterns (e.g. working days and/or evenings, nights only or three-shift work), their workplace, work experience and the sort of patient they most commonly cared for. The nurses were further asked to assess their expertise in pain management and EOL care on a four-point scale (very weak - very good) and the frequency of their encounters with dying or dead patients (never - daily).

The CRS was employed to measure the religiosity of the participants in both groups. It is an internationally validated scale (Huber & Huber 2012) that rests upon the multidimensional model of religion originally presented by Stark and Glock (1968). This model defines religion as the interplay of five sets of factors or dimensions: intellect, ideology, public practice, private practice and experience (Gielen, Van den Branden & Broeckaert 2009a, Huber & Huber 2012, Stark & Glock 1968). The intellect dimension refers to an individual's religious interest and is portrayed by the frequency of one's religious thoughts. An example of a question related to this dimension is "How often do you think about religious issues?" (Huber & Huber 2012). An individual's beliefs in the existence of a transcendent reality and the interactions with the supernatural are represented in the ideology dimension. It includes questions such as: "In your opinion, how probable is it that a higher power really exists?" (Ibid.). The public practice dimension refers to participation in public religious rituals or other shared religious activities, while religious rituals and activities conducted in private spaces are included in the private practice dimension (Ibid.).



Examples of questions of the former and latter are, respectively: “How important is it for you to be connected to a religious community?” and “How important is personal prayer for you?” (Ibid.). The last dimension, experience, relates to the religious experiences and feelings of an individual, probed by questions like: “How often do you experience situations in which you have the feeling that God or something divine is present?” (Ibid.). The CRS is available in three lengths, of which the longest – CRS 15 – was chosen due to strong evidence of its reliability and validity. In the chosen version, each dimension is assessed with three items (Ibid.). Moreover, a major aim of this study was to evaluate the influence of individuals’ religiosity on their attitudes towards death and euthanasia, for which the CRS-15 is claimed to be most suitable (Ibid.).

The DAP-R is a 32-item scale that was developed by Wong et al. (1994) for assessing individuals’ attitudes towards death. It consists of five dimensions: fear of death, death avoidance, neutral acceptance, approach acceptance and escape acceptance (Ibid.). These dimensions are described in section 2.1 of this summary. The fear of death is assessed with seven questions, such as “I am disturbed by the finality of death” (Ibid.). There are five statements referring to death avoidance, including “I avoid thinking about death altogether” (Ibid.). The Neutral approach dimension is assessed using five statements like “Death is a natural aspect of life”, and approach acceptance is evaluated by the largest number of items (10), including statements such as “I look forward to a life after death” (Ibid.). Lastly, the escape approach dimension is evaluated by five statements, such as “I view death as a relief from the burden of life” (Ibid.). The DAP-R employs a seven-point Likert type scale (strongly disagree - strongly agree) for possible responses. The score for a dimension is the mean score for relevant items and is positively associated with agreement with the content of those items (Ibid.). The instrument was selected partly because previous literature encourages multidimensional assessment of individuals’ death-related attitudes (Neimeyer, Wittkowski & Moser 2004) and partly because it is the preferred instrument for assessing dimensions of death acceptance (Ho et al. 2010, Neimeyer, Wittkowski & Moser 2004, Wong & Tomer 2011) that were regarded as significant for this study.

Based on international literature (e.g. Berghs, Dierckx de Casterlé & Gastmans 2005, Cohen et al. 2006, Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010) and findings from the qualitative study, 13 statements regarding individuals’ *attitudes towards euthanasia* were designed. These statements were discussed with a panel of experts in relevant disciplines (nursing science, medicine and theology). Participants were asked to state their agreement with the statements on a five-point Likert type scale (strongly disagree – strongly agree), where higher score indicated stronger agreement.

The CRS was translated from English to Finnish by the researcher, and the translation was discussed with the expert panel. It was then translated from Finnish to English by an authorized translator and compared with the original. The DAP-R was translated by an authorized translator and discussed with the expert panel, and subsequently translated back to English by another, independent authorized translator.

To test the reliability and repeatability of the questionnaire a test-retest was conducted with 19 respondents. Then a preliminary pilot study was conducted with 91 nursing students to confirm the feasibility of the questionnaire. No changes were made to the statements based on the results of these tests, but the data were excluded from this study.

In the study, Cronbach’s  $\alpha$  values of the CRS varied from 0.85 (for the intellect dimension) to 0.93 (for the ideology dimension). The reliability of the CRS dimensions reportedly range from 0.80 to 0.93 (Huber & Huber 2012). Cronbach’s  $\alpha$  values of the DAP-R ranged from 0.58 (for neutral acceptance) to 0.95 (for approach acceptance) in the current study, similar to previous assessments of the DAP-R’s reliability as good to very good, with Cronbach’s  $\alpha$  values ranging from 0.65 (for neutral acceptance) to 0.97 (for approach acceptance) (Wong, Reker & Gesser 1994). However, the neutral acceptance subscale was excluded from analyses by Braun, Gordon & Uziely (2010) due to weak reliability (Cronbach’s  $\alpha$  value, 0.41) and by Nakagi & Tada (2014) for the same reason. By contrast, its reliability and internal consistency

have been confirmed by several others (Cevik & Kav 2013, Ho et al. 2010, Malliarou et al. 2011).

Cronbach's  $\alpha$  values for the dimensions of attitudes towards euthanasia, were 0.91 for euthanasia acceptance, 0.67 for legalization of euthanasia and 0.66 for euthanasia-related communication, indicating good to very good reliability (Field 2013).

### 5.2.3 Data analysis

Prior to data analysis 68 records were removed due to missing data (with a cut-off point of 28.5%, and hence a lack of responses to eight or more items). In addition, one record was removed because the participant was too young. Furthermore, the variable "latest level of education", which originally had nine categories, was recoded into six educational categories, following the ISCED 2011 classification system (Official Statistics of Finland 2014).

The statistical analysis of the data was conducted using SPSS Statistics 21 for Windows. Individual scores for the five dimensions of religiosity were computed deductively. Participants were then categorized into three groups (non-religious, religious and highly religious) based on their aggregate CRS scores (Huber & Huber 2012). Scores for the DAP-R dimensions were computed by calculating individual mean scores for each subscale (Wong, Reker & Gesser 1994).

In addition, Principal Component Analysis (PCA) with orthogonal rotation (Varimax) was applied to responses to the 13 items regarding individuals' attitudes towards euthanasia to reduce the number of dimensions and explore patterns in the data. The PCA revealed that statement 10 ("possible misconduct is a reason for forbidding euthanasia") had weak communality (0.192), and statements 3 ("euthanasia provokes strong reactions in me") and 13 ("when assessing suffering, mental and physical anguish are equal") had weak correlations (0.038 – 0.193) (Field 2013). Furthermore, following discussion an expert group judged that the statements were not sufficiently unambiguous, hence they were excluded from the PCA.

Frequencies, histograms and the Kolmogorov-Smirnov test ( $p < 0.000$ ) showed that distributions of the dependent variables did not meet the criteria for parametric tests (Field 2013). Therefore, Mann-Whitney and Kruskal Wallis tests were applied for further examination of the differences between groups. A  $p$  value of  $< 0.05$  was regarded as the threshold for statistical significance (Field 2013).

In addition to these statistical techniques, Bayesian network (BN) modelling was employed to analyse the data (Ben-Gal 2007, Conrady & Jouffe 2015). This is commonly applied in computer science and mathematics, but less frequently in health sciences, sociology and psychological research (López, Ramírez & Casado 2012). However, it is increasingly used in health technology assessment, furthermore it has been employed in modelling of attitudes in psychology (Cooper et al. 2013, López, Ramírez & Casado 2012).

Here, collected data were analysed with BayesiaLab 5.3.3. First a factor analysis was conducted using a Taboo search algorithm with a structural coefficient value of 0.6. The value of the structural coefficient was optimized using a structural coefficient tool (Conrady & Jouffe 2015). In this step no target mode was set. In variable clustering, 16 factors were suggested by BayesiaLab, of which the most important (euthanasia attitude) was set as target node. Subsequently a new Taboo search was conducted and factors and manifest variables with no association to the target node (euthanasia attitude) were excluded from the model. The connections were analysed with the Augmented Markov Blanket algorithm. This approach was chosen to improve the predictive performance of the model and reveal collinear relationships between the variables. (Conrady & Jouffe 2015.)

### 5.3 ETHICAL CONSIDERATIONS

For the quantitative study ethical approval (5/2014) was obtained prior to the data collection from the Committee on Research Ethics of the University of Eastern Finland. In this study the submission of a filled questionnaire was regarded as evidence of informed consent of the participant (TENK 2009). Information about the study was also presented on the first page of the electronic questionnaire to ensure that each participant had seen it prior to submitting data.

Ethical approval from the Committee was not obtained for the qualitative study, because the participants were not considered as vulnerable and their physical integrity was not violated. This is in accordance with Finnish legislation and guidelines of the Finnish Advisory Board on Research Integrity (TENK 2009). However, research approval was obtained from each participating organization and each interviewee signed an informed consent form prior to the interview.

Both studies followed principles of the Declaration of Helsinki (The World Medical Association 2015) and Responsible Conduct of Research Guidelines, published by the Finnish Advisory Board on Research integrity (TENK 2012). In addition, recommendations of the Association of Internet Researchers (AoIR) regarding ethical decision-making and internet research (Markham & Buchanan 2012) were considered where applicable. Informing participants via social media may have led to information being read by minors, who are not able to give informed consent (Markham & Buchanan 2012). Thus, the ages of participants were checked before analysis, and all records regarding those who did not meet the age criteria were deleted.

Permission to use the CRS instrument was obtained from its developer, S. Huber. Similarly, P.T.P. Wong permitted use of the DAP-R instrument. Permission to publish information about the quantitative study in the chosen discussion forums was obtained from the administrators prior to its publication.

Due to the sensitivity of the research theme particular careful attention was paid to ethical considerations regarding participants' anonymity, the voluntariness of participation and ensuring that the definition of euthanasia was as unambiguous as possible. To ensure the anonymity of the interviewees in the qualitative study, the interviews were randomly labelled "P1" to "P17." In addition, the gender distribution is not reported due to concerns expressed by one interviewee. Interviewees had the possibility to withdraw at any stage of the study, which none of them did. Prior to the interviews the researcher described the definition of euthanasia to the nurses in order to avoid ambiguity.

In the quantitative study, protection of participants' anonymity was ensured by the method of recruitment and data collection. The voluntariness of the participation was emphasized by the participants' ability to complete the questionnaire at any time and place of their choice. Apart from the voluntariness of participation, this was also seen as a method to reduce possible pressure on participants to give responses they considered to be representative of common or acceptable opinions. (Ryynänen et al. 2002, Otieno & Matoke 2014.) Withdrawal after submission of the questionnaire was not possible due to the ensured anonymity, as clearly stated in the study's information sheet. The definition of euthanasia used in this study ("a deliberate act intended to terminate a person's life at his/her own explicit request") was placed before the statements regarding euthanasia-related attitudes.

The ethical aspects and accordance with responsible conduct of research (Finnish Advisory Board on Research Integrity 2012) of the study were assessed in each phase of the process, from planning the study until reporting the results.

## 6 Results

### 6.1 DEATH-RELATED ATTITUDES (ORIGINAL PUBLICATION IV)

Participants' death-related attitudes were assessed in five dimensions: fear of death, death avoidance, neutral acceptance, approach acceptance and escape acceptance. Apart from fear of death statistical significant differences between attitudes of the nurses and general public were found in all dimensions. Both groups' scores were strongest for the neutral approach, and weakest for death avoidance. Their escape acceptance scores were also higher than their approach acceptance scores (but in the latter case there was a greater difference between the groups). In addition, higher proportions of nurses than members of the general public were categorised as religious or highly religious (Figure 6). Generally, nurses' scores for fear of death, death avoidance, neutral acceptance and escape acceptance were lower, while their approach acceptance scores were higher, than those of the general public.

Table 6. Religiosity of the nurses (n=1003) and general public (n=2796)

Degree of religiosity	Nurses		General public	
	f	%	f	%
Non-religious	424	42.3	1552	55.5
Religious	510	50.8	1075	38.5
Highly religious	69	6.9	168	6.0

#### 6.1.1 Fear of death

The mean scores for this dimension were 2.91 (SD, 1.25) among the nurses and 3.03 (SD, 1.37) among the general public, indicating low levels of fear in both groups. In both groups the younger participants reported greatest agreement with the dimension, indicating that they fear death the most. Among the general public males had lower scores in this dimension than females, but the between-gender difference was not significant among the nurses. Representatives of the general public (but not nurses) who were married or in a relationship were also more afraid of death than others. Furthermore, having children or the lowest level of education was associated with greater fear of death among the general public but not among the nurses. In both groups the highly religious individuals were the least afraid of death followed by those who were non-religious, and those categorised as religious reported the greatest levels of fear of death. Fear of death decreased with increasing work experience among the nurses. In addition, nurses who encountered dead patients on a daily basis or assessed their expertise in pain management or EOL care as very good had the lowest scores in this dimension, indicating that they feared death the least.

#### 6.1.2 Death avoidance

Mean scores were lowest for this dimension in both groups: 2.05 (SD, 1.13) among nurses and 2.34 (SD, 1.28) among the general public. Representatives of the general public who were married, in a relationship or had children avoided death more than others, while bachelor degree-level or higher latest education reduced avoidance of death among this group. None of these associations was statistical significant among nurses. By contrast, age was negatively associated with death avoidance among the nurses, but no significant age-effect in this dimension was found among the general public. Individuals categorised as highly religious avoided death least in both groups. The non-religious nurses were also the most death avoidant, but the difference in mean scores of non-religious and religious representatives of

the general public was practically non-existent (0.01). Caring for dying patients, encountering dead patients, and very good expertise in pain management or EOL care were all negatively associated with death avoidance among nurses. However, nurses who assessed their expertise in pain management as very weak reported the lowest level of death avoidance.

### **6.1.3 Neutral approach**

Mean scores of the nurses (6.02; SD, 0.78) and general public (6.08; SD, 0.81) were closest in this dimension. Males expressed higher levels of neutral acceptance than females in both groups. Moreover, bachelor-level or higher latest level of education was associated with higher than average scores for the neutral approach towards death among the general public but not among nurses. In both groups the non-religious individuals presented the most neutral attitudes, whereas the religious nurses and highly religious representatives of the general public expressed the least neutral attitudes. Among nurses, neutral acceptance of death was also strongest among those who assessed their expertise in pain management or EOL care as very weak.

### **6.1.4 Approach acceptance**

Nurses had a higher mean score for approach acceptance (3.71 SD, 1.55) than members of the general public (3.17 SD, 1.67). In both groups females and individuals who had children or were 50 to 69 years old expressed the highest level of approach acceptance. Widowed nurses and divorced representatives of the general public agreed most strongly with statements linked to this dimension. Among nurses there was a negative association between the highest level of latest education and approach acceptance. By contrast, approach acceptance was strongest among representatives of the general public with the highest level of education. Religiosity was positively linked to scores for this dimension in both groups. The most experienced nurses and those who assessed their expertise in EOL care as very good had higher mean scores for approach acceptance of death than their colleagues.

### **6.1.5 Escape acceptance**

Representatives of the general public had a higher mean score for escape acceptance (4.75; SD, 1.34) than the nurses (4.54; SD, 1.24). In both groups scores in this dimension were lowest for young individuals and highest for those with upper secondary education (but also high for widowed nurses and divorced representatives of the general public). Moreover, highly religious or experienced nurses, as well as those with two-shift work expressed stronger escape acceptance than other nurses.

## **6.2 NURSES' PERCEPTIONS OF EUTHANASIA (ORIGINAL PUBLICATION I)**

Nurses expressed conflicting perceptions of euthanasia, highlighting its multifaceted nature. On one hand they regarded euthanasia as a way to alleviate a patient's suffering in a manner that was considered to be humane. Some of the nurses even considered that they could possibly request euthanasia themselves in certain situations. Compared with suicide, euthanasia was seen as a better option. On the other hand, they emphasized the value of life and stated that no one has a right to terminate it, even when a patient is asking for it.

The nurses raised concerns about the finality of euthanasia and reliability of euthanasia requests, as well as patients' possible regrets and ability to make decisions. However, they also expressed concern that denial of euthanasia could mean patients being left alone in misery.

Nurses stated that their experience in nursing had influenced their perceptions of euthanasia. Their responses indicated that negative feelings such as helplessness and distress when encountering human suffering, and experiences of insufficient pain management,

strengthened their support for euthanasia. However, nurses emphasized their ethical obligation to protect life, which strengthened the opposing perceptions of euthanasia, although those who highlighted their duty to help a suffering patient did not think that euthanasia conflicted with nursing ethics. Nurses' religiosity was found to influence their perceptions either negatively or positively, depending on their attitude towards euthanasia.

Patient's own wishes for euthanasia, based on thorough consideration, were seen as essential for acceptable euthanasia. Other requirements for euthanasia emphasized by the nurses included capacity of the patient, unbearable suffering and ongoing terminal illness. Some of the nurses drew no distinction between psychological and physical agony in this respect, but others regarded only physical suffering as justifiable grounds for euthanasia. Another relevant factor according to the nurses was the expected nature of the patient's death.

Euthanasia was considered a difficult topic of discussion both within the health care team and with patients or their relatives. According to nurses, the strong differences in opinions and the finality and stigma associated with euthanasia impeded conversations about it. Despite the expressed challenges, nurses regarded open dialogue about the issues as important. Based on nurses' experiences, patients seldom make euthanasia requests. However, nurses stated that some appeals may be expressed in a way that nurses may not, or may not want to, identify as euthanasia requests.

The media were the main sources of information regarding euthanasia for nurses, although they were considered unreliable. Nurses associated the paucity of available information with the sensitive nature of the topic. However, they hoped that access of health care professionals to relevant information would be improved. Furthermore, they regarded reliable knowledge as important for clarification of their opinions and discussions about euthanasia.

Most of the nurses believed that euthanasia would be legalized in Finland in the future, and that familiarization with euthanasia legislation and practices elsewhere would be beneficial for formulation of appropriate regulations and practices in Finland. Although risks related to insufficient consideration and potential misuse were regarded as important, nurses did not consider them to be sufficient to withhold euthanasia from all individuals who request it. However, nurses' right of conscientious objection to the whole euthanasia process was regarded as the most important requirement for any future legalized procedure. Involuntary participation was considered as traumatic for health care personnel and could lead to increased career changes.

Nurses who expressed negative perceptions of euthanasia emphasized the potential risks of legalization of euthanasia and regarded improvement of palliative care as a priority. By contrast, nurses with positive opinions about euthanasia highlighted the significance of clear criteria and rules in order to avoid conflicts that could arise. Further they associated legalization of euthanasia with greater protection of health care professionals against threats or legal actions arising from complaints by patients and their relatives.

Extension of euthanasia to individuals who cannot make independent decisions was seen as a risk by the nurses. They were also concerned that some individuals could be pressured to accept euthanasia by their relatives, physicians or society. Moreover, hasty abandonment of treatment following the evaluation of an individual's life by another was regarded as a future risk.

According to the nurses, legalization would affect the image of their profession both positively and negatively. Stigmatization as "death angels" and conflicts within the profession were regarded as negative, but the improved ability to help suffering patients was seen as enhancing the image of nursing. Furthermore, nurses regarded such effects as transient and pointed out that, if legalized, euthanasia would be part of normal health care for future generations of nurses.

### **6.3 EUTHANASIA-RELATED ATTITUDES (ORIGINAL PUBLICATIONS II-III)**

Overall, the survey of euthanasia-related attitudes found more approval for euthanasia among the general public than among the nurses in Finland (Table 7). However, most of both groups (85.2 and 74.4%, respectively) indicated that they would accept euthanasia as part of Finnish health care. Moreover, more than nine out of ten representatives of both groups disagreed with the statement that euthanasia is reprehensible under any circumstances.

More than half of the nurses (62.1%) and general public (67.0%) agreed that Finland would benefit from a law permitting euthanasia (about 20% of representatives of both groups were undecided). In addition, slightly more (68.8 and 76.6%, respectively) agreed that legalization of euthanasia in Finland was likely in the future. Possible misconduct was regarded as a reason for forbidding euthanasia by substantial minorities of nurses (37.2%) and the general public (28.4%).

Euthanasia was regarded as a humane method to help sick persons by 80.4% of the nurses and 89.4% of the general public. Similar proportions of participants in both groups considered it likely that they would express a euthanasia request themselves in certain situations. Very similar proportions of nurses (81.9%) and the general public (90.0%) also expressed the opinion that people should have the right to decide about their own death. Roughly two thirds of nurses (66.1%) and representatives of the general public (65.0%) regarded mental and physical suffering as equal grounds for assessing a case for euthanasia.

Discussing euthanasia was considered to be easy by 58.6% of the nurses and 69.3% of the general public. A slightly higher proportion of the general public (75.4%) than nurses (69.8%) stated that they had enough information about euthanasia to participate in discussion on the topic. Around half of the participants in both groups considered that euthanasia does not provoke strong feelings in them. Furthermore, 21.3% of the general public and 28.9% of nurses agreed that they have conflicting attitudes towards euthanasia.

Table 7. Attitudes of nurses and the general public towards euthanasia

Statement	Nurses (n=1003)			General public (n=2796)		
	Disagree f (%)	Cannot say f (%)	Agree f (%)	Disagree f (%)	Cannot say f (%)	Agree f (%)
1. I have enough information about euthanasia to take part in discussion on the topic.	225 (22.4)	78 (7.8)	700 (69.8)	369 (14.2)	290 (10.4)	2108 (75.4)
2. I find it easy to discuss euthanasia.	346 (34.5)	69 (6.9)	588 (58.6)	665 (23.8)	192 (6.9)	1934 (69.3)
3. Euthanasia provokes strong reactions in me.	531 (52.9)	122 (12.2)	350 (34.9)	1436 (51.4)	363 (13.0)	995 (35.6)
4. Euthanasia is a humane method to help a sick person.	123 (12.3)	73 (7.3)	806 (80.4)	187 (6.7)	110 (3.9)	2494 (89.4)
5. A person must have the right to decide on his or her own death.	143 (14.3)	38 (3.8)	821 (81.9)	194 (6.9)	86 (3.1)	2516 (90.0)
6. I accept euthanasia as a part of Finnish health care.	165 (16.5)	91 (9.1)	745 (74.4)	251 (9.0)	162 (5.8)	2374 (85.2)
7. My attitude towards euthanasia is conflicting.	651 (65.0)	61 (6.1)	289 (28.9)	1996 (71.6)	198 (7.1)	595 (21.3)
8. Euthanasia is reprehensible under any circumstances.	907 (90.7)	32 (3.2)	61 (6.1)	2600 (93.1)	83 (3.0)	109 (3.9)
9. Finland would benefit from a law permitting euthanasia.	165 (16.5)	214 (21.4)	620 (62.1)	295 (10.6)	626 (22.4)	1868 (67.0)
10. Possible misconduct is a reason for forbidding euthanasia.	478 (47.9)	149 (14.9)	371 (37.2)	1591 (57.1)	406 (14.5)	791 (28.4)
11. I consider it likely that euthanasia will be legalized in Finland in the future.	180 (18.0)	133 (13.3)	689 (68.8)	313 (11.2)	340 (12.2)	2134 (76.6)
12. I consider it likely that I myself would make a request for euthanasia in a certain situation.	146 (14.6)	79 (7.9)	776 (77.5)	268 (9.6)	209 (7.5)	2315 (82.9)
13. When assessing suffering, mental and physical anguish are equal.	217 (21.7)	122 (12.2)	660 (66.1)	569 (20.4)	409 (14.6)	1816 (65.0)



Two significant components were obtained from the PCA, one of which was divided into two based on the content of associated statements, resulting in three components labelled: “Acceptance of euthanasia”, “Legalization of euthanasia” and “Euthanasia-related communication” (Table 8). Mean scores for each component varied between one and five, with higher scores indicating stronger agreement with the associated statements. These components, and factors influencing them are further discussed below.

Table 8. Mean scores of the euthanasia-related components

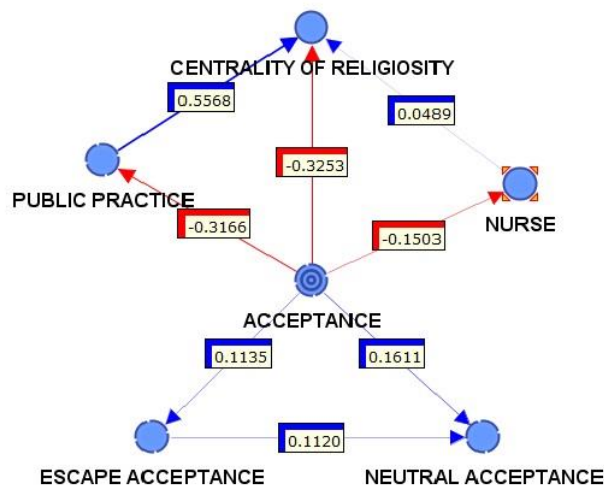
Component	Nurses		General public		p-value
	Mean	SD	Mean	SD	
Acceptance of euthanasia	4.03	1.01	4.40	0.92	>.001
Legalization of euthanasia	3.98	0.87	4.21	0.78	>.001
Euthanasia related communication	3.53	0.95	3.85	0.93	>.001

Higher score (1-5) indicates stronger agreement with the component.

### 6.3.1 Acceptance of euthanasia

Age was negatively associated with acceptance of euthanasia among nurses, while among the general public acceptance was lowest among participants under 20 or over 70 years old. In both groups higher level of religiosity indicated lower acceptance of euthanasia. Nurses who were widowed or married expressed the lowest acceptance of euthanasia, whereas single nurses were most approving. Having children or being inexperienced indicated further objection to euthanasia among nurses. Short-cycle tertiary or at least master level education was associated with lower acceptance of euthanasia than other educational levels.

A Bayesian network (BN) map of acceptance of euthanasia (Figure 5) illustrates the causal relationships of this component with 74% predictability. The BN map reveals that being a nurse influences acceptance of euthanasia negatively. The centrality of religion in one’s life and importance of public practice of religion also negatively influence euthanasia acceptance. These two factors are positively connected with each other, as are the centrality of religion and being a nurse. By contrast, neutral and escape acceptance of death positively influence individuals’ acceptance of euthanasia, and these two approaches to death are also positively connected.



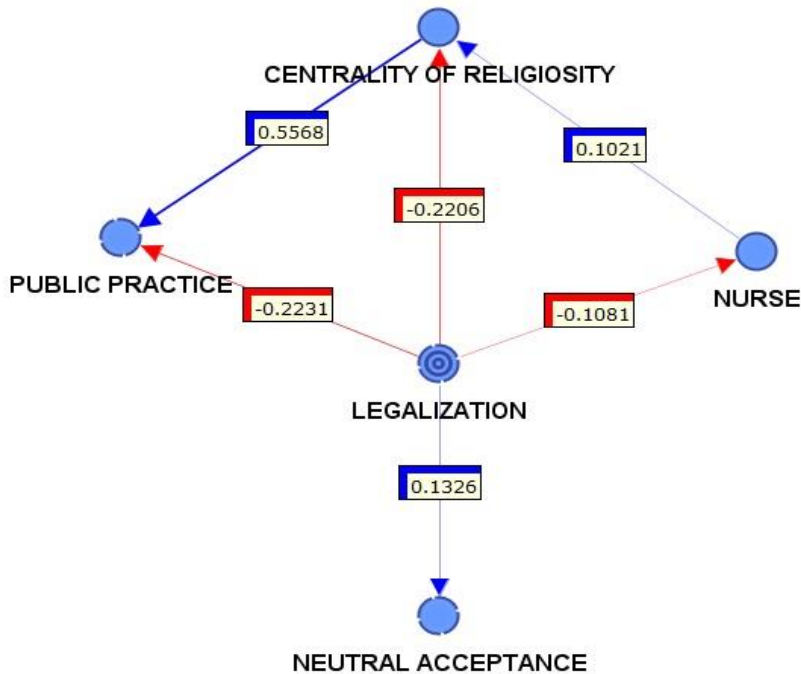
Red and blue arcs respectively indicate negative and positive correlations between the nodes. The node tags indicate Pearson’s correlation coefficients of the connections.

Figure 5. Bayesian network map of acceptance of euthanasia.

### 6.3.2 Legalization of euthanasia

Representatives of the general public aged 20 to 49 were most supportive of the legalization of euthanasia. By contrast, increasing age of a nurse indicated greater rejection of euthanasia's legalization. Representatives of the general public who did not want to state their gender expressed the greatest agreement with the legalization of euthanasia. In both groups the non-religious participants showed the most, and highly religious individuals the least, approval for euthanasia's legalization. Among nurses lower levels of education indicated greater agreement with its legalization. In addition, inexperienced or childless nurses were most likely to accept its legalization. Being widowed or married indicated the greatest objection to legalization of euthanasia among the nurses.

The BN map of legalization of euthanasia (Figure 6) reveals the causal connections of this component with 64% predictability. Neutral acceptance of death increases agreement with legalization of euthanasia. By contrast, the centrality of religion and importance of public practice of religion decrease acceptance of euthanasia's legalization. These factors are positively connected with each other. There is a further positive connection between centrality of religiosity and being a nurse, which also influences agreement with legalization of euthanasia negatively.



Red and blue arcs respectively indicate negative and positive correlations between the nodes. The node tags indicate Pearson's correlation coefficients of the connections.

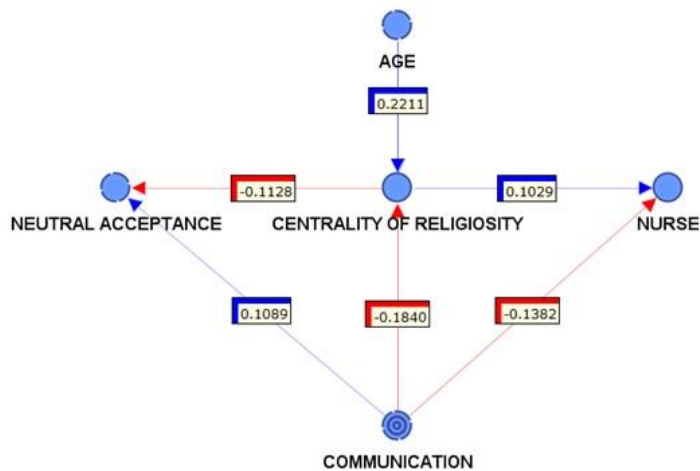
Figure 6. Bayesian network map of acceptance of legalization of euthanasia.

### 6.3.3 Euthanasia-related communication

The youngest and female representatives of the general public were least likely to support euthanasia-related communication. Being widowed indicated greater support for euthanasia-related communication among the general public, whereas among nurses the single participants were most supportive. The highly religious participants among the general public most strongly objected to euthanasia-related communication, whereas it was

most strongly opposed by the religious nurses. Having children indicated lower support for euthanasia-related communication among nurses. However, nurses who assessed their expertise in pain management or EOL care as very good were most likely to support euthanasia-related communication. Furthermore, nurses who assessed their expertise in EOL care as very weak expressed the second highest support for euthanasia-related communication.

Causal connections of support for euthanasia-related communication are presented in the BN map shown in Figure 7, which has 63% predictability. Centrality of religion in one's life influences support for it negatively. Moreover, it has a negative connection to the neutral acceptance of death, which has a positive impact on support for euthanasia-related communication. Centrality of religion is positively connected with an individual's age and being a nurse. Age has no direct influence on support for euthanasia-related communication whereas being a nurse affects it negatively.



Red and blue arcs respectively indicate negative and positive correlations between the nodes. The node tags indicate Pearson's correlation coefficients of the connections.

Figure 7. Bayesian network map of support for euthanasia-related communication.

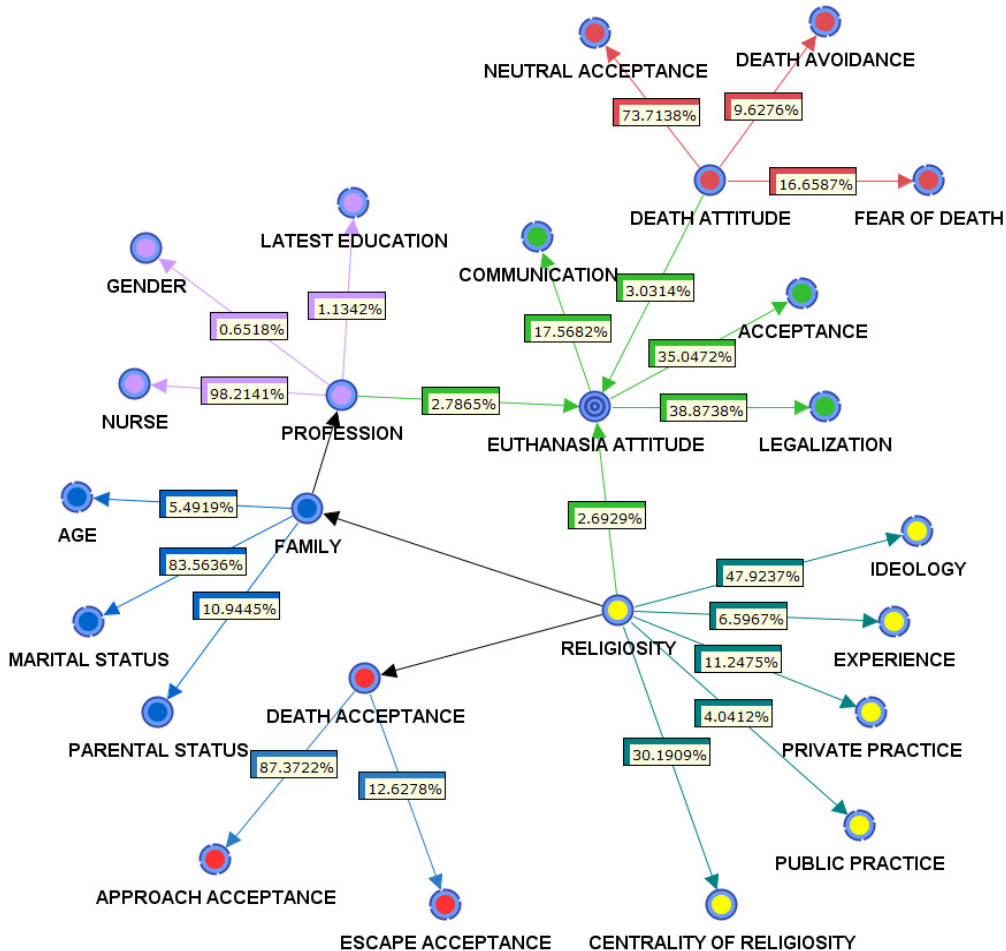
## 6.4 EMPIRICAL MODEL OF EUTHANASIA-RELATED ATTITUDES

Factor analysis of individuals' attitudes towards euthanasia resulted in an empirical model with the following six factors: *Euthanasia attitude*, *Death attitude*, *Profession*, *Religiosity*, *Family* and *Death acceptance*, indicated by 19 manifest variables (Figure 8). Three of the factors are directly connected with *Euthanasia attitude*, which is treated as the target factor in this model. Two factors have no direct connection to *Euthanasia attitude*, but have direct connection with one or more of the other factors, and thus affect individuals' attitudes towards euthanasia indirectly. Each factor is indicated by two to five manifest variables such as *age* or *Fear of death*.

The factor *Euthanasia attitude* is indicated by three manifest variables: *acceptance*, *legalization* and *communication*. Acceptance here refers to the acceptance of euthanasia, legalization to support for legalization of euthanasia and communication to support for euthanasia-related communication. Of these manifest variables legalization is the most determinant (42.5%) followed by acceptance (38.3%) and communication (19.2%).

*Death attitude* is indicated by three manifest variables: *neutral acceptance*, *death avoidance* and *fear of death*. Neutral acceptance is the most determinant (73.7%), followed by fear of death (16.7%) and death avoidance (9.6%). A further factor, *Profession*, is indicated by three manifest variables: *latest education*, *gender* and *nurse*. Nurse is the most determinant (98.2%) for this factor, followed by latest education (1.1%) and gender (0.7%). *Religiosity* is the third factor with direct connection to *Euthanasia* attitude in this model. It is indicated by five manifest variables: *ideology*, *experience*, *private practice*, *public practice* and *centrality of religion*. Of these ideology (47.9%) is the most determinant, followed by centrality of religion (30.2%), private practice (11.2%), experience (6.6%) and public practice (4.0%).

*Death acceptance* is one of the factors with no direct connection to *Euthanasia* attitude. It is indicated by *approach acceptance* and *escape acceptance*, of which the former is more determinant (87.4%) than the latter (12.6%). Death acceptance is connected with the factor religiosity. The other factor that has no direct connection with *Euthanasia attitude*, is *Family*. It is indicated by three manifest variables: *age*, *marital status* and *parental status*. The most determinant of these three is marital status (83.6%), followed by parental status (10.9%) and age (5.5%). This factor is connected with individuals' religiosity and profession.

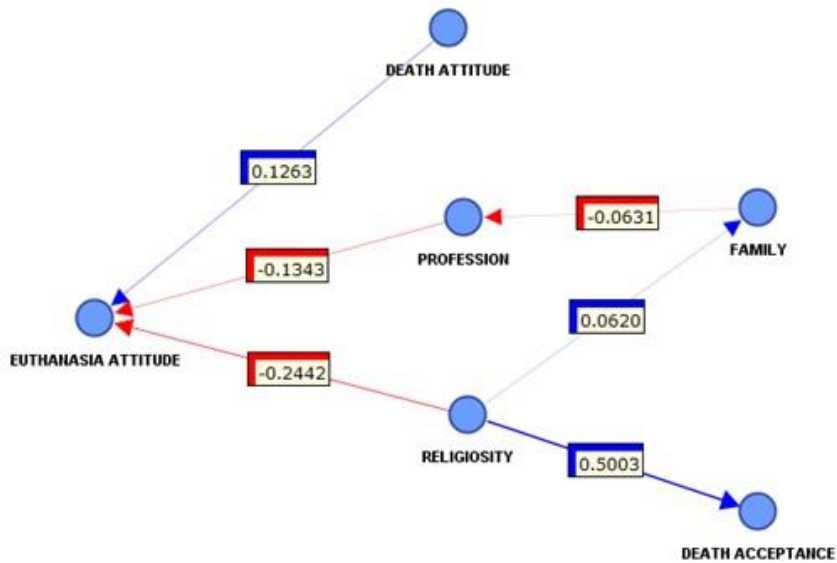


The node tags indicate the contribution of the manifest variables to the factor variable.

Figure 8. Empirical model of factors associated with individuals' attitudes towards euthanasia.

Influence path to target analysis identified two paths from *age* to target: *age* → *family* → *religiosity* → *euthanasia attitude* (score -12.99), and *age* → *family* → *profession* → *euthanasia* (score -15.39). The scores indicate how much information is lost along the paths, thus the first path through religiosity (indicating an association between age and religiosity) is stronger, but there is also clear evidence of an alternative path through profession.

The factors most strongly correlated with Euthanasia attitude (Figure 9) are religiosity (-0.20), followed by Death attitude (0.15) and Profession (-0.14). Moreover, Death acceptance (0.47) correlates positively with Religiosity. Family has a positive correlation with Religiosity (0.05) and negative correlation with Profession (-0.06).



Red and blue arcs respectively indicate negative and positive correlations between the nodes. The node tags indicate Pearson's correlation coefficients of the connections.

Figure 9. Summary of factors influencing attitudes towards euthanasia.

The correlations between manifest variables and connected factors, ranged from 0.08 (between parental status and Family) to 0.98 (between nurse and Profession). Two manifest variables, death avoidance and fear of death, correlate negatively with the factor Death attitude (Figure 10).



Table 9. Fixation table of the empirical model of individuals' acceptance of euthanasia

Model number	Predicting variables			Target variable
	Religiosity 1 = non-religious 2 = religious 3 = highly religious	Death attitude 1 = fearful 2 = neutral	Profession 1 = general public 2 = nurse	Euthanasia acceptance
1	1= 64% 2= 30% 3= 6%	1= 53% 2= 47%	1= 75% 2= 25%	No= 40% Yes= 60%
2	1= 100% 2= 0% 3= 0%	1= 52% 2= 48%	1= 76% 2= 24%	No= 33% Yes= 67%
3	1= 0% 2= 100% 3= 0%	1= 54% 2= 46%	1= 73% 2= 27%	No= 46% Yes= 54%
4	1= 0% 2= 0% 3= 100%	1= 58% 2= 42%	1= 71% 2= 29%	No= 75% Yes= 25%
5	1= 63% 2= 31% 3= 6%	1= 100% 2= 0%	1= 74% 2= 26%	No = 47% Yes = 53%
6	1= 65% 2= 30% 3= 5%	1= 0% 2= 100%	1= 76% 2= 24%	No = 32% Yes = 68%
7	1= 65% 2= 30% 3= 5%	1= 52% 2= 48%	1= 100% 2= 0%	No= 36% Yes= 64%
8	1= 61% 2= 32% 3= 7%	1= 54% 2= 46%	1= 0% 2= 100%	No= 51% Yes = 49%
9	1= 100% 2= 0% 3= 0%	1= 0% 2= 100%	1= 100% 2= 0%	No= 24% Yes= 76%
10	1= 0% 2= 0% 3= 100%	1= 100% 2= 0%	1= 0% 2= 100%	No = 86% Yes = 14%
11	1= 0% 2= 0% 3= 100%	1= 100% 2= 0%	1= 100% 2= 0%	No = 77% Yes = 23%

## 7 Discussion

In accordance with their purpose, the studies this thesis is based upon has revealed and described the attitudes towards death and euthanasia among the Finnish general public and nurses. They provide the first indications of attitudes towards these issues in Finland this millennium, and extend knowledge of these attitudes more generally, which have not been intensively studied in Finland. This is timely because euthanasia and related issues are becoming increasingly important with medical advances and demographic changes. Euthanasia has already been legalized in some countries. Possible legalization in Finland would have profound implications for both Finnish nurses and the general public. Thus, it is important to hear their voices, as expressed in the presented findings.

The studies have provided answers to all the research questions that were posed. First, the results highlight the multifaceted nature of nurses' perceptions of euthanasia, which are partly conflicting and rooted in similarly conflicting ethical principles and guidelines of the nursing profession. Moreover, the results indicate strong support for euthanasia and its legalization among both nurses and the general public, which answers the second research question. Regarding the third research question, factors traditionally associated with the issues do not adequately explain individuals' attitudes towards euthanasia, so further characterisation is recommended. Regarding the last research question, connections between death- and euthanasia-related attitudes, as well as influential factors, have been identified through development of a novel empirical model.

The empirical model emphasizes the multifaceted nature of euthanasia and provides new insights into the complex, interacting factors that influence individuals' attitudes towards both euthanasia and death. Connections between peoples' attitudes towards death and euthanasia have received little research attention (Gielen et al. 2009). Thus, in addition to potentially facilitating future research, the empirical model of factors associated with individual's attitudes towards euthanasia and death, together with the findings, addresses an important knowledge gap.

### 7.1 DISCUSSION OF THE RESULTS

The DAP-R instrument has been used in 11 studies: the quantitative study presented here and 10 previous studies (Table 2). The levels of fear of death and neutral acceptance found among the Finnish general public were the second highest and highest reported to date, respectively. Accordingly, their death avoidance was lower than previously found among social workers in the USA (Black 2005). By contrast, representatives of the general public expressed lower than previously reported levels of approach acceptance and higher levels of escape acceptance (Black 2005, Boyraz, Waits & Horne 2015, Daaleman & Dobbs 2010). Similarly, the Finnish nurses indicated lower levels of fear of death and death avoidance, as well as higher levels of neutral acceptance, than found in previous surveys of other groups (Black 2007, Braun, Gordon & Uziely 2010, Cevik & Kav 2013, Dunn, Otten & Stephens 2005, Lange, Thom & Kline 2008, Malliarou et al. 2011, Zyga et al. 2011). Moreover, the nurses expressed a higher level of escape acceptance than found in any of the previous studies, while their approach acceptance scores were the third lowest (Black 2007, Braun, Gordon & Uziely 2010, Cevik & Kav 2013, Dunn, Otten & Stephens 2005, Lange, Thom & Kline 2008, Malliarou et al. 2011, Zyga et al. 2011).

The level of individual's approach acceptance has been linked with their religiosity (Wong, Reker & Gesser 1994), thus these results may be partly explained by the relatively secular culture in Finland (Cohen et al. 2014). By contrast, levels of escape acceptance detected in the



quantitative study indicate that many Finns of both groups see death as a possibility to escape from a life that is regarded as bad (Wong, Reker & Gesser 1994). This raises questions about their perceptions of quality of life and both provided care and symptom or pain management. However, further research is required to address these questions.

A further question is whether the reported levels of death anxiety and neutral approach are consequences of individuals' alienation from death. Nowadays, 65% of people die in a health care facility in Finland (Official Statistics of Finland 2015a), in accordance with trends in other developed countries (Bloomer et al. 2013, Cohen et al. 2008). Therefore, death has become largely separated from individuals' daily lives, which may have led to its alienation, possibly masked as a fearless, neutral approach.

Most of the general public and nurses stated that they would accept euthanasia as part of Finnish health care (Table 7). Moreover, over half believed that Finland would benefit from a law permitting euthanasia, and even higher proportions believed that it will be legalized in Finland in the future. These results indicate strong support for euthanasia among the Finnish nurses and general public. However, more than 20% of nurses and representatives of the general public chose the option "Cannot say" when asked if legalization of euthanasia in Finland would be beneficial. This may be interpreted either as insecurity or concerns about the issue among the participants. Either way, these findings suggest that an open and objective dialogue about euthanasia, from different perspectives, is required in Finnish society.

Younger individuals were presumed to have more neutral attitudes towards death and to be more supportive towards euthanasia than older ones. This presumption was not entirely validated. The findings indicate that individuals aged 50 or more have the most neutral attitudes towards death, while the youngest members of both groups have the lowest levels of neutral approach. This conflicts with some previous findings (Black 2007, Dezutter et al. 2009), but is consistent with others suggesting that older nurses have a more neutral view of death than younger colleagues (Dunn, Otten & Stephens 2005, Lange, Thom & Kline 2008).

The latter has been explained by nurses' experience of caring for dying patients (Lange, Thom & Kline 2008) and death exposure (Gerow et al. 2010, Hinderer 2012). However, this explanation is not supported by findings of the quantitative study that there were no statistical significant connections between nurses' neutral approach and either their work experience or frequency of encountering dying or dead patients. Another possible explanation is that thoughts about death become increasingly frequent with increasing age, due to the experiences of loved ones (Mak 2012, Missler et al. 2011, Suhail & Akram 2002). Although these experiences are mainly associated with increases in death anxiety (Missler et al. 2011), witnessing a peaceful death may improve individuals' death acceptance (Mak 2012).

By contrast, younger nurses in the quantitative study were more prone to accept euthanasia and its legalization than the older ones, confirming some of the previous findings (Bendiane et al. 2009, Cohen et al. 2014, Köneke 2014, Mickiewicz et al. 2012, Ryyänen et al. 2002). The lack of consistent relationships and the small differences in mean scores of different age groups among the general public suggest that the significant correlations are artefacts arising from a large sample size (Field 2013). Thus, no clear conclusions about age effects in this group can be drawn.

Nurses' rejection of euthanasia usually increases with increasing work experience, and thus greater experience of caring for dying patients. The findings presented here suggest that in addition to younger nurses, inexperienced nurses agree more strongly than average with euthanasia and its legalization. However, no statistically significant connection between euthanasia-related attitudes and frequencies of encountering dying or dead patients was detected. This conflicts with previous findings that frequent contact with terminally ill patients decreases nurses' acceptance of euthanasia (Berghs, Dierckx de Casterlé & Gastmans 2005, Holt 2008, Verpoort et al. 2004).

The presumption that younger individuals have more neutral attitudes towards death and are more supportive towards euthanasia than older ones was not confirmed. However, the presented empirical model of factors associated with individual's attitudes towards euthanasia demonstrates a positive correlation between attitudes towards death and euthanasia. Furthermore, neutral acceptance is the most determinant variable in the Death attitude factor. Thus, greater neutral acceptance of death is a predictor of greater acceptance of euthanasia, regardless of the age of the individual. According to the presented model, individual's age has no direct influence on attitudes towards death. This may explain why some previous studies detected no statistically significant connection between age and euthanasia-related attitudes (Carter et al. 2007, Gielen et al. 2009, Naseh, Rafiei & Heidari 2015, Stronegger et al. 2013).

A further presumption was that females have greater fear of death and lower acceptance of euthanasia than males. Unsurprisingly, the gender-effect could not be confirmed among nurses. However, males among the general public expressed less fear of death than the females. This finding is consistent with a substantial body of previous literature, e.g. Abdel-Khalek et al. (2009), Dönmez, Yilmaz & Helvacı (2015), Ellis, Wahab & Ratnasingan (2013) and Tang et al. 2011).

A possible explanation for women's higher fear of death is their role in society. Although gender equality in Finland is very high (Ministry of Social affairs and Health 2015), women still have the main nurturing role in many families. Support for this explanation may be found in the literature regarding these aspects in other cultures (Abdel-Khalek et al. 2009, Missler et al. 2011, Russac et al. 2007). It has also been suggested that women may be more open about their emotions and more willing to admit their fears than males (Russac et al. 2007). The possible presence of such gender differences in Finnish culture cannot be excluded, and should therefore be considered as a contributory factor.

The presented findings do not verify the presumed gender effect on individuals' attitudes towards euthanasia. Among nurses no statistically significant between-gender difference in this respect was found, whereas representatives of general public who did not want to state their gender expressed the most supportive attitudes towards legalization of euthanasia. Thus, the results neither corroborate nor refute previous findings that males tend to support euthanasia more strongly than females (Bendiane et al. 2009, Cohen et al. 2014, Ryyänänen et al. 2002, Televantos et al. 2013, Turla et al. 2006).

By contrast, the results are consistent with studies that found no significant connection between participants' gender and euthanasia-related attitudes, e.g. Gielen et al. (2009), Naseh, Rafiei & Heidari (2015), Roelands et al. (2015) and Stronegger et al. (2013). However, they suggest that discussing euthanasia is easier for males than for females. Based on the presented empirical model, this may be due to males' lower fear of death, not the gender itself.

The third presumption was that religious individuals have less fear of death and acceptance of euthanasia than non-religious individuals. Interestingly, however, both the non-religious and highly religious participants expressed lower fear of death than the religious individuals. This may be associated with a certain level of insecurity or doubts that the religious participants may have about the existence of God or an afterlife. The non-religious individuals do not usually believe in either of them, whereas highly religious people are usually convinced that both exist (Ellis, Wahab & Ratnasingan 2013). Support for the latter is provided by findings regarding the approach acceptance, which indicates belief in a happy afterlife.

An association between religiosity and approach acceptance was detected, corroborating the hypothesis that non-religious individuals are likely to reject the idea of an afterlife while highly religious individuals are likely to be certain of its existence. Individuals in the intermediate category of religiosity may question the existence of an afterlife, at least to some extent, which may raise uncertainty that increases their fear of death. However, further research is needed to validate this possible explanation, therefore it should be treated

cautiously. Although a connection between approach acceptance and individuals' religiosity has been previously reported (Braun, Gordon & Uziely 2010, Daaleman & Dobbs 2010, Falkenhain & Handal 2003), it should also be noted that the concept of afterlife has various meanings, depending on individuals' culture and religion. Moreover, some of the concepts may not decrease individuals' fear of death (Ho et al. 2010, Hui & Coleman 2012).

The findings also demonstrate a negative correlation between religiosity and euthanasia-related attitudes: in both groups increasing religiosity indicated decreasing support for euthanasia. These results confirm findings of several previous studies, e.g. Cohen et al. (2014), Inghelbrecht et al. (2009a), Kranidiotis et al. (2015) and Televantos et al. (2013). However, others have found no correlation between religiosity and euthanasia-related attitudes (Kumas, Oztunc & Alparslan 2007, Naseh, Rafiei & Heidari 2015, Roelands et al. 2015, Vézina-Im et al. 2014), possibly due to difficulties in the operationalisation of religiosity (Gielen, Van den Branden & Broeckaert 2009a, Huber & Huber 2012, Vézina-Im et al. 2014). Thus, religion may only be a concrete predictor of individuals' euthanasia-related attitudes when it is divided into multiple dimensions that are separately assessed, as in the quantitative study.

The presented empirical model demonstrates the divergent associations of the considered dimensions of individuals' religiosity with their euthanasia-related attitudes. Ideology is the strongest determinant variable of the factor Religiosity in the model, indicating that a large part of individuals' religiosity depends on the strength of their belief in the existence of a transcendent reality (Huber & Huber 2012, Stark & Glock 1968). Whether this dimension can be adequately captured by simply asking individuals to state their denomination etc. is questionable (Gielen, Van den Branden & Broeckaert 2009a). However, when treated appropriately individuals' religiosity is a strong predictor of their euthanasia-related attitudes, as demonstrated by the presented empirical model.

The last presumption of the study was that nurses' assessments of their expertise in EOL care or pain management would be negatively associated with their attitudes towards euthanasia. Somewhat surprisingly no empirical support for this presumption was found. There was no statistically significant correlation between the nurses' expertise in either EOL care or pain management and the components acceptance of euthanasia or legalization of euthanasia. Furthermore, there was no statistically significant correlation between nurses' frequency of encountering dying or dead patients and their euthanasia-related attitudes.

These results conflict with a body of literature suggesting that increases in expertise in palliative medicine or frequent contact with terminally ill patients reduces nurses' support for euthanasia (Bendiane et al. 2009, Berghs, Dierckx de Casterlé & Gastmans 2005, Holt 2008, Verpoort et al. 2004, Zenz, Tryba & Zenz 2015). By contrast, both of these elements of nurses' expertise were significantly correlated with euthanasia-related communication: in both cases higher level of expertise indicated higher support for communication related to euthanasia. It should be noted that nurses who assessed their expertise in EOL care as very weak also scored highly in this component. However, the size of that group was very small, thus the relevance of this relationship is difficult to gauge.

A possible explanation for this result lies in the increasing exposure to death that inevitably accompanies the accumulation of expertise in EOL care. Nurses who are skilled in pain management, and particularly in EOL care, are also most likely to be frequently confronted with discussions regarding diverse aspects of EOL, including euthanasia-related issues. This may have influenced their attitudes in this regard. The finding warrants further consideration because communication is an important element of the key role that nurses' play in the euthanasia process (De Bal, Gastmans & Dierckx de Casterlé 2008, Denier et al. 2010, Dierckx de Casterlé et al. 2010, Francke et al. 2015), but little is known about the factors that influence nurses' attitudes towards euthanasia-related communication.

On the other hand, the presented empirical model connects individuals' attitudes towards death and their attitudes towards euthanasia (which include euthanasia-related communication). It also indicates that attitudes of both nurses and the general public are

related to their level of death avoidance and fear of death, both of which have been regarded as obstacles for EOL care and, particularly, death-related communication (Brisley & Wood 2004, Depaola et al. 2003, Neimeyer, Wittkowski & Moser 2004, Peters et al. 2013a, Zimmermann 2012). However, further research is required to determine whether or not this also applies to euthanasia-related communication.

## **7.2 DISCUSSION OF THE EMPIRICAL MODEL**

The presented empirical model of factors associated with individuals' attitudes towards euthanasia rests on a large and heterogeneous dataset, which may be seen as one of its strengths. Furthermore, the empirical model may be regarded as multifaceted. It includes traditionally recognized factors related to attitudes towards euthanasia (Original publication II) and individuals' death-related attitudes, demonstrating for the first time the influence of the latter on individuals' euthanasia-related attitudes (Gielen et al. 2009). The model also reveals factors that indirectly influence individuals' attitudes towards euthanasia, through effects on other factors included in the model.

However, it should be noted that the presented model does not include other potentially relevant factors, for example patient-related factors (e.g. the age of the patient, nature of his/her suffering and the proximity of expected death). Thus, further development of the model is required. Moreover, the model reveals that even the strongest correlation (-0.20) between individual's religiosity and euthanasia-related attitudes is rather weak (Field 2013). This also strongly indicates a need for further research about additional factors that could explain and predict individuals' attitudes towards euthanasia.

Despite the possible limitations of the presented model it provides new openings for future research. In previous studies (sections 2.2.4 and 3.2) individuals' attitudes towards euthanasia have been largely explained by individual characteristics of participants. The empirical model presented here indicates that factors related to the people making euthanasia requests and the context of the requests should be more strongly considered in future research.

Nevertheless, even in its current form the empirical model has provided information about new aspects of the phenomenon and thus deepened understanding of factors that are connected with individuals' attitudes towards euthanasia.

## **7.3 DISCUSSION OF ETHICAL ASPECTS OF EUTHANASIA**

The findings of the presented studies clearly show that the surveyed groups strongly agreed that people should have the right to make decisions about their own lives (Table 7), and hence supported respect for autonomy (Beauchamp & Childress 2012, Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010). In addition, large proportions of the participants stated that they could potentially express a euthanasia request themselves in certain situations. The qualitative study also revealed that nurses' hoped that somebody would help them in such a situation (Original publication I).

However, by definition euthanasia always involves at least two people: one who requests it and another who performs it. Furthermore, death, to which euthanasia inevitably leads, involves also societal and cultural components (Wong & Tomer 2011). It does affect an individual's environment in several ways, for example by starting the mourning process by the relatives. In addition, it has been reported that nurses find it important to "pay their last respects" to the patient, who has died on euthanasia (Dierckx de Casterlé et al. 2010). These factors may be seen emphasizing the social context of euthanasia and may rise a question of its individual nature. Although a euthanasia request needs to be based on one's free and individual will, the process itself and the outcome do impact several others and their

individual choices and actions. Thus they may be seen highlighting the concept of relational autonomy (Beauchamp & Childress 2012) that has received less attention in the debate on euthanasia as well as in the previous literature.

The possible misconduct of euthanasia was not generally regarded as sufficient reason to forbid euthanasia in the presented studies (Original publications I-III, Table 7 in the summary). Thus, little support for the slippery slope argument (Köneke 2014, Verbakel & Jaspers 2010) was found. However, interviewed nurses expressed concerns regarding the possible extension of euthanasia to elderly or vulnerable people. This concern has been raised by extension of the euthanasia law in Belgium to cover minors, which some regarded as evidence of movement towards a slippery slope (Raus 2016). It has also been suggested that abuses leading towards a slippery slope may develop over time (Beauchamp & Childress 2012). Thus, possible extensions should be considered in discussions about euthanasia, even if they seem unlikely to occur in a foreseeable timeframe. Moreover, the concept of vulnerability raises further questions, because anyone who has a terminal illness or is suffering unbearably could also be regarded as vulnerable, so the concept should perhaps be reconsidered.

The nurses interviewed in the qualitative study emphasized the value of life and questioned the right to terminate it, even at an individual's own request (Original publication I), which may be interpreted as consistent with the principle of non-maleficence and its first rule (Beauchamp & Childress 2012). In accordance with a previous study (Quaghebeur, Dierckx de Casterlé & Gastmans 2009) the interviewed nurses regarded the finality of euthanasia as a reason to oppose it. However, euthanasia was also seen as a humane method to help a sick person by most of the nurses (Original publication I, Table 7 in the summary), which may be seen as consistent with the ethical principle of beneficence (Beauchamp & Childress 2012).

The interviewed nurses expressed understanding of suffering patients' euthanasia requests, and some described feelings of helplessness and distress when confronted with patients' agony. (Original publication I). These findings support suggestions that proponents of euthanasia are likely to value the quality of life more highly than its length (Quaghebeur, Dierckx de Casterlé & Gastmans 2009, Verbakel & Jaspers 2010), and that experiences of suffering influence individuals' attitudes towards euthanasia (Hendry et al. 2013).

However, nurses' duties to protect life and alleviate suffering may be seen as sources of conflict in this matter. This is supported by findings that some participants who did not agree that euthanasia should be part of Finnish health care, disagreed with the statement that euthanasia is reprehensible under any circumstances (Table 7). This may be considered to be consistent with the statement of ETENE (2012) that euthanasia may be ethically justifiable in occasional situations.

According to the principle of justice equals should be treated equally (Beauchamp & Childress 2012), and thus (in this context) suffering individuals should be treated equally in any considerations related to euthanasia, regardless of the nature of their suffering. Interestingly, in this respect although most surveyed nurses and members of the general public in Finland agreed with the statement that mental and physical suffering should be equally treated in assessments (Table 7), more than a third either disagreed or chose the "cannot say" option. Moreover, the interviewed nurses noted evaluation of the value of an individual's life by another as one of the risks associated with legalization of euthanasia (Original publication I). However, they also questioned the validity of treating mental suffering as grounds for euthanasia (Original publication I), raising questions about the degree to which suffering individuals are seen as equal in Finnish society regardless of the nature of their agony.

Generally, although principlist ethics are commonly used in health sciences, whether they are fully applicable in situations associated with euthanasia can be questioned. The principles may be interpreted as focusing merely on the performance of euthanasia and the ethical justification of the act itself. Thus, less attention is paid to the entire process and the

contextual and inter-relational aspects that are connected with a person requesting euthanasia or individuals who are participating in the process in one way or another. However, the presented results highlight the strongly contextual nature of the whole euthanasia process, suggesting that relational ethics, for example, may be more appropriate for the ethical assessment of euthanasia

Responses of nurses included in the presented studies highlight a conflict between their professional ethical guidelines and euthanasia (Original publications I & III), which may lead to more personal conflicts for nurses. Previous literature suggests that nurses value their own philosophy of life more than the professional code of ethics in connection with euthanasia (Brzostek et al. 2008). Furthermore, it has been argued that the arguments regarding euthanasia in the ethical guidelines are not strongly supported by nurses (Berghs, Dierckx de Casterlé & Gastmans 2005). The strong support for euthanasia found in the presented studies (Table 7) indicate a need for reflection of the Ethical Guidelines of Nursing (The Finnish Nurses Association 1996) in this regard. Clearly, the professional guidelines of nurses must be in line with national legislation. However, in order to be approved by the nurses, the guidelines should reflect their values.

## 7.4 STRENGTHS AND LIMITATIONS OF THE STUDY

The quantitative study was based on a large, heterogeneous sample, recruited using a novel sampling strategy, which may be seen as one of its strengths. A limitation is the exclusion of individuals with no computer or internet connection (Khatri et al. 2015, Otieno & Matoke 2014). However, since 87% of 16-89 years old Finns reportedly use the internet (Official Statistics of Finland 2015b) and diverse channels were used to recruit participants, this limitation may be regarded as rather small. Another strength is that in order to avoid sampling bias no information about the study was published in discussion forums or social media sites that are based on religious faith or take a public stand for or against euthanasia.

The large age range (18-84 years) of participants in the quantitative study is also a strength, as it avoided possible age bias. However, 80% of the participants representing the general public were female, so there was indisputable gender bias, limiting the generalizability of findings regarding this group. Between-gender differences and representation have also been reported in previous studies regarding euthanasia, e.g. Aghababaei (2014), Louhiala et al. (2015) and Televantos et al. (2013). Furthermore, regardless of the gender distribution of social media users, the quantitative study suggests that females are more likely to participate in web-based surveys than males.

Participating members of the general public had slightly younger mean ages (males 39.3 years, females 39.7 years) than the Finnish population (males 40.9 years and females 43.6 years) according to Official Statistics of Finland (2016). However, comparison of the sample of nurses with a sample in a previous study (Ryynänen et al. 2002), randomly drawn from the national register of the Finnish Nurses Association, revealed no differences in gender distribution or mean age of the participants, strengthening the generalizability of results concerning the nurses.

This study had a cross-sectional design, which imposes limitations on the results. For example, it is impossible to assess possibilities that a detected connection between age and either death- or euthanasia-related attitudes is due to cohort-effects or the aging process *per se*. However, this is a general limitation of all cross-sectional studies.

The validity and reliability of the designed questionnaire were tested prior to the data collection, as described in section 5.2.2. Scores for three of the euthanasia-related statements in the test-retest study were below 0.5, indicating only moderate correlation (Field 2013). However, euthanasia is a topic that provokes strong feelings (Ryynänen et al. 2002). Thus, participation in the test-retest study may have initiated a deep thought process that affected some participants' answers in the second round. It should also be noted that participants in

the quantitative study were asked to state their latest rather than highest level of education. This may have influenced detected connections between educational level and both death- and euthanasia-related attitudes. Although this limitation is genuine, its practical relevance was estimated to be minor.

A further limitation is that some relevant articles may not have been identified in the literature review, although it was very rigorous, due to the large numbers of titles retrieved in the searches.

A further major strength is that several concerns raised regarding previous studies were addressed. Notably, interpretation of the results of some studies has been hindered by ambiguity in the definition of euthanasia (Gamliel 2013, Hagelin et al. 2004, Holt 2008, Johansen et al. 2005), thus it was unambiguously defined in both of the presented studies and the designed questionnaire. Furthermore, BN modelling was applied as one of several analytical methods to meet calls for more powerful statistical analyses (Vézina-Im et al. 2014). In addition, the CRS instrument was employed to incorporate multiple dimensions of religiosity to address concerns regarding the operationalisation of religiosity in previous studies (Gielen, Van den Branden & Broeckaert 2009a).

The results highlight the complexity of issues and attitudes related to both death and euthanasia, which can be seen as a further strength of the studies. However, the need for further development of the model and the questionnaire used is acknowledged.

## **7.5 SUGGESTIONS FOR FURTHER RESEARCH**

Based on the results of the studies the following suggestions are made for future research:

1. Further elaboration of individuals' attitudes towards death and euthanasia from perspectives of relational ethics using both qualitative and quantitative methods;
2. Investigation of how education regarding death impacts nurses' and nursing students' attitudes towards death and euthanasia;
3. International comparison of the attitudes of nurses and the general public towards death and euthanasia;
4. Further development and validation of the designed questionnaire in national and international contexts;
5. Further development and validation of the empirical model of factors associated with individuals' attitudes towards euthanasia.

## 8 Conclusions

The studies this thesis is based upon have provided new knowledge about attitudes towards death and euthanasia of nurses and the general public in Finland. In addition, a new empirical model of factors associated with individuals' attitudes towards euthanasia has been developed and Bayesian network modelling has been employed for the first time in nursing science to model individual's attitudes. The following conclusions can be drawn from the results.

1. Nurses and the general public in Finland would accept euthanasia as part of Finnish health care. Furthermore, they believe that Finland would benefit from legislation permitting euthanasia. Thus an open and objective dialogue about the themes in all levels of the Finnish society is crucial.
2. Attitudes of nurses and the general public in Finland towards death and euthanasia are complex. Factors included in the traditional model fail to explain individuals' attitudes towards euthanasia, strongly indicating a need for further characterisation of the factors that influence people's euthanasia-related attitudes.
3. The presented empirical model of factors associated with individuals' attitudes towards euthanasia revealed death-related attitudes, profession and religiosity to be predictors of individuals' attitudes towards euthanasia. However, in order for religiosity to be a true predictor of attitudes, different dimensions of religiosity must be taken into account.
4. Nurses' expertise in pain management and EOL care influence their attitudes towards death and the quality of provided care. Therefore, more information and education on death-related themes should be offered to nurses and nursing students.
5. Nurses' attitudes conflict with their professional ethical guidelines, which may cause personal and professional conflicts, and lead to avoidance of euthanasia-related themes and discussions. Thus constant, open dialog about values prevailing within the nursing profession and among nurses themselves is crucial.



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## ANJA TERKAMO-MOISIO

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*This thesis explores the attitudes of nurses and the general public towards death and euthanasia in Finland. An empirical model of factors associated with the attitudes of individuals towards euthanasia was developed based on the results. The results revealed rather neutral attitudes towards death among both groups. By contrast, favourable attitudes towards euthanasia were found in both target groups. It is thus crucial to maintain open dialogue about death and euthanasia at all levels of the society. Attitudes towards death and euthanasia also require further characterization.*



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