

REETTA PIILI

# End-of-Life Decision-Making in Cancer Patients

*Attitudes, ethics and background factors among  
Finnish physicians and medical students*



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ACADEMIC DISSERTATION

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of Tampere University,  
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# ACADEMIC DISSERTATION

Tampere University, Faculty of Medicine and Health Technology  
Finland

<i>Responsible supervisor and Custos</i>	Professor Emerita Pirkko-Liisa Kellokumpu-Lehtinen Tampere University Finland	
<i>Supervisor</i>	Docent Juho Lehto Tampere University Finland	
<i>Pre-examiners</i>	Docent Ritva Halila University of Helsinki Finland	Docent Sakari Karjalainen Tampere University Finland
<i>Opponent</i>	Docent Liisa Pylkkänen University of Turku Finland	

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*Life is short, and Art long; the crisis fleeting; experience perilous, and decision difficult.*

Hippocrates



# ABSTRACT

Appropriate and well-timed decision-making is mandatory to change the goal of care from life-prolonging therapies to high-quality end-of-life (EOL) care in order to prevent non-beneficial treatments and relieve suffering. The decisions include, but are not limited to, statements on cardiopulmonary resuscitation, parenteral fluids, and diagnostic tests. This decision-making is a challenging process as physicians have to strike a balance between the wishes of the patient and family, legal and ethical aspects, and the potential benefits, harms and costs of care. Decision-making should be based on similar principles in the same types of clinical situations regardless of the specialty, experience or attitudes of the physician who is responsible for the care of the patient. Therefore, all physicians should have the skills to recognize the need for palliative care and approaching death.

Concurrently with the growing status of palliative care, discussions about the ethical justification of hastened death due to unbearable suffering have been ongoing for many years around the world. Public support for euthanasia and physician-assisted suicide is mounting all over Western Europe. This changing atmosphere may modify the practices and ethics of EOL decision-making.

This study was conducted to examine the decision-making and attitudes of physicians and medical students regarding the EOL care of cancer patients, and whether there have been changes in these issues over the past sixteen years.

A questionnaire including seven hypothetical patient scenarios was sent to 1 182 and 1 327 Finnish physicians in 1999 and 2015, respectively. In addition, the questionnaire was offered to all graduating Finnish medical students (n=639) during their last year of medical school in 2015-2016. For this thesis five of the cancer patient scenarios were included. The first scenario presented an 82-year-old prostate cancer patient with bone metastases and a deteriorating overall condition. Responders were asked to choose a palliative, active or intensive care approach. The second patient scenario presented a 68-year-old breast cancer patient with bone metastases wishing a voucher for hospice. The responders' willingness to issue a voucher was evaluated. The third scenario presented a 60-year-old prostate cancer patient with metastases and paraparesis, who asked for doubling his morphine dose which might lead to a hastened death. The responders' acceptance for increasing the

morphine dose was investigated. The fourth patient scenario presented a 32-year-old female with an inoperable, late-stage brain cancer having a cardiac arrest. The responders were asked whether they would resuscitate the patient or not. The fifth scenario presented a 62-year-old male patient with a metastatic end-stage lung cancer. The responders' willingness to withhold or withdraw different treatment options were questioned. The attitudes, values and background factors of the responders were also enquired and taken into account.

In total, 1 763 valid responses were received, giving an overall response rate of 56%. Decision-making was influenced by the year of the survey (1999 vs 2015), by whether the physician had special competency in palliative medicine (cPM) or not and by the clinical experience of the responder. The physicians with cPM chose less aggressive options in EOL care, although the impact of cPM on decision-making varied among treatments. The graduating medical students were more unwilling to withhold and withdraw therapies suggested to be futile in EOL care than were the experienced general practitioners (GPs), but there was no difference between the students and the GPs when choosing a palliative care approach in EOL situations or in the willingness to issue a voucher for hospice. In 2015, the physicians accepted the risk of hastened death with increasing morphine dose more frequently than in 1999. The experienced GPs were more willing to accept the risk of hastened death compared to the medical students, even though the students considered euthanasia and assisted suicide less reprehensible than the GPs. Physicians' decisions to choose palliative care approaches significantly increased from 1999 to 2015. When making this decision, the physicians answering in 2015 were more influenced by the patient's benefit and less influenced by the family's benefit than in 1999. Physicians were also more willing to issue a voucher for hospice in 2015. Physicians' attitudes and values influencing EOL decision-making have changed over the past sixteen years; for example, euthanasia was considered to be less reprehensible and religion less influential in 2015 than in 1999.

The changing public atmosphere, advances in medicine, growing knowledge of the benefits of palliative care and education in palliative medicine might have significant influence on the essential decision-making in EOL care, although the impact of these aspects has not yet been investigated. Based on the results of this thesis, the attitudes, education and experience of a physician seem to play an important part in their EOL decision-making. To ensure that all patients receive equal and high-quality EOL care, education in EOL decision-making, including ethical and juridical aspects, should be mandatory for all medical students and physicians in specialty training.



# TIIVISTELMÄ

Asianmukainen ja oikea-aikainen päätös muuttaa hoidon tavoite elämää pitkittävästä hoidosta korkealaatuiseen saattohoitoon on tärkeää hyödyttömien hoitojen välttämiseksi ja kärsimyksen lievittämiseksi. Näihin päätöksiin sisältyy esimerkiksi kannanotot elvytyksestä, suonensisäisestä nesteytyksestä ja diagnostisista tutkimuksista. Päätöksenteossa lääkärit joutuvat huomioimaan potilaan ja läheisten toiveet, lainsäädännön ja eettiset näkökulmat sekä arvioimaan hoitojen hyötyjä, haittoja ja kustannuksia. Päätöksenteon pitäisi olla yhdenmukaista samanlaisissa kliinisissä tilanteissa ja palliatiivisen hoidon tarve tulisi tunnistaa riippumatta hoitovastuussa olevan lääkärin erikoisalasta tai kokemuksesta.

Samanaikaisesti palliatiivisen hoidon aseman paranemisen kanssa eutanasian ja avustetun itsemurhan kannatus on nousussa läntisessä Euroopassa. Tämä muuttuva ympäristö saattaa muokata vallitsevia elämän loppuvaiheen päätöksenteon käytänteitä ja etiikkaa.

Tämän tutkimuksen tavoitteena oli tutkia lääkäreiden ja lääketieteen opiskelijoiden elämän loppuvaiheen päätöksentekoa ja suhtautumista syöpäpotilaiden elämän loppuvaiheen hoitoon sekä näissä mahdollisesti tapahtuneita muutoksia edeltävien kuudentoista vuoden aikana.

Seitsemän hypoteettista potilastapausta sisältänyt kysely lähetettiin 1 182 ja 1 327 suomalaiselle lääkärille vuosina 1999 ja 2015 sekä jaettiin valmistuville lääketieteen opiskelijoille (n=639) vuosina 2015-2016. Tähän väitöskirjatutkimukseen sisällytettiin viisi syöpäpotilastapausta. Ensimmäinen potilastapaus oli luustoon levinnyttä eturauhassyöpää sairastava 82-vuotias mies, jonka yleisvointi on nopeasti heikentynyt. Vastaaajia pyydettiin valitsemaan joko palliatiivinen hoito, aktiivinen hoito tai tehohoito. Toinen potilastapaus oli luustoon levinnyttä rintasyöpää sairastava 68-vuotias nainen, joka on hoidossa terveyskeskuksen vuodeosastolla ja toivoo pääsyä saattohoitokotiin. Vastaaajilta kysyttiin halukkuutta myöntää maksusitoumus hoitokotiin. Kolmas potilastapaus oli 60-vuotias mies, jolla on luustoon levinneen eturauhassyövän aiheuttama alaraajahalvaus. Hän pyytää nostamaan morfiiniannoksensa tasolle, jonka arvellaan jouduttavan potilaan kuolemaa. Vastaaajilta kysyttiin, hyväksyisivätkö he morfiiniannoksen noston. Neljäs potilastapaus oli 32-vuotias nainen, jolla on leikkaushoidon ulkopuolella oleva,

pitkälle edennyt aivokasvain. Hän menee elottomaksi päivystyksessä ja vastaajilta kysyttiin, aloittaisivatko he elvytyksen vai eivätkö. Viides potilastapaus oli 62-vuotias mies, jolla on loppuvaiheen levinnyt keuhkosityöpä. Hänen kohdallaan vastaajia pyydettiin arvioimaan, kuinka todennäköisesti he lopettaisivat tai eivät aloittaisi eri hoitovaihtoehtoja. Lisäksi kysyttiin vastaajien mielipiteitä, arvoja ja taustatietoja.

Kyselyyn saatiin yhteensä 1 763 vastausta ja kokonaisvastausprosentti oli 56. Päätöksentekoon vaikutti merkittävästi kyselyyn vastaamisen vuosi, lääkärin palliatiivisen lääketieteen erityispätevyys ja vastaajan kliininen kokemus. Lääkärit, joilla oli palliatiivisen lääketieteen erityispätevyys, tekivät vähemmän hoidollisesti aggressiivisia päätöksiä elämän loppuvaiheessa, mutta erityispätevyyden ja erikoisalan vaikutus päätökseen vaihteli hoidosta riippuen. Valmistuvat lääketieteen opiskelijat olivat haluttomampia lopettamaan ja olemaan aloittamatta hyödyttömiksi ajateltuja hoitoja elämän loppuvaiheessa verrattuna kokeneisiin yleislääkäreihin, mutta palliatiivisen hoidon valinnassa tai maksusitoumuksen myöntämisessä saattohoitokotiin ei ollut eroa. Vuonna 2015 lääkärit valitsivat palliatiivisen hoidon useammin kuin aktiivisen tai tehohoidon. Tätä päätöstä tehdessään heihin vaikutti vuonna 2015 enemmän potilaan etu ja vähemmän perheen etu kuin vuonna 1999. Lääkärit myös myönsivät maksusitoumuksen saattohoitokotiin useammin vuonna 2015 kuin 1999. Vuonna 2015 lääkärit olivat valmiimpia hyväksymään mahdollisen kuoleman jouduttamisen morfiiniannosta nostamalla kuin vuonna 1999. Lisäksi kokeneet yleislääkärit olivat valmiimpia hyväksymään mahdollisen kuoleman jouduttamisen morfiiniannosta nostamalla kuin lääketieteen opiskelijat, vaikka opiskelijat pitivät eutanasiaa ja avustettua itsemurhaa vähemmän tuomittavina kuin nämä kokeneet yleislääkärit. Lääkäreiden mielipiteet ja arvot, jotka vaikuttavat elämän loppuvaiheen päätöksentekoon ovat muuttuneet kuudentoista vuoden aikana. Esimerkiksi eutanasiaa pidettiin vähemmän tuomittavana ja uskontoa vähemmän päätöksiin vaikuttavana vuonna 2015 kuin 1999.

Muuttuvat yleiset mielipiteet, lääketieteen kehitys, kasvava ymmärrys palliatiivisen hoidon hyödyistä ja palliatiivisen lääketieteen koulutus vaikuttanevat elämän loppuvaiheen päätöksentekoon, vaikka aiempi tutkimustieto tästä on ollut vähäistä. Tämän tutkimuksen perusteella lääkärin kokemus, asenteet ja koulutus näyttävät vaikuttavan merkittävästi elämän loppuvaiheen päätöksentekoon, vaikka tämä vaihtelee merkittävästi riippuen kliinisestä tilanteesta ja eettisistä näkökulmista. Jotta yhdenmukainen ja korkealaatuinen saattohoito voitaisiin taata kaikille potilaille, elämän loppuvaiheen päätöksenteon opetuksen, joka sisältää myös eettiset ja juridiset näkökohdat, pitäisi kuulua pakollisena lääketieteen perusopetukseen sekä lääkärin erikoistumiskoulutukseen.

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# ABBREVIATIONS

ACP	Advance Care Planning
AD	Advance Directive
CI	Confidence Interval (95% if not stated otherwise)
cPM	Special competency in Palliative Medicine
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DNR	Do Not Resuscitate
CRP	Cardio-Pulmonary Resuscitation
DVD	Digital Video Disc
EAPC	European Association for Palliative Care
EOL	End-of-Life
ETENE	National Advisory Board on Social Welfare and Health Care Ethics
GI	Gastrointestinal
GP	General Practitioner
ICU	Intensive Care Unit
IAHCP	International Association for Hospice and Palliative Care
IQR	Inter Quartile Range
LST	Life-Sustaining Treatment
OR	Odds Ratio
PAS	Physician-Assisted Suicide
PM	Palliative Medicine
VALVIRA	National Supervisory Authority for Welfare and Health
VAS	Visual Analogue Scale
WHO	World Health Organization
WMA	World Medical Association





## ORIGINAL PUBLICATIONS

- Publication I Piili RP, Lehto JT, Luukkaala T, Hinkka H, Kellokumpu-Lehtinen PL. Does special education in palliative medicine make a difference in end-of-life decision-making? *BMC Palliat Care*. 2018 Jul 18;17(1):94.
- Publication II Piili RP, Metsänoja R, Hinkka H, Kellokumpu-Lehtinen PL, Lehto JT. Changes in attitudes towards hastened death among Finnish physicians over the past sixteen years. *BMC Med Ethics*. 2018 May 30;19(1):40.
- Publication III Piili RP, Lehto JT, Metsänoja R, Hinkka H, Kellokumpu-Lehtinen PL. Has there been a change in the end-of-life decision-making over the past 16 years? *BMJ Support Palliat Care*. 2019 Aug 8. pii: bmjspcare-2019-001802. doi: 10.1136/bmjspcare-2019-001802. [Epub ahead of print].
- Publication IV Alminoja A, Piili R, Hinkka H, Metsänoja R, Hirvonen O, Tyynelä-Korhonen K, Kaleva-Kerola J, Saarto T, Kellokumpu-Lehtinen PL, Lehto JT. Does decision-making in end-of-life care differ between graduating medical students and experienced physicians? *In Vivo*. 2019 May-Jun;33(3):903-909.



# 1 INTRODUCTION

The World Health Organization (WHO) has defined that palliative care aims to improve patients' and their families' quality of life when they are facing life-threatening illness<sup>1</sup>. Palliative care intends neither to hasten nor postpone death<sup>1</sup>. Approximately 20 million people worldwide are annually in need of palliative care at their end-of-life (EOL)<sup>2</sup>. This demand is highest in Europe due to the ageing population and the increase of noncommunicable diseases<sup>2</sup>.

Well-timed palliative care improves patient quality of life and symptom control, reduces invasive procedures and costs, and might even improve survival<sup>3-11</sup>. Although the awareness of the benefits of high-quality palliative care is rising, the use of non-beneficial and even futile treatments is common in EOL care<sup>12</sup>. In recent years, medical developments have led to increased possibilities to prolong life in patients suffering from very advanced diseases<sup>13</sup>. However, attempts to prolong life at any cost may be futile and done at the expense of quality of life<sup>14</sup>. This complexity makes it even more challenging to choose worthwhile therapies for each patient especially in EOL care.

Appropriate decision-making is mandatory in high-quality EOL care to prevent non-beneficial treatments, to relieve suffering and to utilize resources to the most valuable treatment modalities. Decisions include, but are not limited to, statements on cardiopulmonary resuscitation, parenteral fluids, and diagnostic tests. Decision-making in EOL care is a challenging process involving many ethical, legal, medical and psychological aspects<sup>15-22</sup>. The background characteristics, specialties, attitudes and values of physicians all play a part in this complex process<sup>16-18,23-26</sup>. The education and experience of a physician also influences the decision-making in EOL care<sup>27-32</sup>. Although newly graduated physicians often feel unprepared for providing EOL care, they face the complexity of the decision-making process just as the senior physicians do<sup>27,28,30</sup>. Nevertheless, decision-making should be consistent in the same types of clinical situations in EOL care regardless of the physician who is responsible for the care of the patient.

Most patients wish for their closest loved ones to be involved in the decision-making and, therefore, discussions with family members are essential<sup>33-35</sup>. Physicians'

decision-making is influenced by families' opinions, although discordance between a patient's wishes, the caregiver's preferences and the caregiver's predictions of the patient's preferences may exist<sup>18,35-38</sup>. Advance directives reinforces patient participation and commonly make decision-making easier<sup>17,18,36,37,39</sup>. However, concerns have been raised as to whether advance directives genuinely express a patient's own will, and there is variation on how advance directives are understood and taken into account in clinical practice<sup>5,40,41</sup>.

When taking care of dying patients, physicians are forced to make decisions regarding forgoing different therapies. In EOL decision-making, withdrawing and withholding treatments are generally considered ethically and legally equivalent, but medical professionals feel that withdrawing treatment is more difficult and ethically more problematic than withholding it<sup>13,42-46</sup>. Studies also show that decisions to withdraw are taken less frequently than decisions to withhold<sup>42-46</sup>. In addition, these decisions vary between different therapies or treatments<sup>47,48</sup>. For example, intravenous hydration is often continued in EOL care whereas antibiotics are more frequently discontinued<sup>47,48</sup>.

Today, shared decision-making and patient-centred care are preferred by most physicians and patients; this might reflect the changing atmosphere due to the rise of individualism, autonomy and human dignity in western countries<sup>49-57</sup>. At the same time, concerns have been raised about the excessive autonomy of patients, which can result in costly, ineffective and even futile treatments<sup>58</sup>. The 1948 Universal Declaration of Human Rights made by the United Nations General Assembly sets a basis for patient rights<sup>59</sup>. After this declaration, several countries, including Finland, ratified international conventions in which human and patient rights were prominent<sup>52,53,56,57</sup>. The right of the patient to be involved in treatment decisions was included in Finnish law in 1992<sup>60</sup>. In the United States the Patient Self-Determination Act was passed by the US congress only two years earlier<sup>61</sup>. Respecting the wishes of a patient is also one of the fundamental principles in the ethical guidelines of the Finnish Medical Association<sup>62</sup>. However, the Finnish National Supervisory Authority for Welfare and Health (VALVIRA) has stated that ineffective or futile therapies should not be used even though the patient requests them<sup>63</sup>.

Discussions about the ethical justification of hastened death due to unbearable suffering have been ongoing for many years around the world. Thus far, assisted dying through euthanasia or physician-assisted suicide (PAS) has been legalized in seven countries (and in five states in the United States of America)<sup>64</sup>. In addition, public support for euthanasia and PAS is mounting across Western Europe, while

some decline has been observed in the USA and Eastern Europe<sup>64</sup>. Hastening death in end-of-life care is even more complex and ethically ambivalent than euthanasia and physician-assisted suicide. Withdrawing life-sustaining treatments (LSTs), euthanasia and physician-assisted suicide are sometimes mixed up among the public and physicians alike; for example, terminating life-sustaining treatment is sometimes considered to be euthanasia<sup>65</sup>. Further, the term ‘double effect’ has been used when the ethics of hastening death are discussed. It applies to situations in which an act intended to do good turns to a foreseeable danger of harm or risk of death<sup>66</sup>.

There is a gap of knowledge on how the changing public atmosphere, advances in medicine, growing knowledge of the benefits of palliative care and education in palliative medicine influence the essential decision-making in EOL care. In this study, a cross-sectional survey with a questionnaire including hypothetical and ethically complex patient scenarios was used to evaluate the decision-making of physicians and medical students regarding the EOL care of cancer patients and the factors influencing this decision-making.

## 2 REVIEW OF THE LITERATURE

### 2.1 Palliative care and end-of-life care

#### 2.1.1 Definitions of palliative care and end-of-life care

Palliative care and end-of-life care have evolved from the hospice movement started in 1960's by Dame Cicely Saunders in England<sup>13,67</sup>. Terminology around hospice care, terminal care, supportive care, palliative care and end-of-life (EOL) care has changed over the past decades<sup>68,69</sup>. Currently, the term palliative care has an established status and it is defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>1</sup>. Although this clear definition from WHO is widely accepted, different definitions with slight variations between the content exist. For example, a review from 2012 and another from 2013 found 16 and 24 different definitions of palliative care, respectively<sup>68,70</sup>. The most commonly used definitions are summarized in Table 1. In spite of the well-established status of palliative care, a lack of awareness and misperceptions are common. In a recent study from the USA, only 27% of community-dwelling adults were able to define palliative care, and of those, only 26% mentioned that it provided symptom management to patients; more than 50% had misperceptions, for example, that palliative care is only for the elderly and is applicable only at the end-of-life<sup>71</sup>.

**Table 1.** Different definitions for palliative care.

The World Health Organization <sup>1</sup>	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
The European Association for Palliative Care <sup>72</sup>	Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.
The International Association for Hospice and Palliative Care <sup>73</sup>	Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life.
The American Society of Clinical Oncology <sup>74</sup>	The integration into cancer care of therapies that address the multiple issues that cause suffering for patients and their families and impact their life quality.
The American Academy of Hospice and Palliative Medicine <sup>75</sup>	Palliative care focuses on improving a patient's quality of life by managing pain and other distressing symptoms of a serious illness. Palliative care should be provided along with other medical treatments.
The National Comprehensive Cancer Network <sup>76</sup>	Both a philosophy of care and an organized highly structured system for delivering care to persons with life-threatening or debilitating illness. Palliative care is patient and family centered care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures.
The National Supervisory Authority for Welfare and Health (Valvira) <sup>77</sup>	Palliatiivinen eli oireenmukainen hoito on kuolemaan johtavan tai henkeä uhkaavan sairautta sairastavan potilaan ja hänen läheistensä aktiivista kokonaisvaltaista hoitoa, jolla pyritään ehkäisemään ja lievittämään kärsimystä ja vaalimaan elämänlaatua.

As well as the use of the term palliative care, the use of the term EOL care has increased in recent years<sup>68</sup>. However, there is no exact definition of EOL, probably because of the difficulty of prognostication of the illness trajectory<sup>69</sup>. The USA National Institutes of Health suggests, based on evidence, the following components of EOL: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist, but may also fluctuate; and (2) symptoms or impairments resulting from the underlying irreversible disease requiring formal (paid, professional) or informal (unpaid) care and can lead to death<sup>69</sup>. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of EOL.<sup>69</sup> The European Association for Palliative Care (EAPC) stated in 2009 that EOL care may be used synonymously with palliative care or hospice care if the end of life is

understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of the illness<sup>72</sup>. In addition, according to EAPC, it also may be understood more specifically as the comprehensive care for dying patients in the last few hours or days of life<sup>72</sup>. In contrast to the long time period set by the EAPC, in a review by Hui et al., one of the key features defining end-of-life was an expected survival time presented in terms of months or less<sup>78</sup>. This wide range of timeframe makes the use of the term EOL challenging in scientific literature; therefore, a more detailed definition is called for.

In Finland, the definition of palliative care, as “palliatiivinen hoito” in Finnish, is adapted from the definition of WHO (Palliatiivisella hoidolla tarkoitetaan parantumattomasti sairaan tai henkeä uhkaavaa sairautta sairastavan potilaan ja hänen läheistensä aktiivista kokonaisvaltaista hoitoa. Palliatiivisen hoidon tarkoituksena on vaalia elämänlaatua ja ehkäistä ja lievittää kärsimystä. Kärsimyksellä tarkoitetaan niin fyysistä, psykososiaalista kuin eksistentiaalista kärsimystä.)<sup>77,79</sup>. The term end-of-life care is translated as “saattohoito”<sup>79,80</sup>. “Saattohoito” in Finland is defined as part of palliative care occurring close to a patient’s death (last weeks or days)<sup>80,81</sup>.

Compared to the terms palliative and EOL care the previously used term terminal care (“terminaalihoito”) is considered to be old fashioned and inappropriate<sup>72</sup>. Nevertheless, it is still occasionally used by physicians together with the term terminally ill, which is described most often as life-limiting disease with irreversible decline and a survival of less than six months<sup>78</sup>.

## 2.1.2 Practices in palliative care

### 2.1.2.1 Globally

Symptom control has been an essential and crucial part of medicine since the very beginning of the profession, as it was stated in the Oath of Hippocrates: “I will use treatment to help the sick according to my ability and judgement”. However, the modern history of palliative care started in the UK, where the first hospices were opened over a century ago<sup>13,67</sup>. The palliative care and hospice movement rose in the 1960s through the work of Dame Cicely Saunders<sup>13,67</sup>. The number of hospices increased around the western world, and hospital palliative care teams began to form in the late 1970s<sup>13,67</sup>. Further, the EAPC was established in 1988 in Milan, Italy and



the International Association for Hospice and Palliative Care (IAHCP) was established in the mid 1990s in the US<sup>13,67</sup>. Today, WHO considers palliative care to be a human right, but only 20 countries globally (9%) have achieved the advanced integration of palliative care within the wider health services, which is characterized by the following: the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities and society in general; unrestricted availability of morphine and all other strong pain-relieving medicines; substantial impact of palliative care upon policy, in particular upon public health policy; the development of recognized education centres; academic links forged with universities; and the existence of a national palliative care association<sup>2</sup>. In 2011, 136 of the world's 234 countries (58%) had one or more hospices or other palliative care services established<sup>2</sup>.

Palliative care should be applicable already in the early course of illness; it is no longer thought to be an option for other treatment modalities, but rather a parallel model of care<sup>1,13,82</sup>. There are numerous ways of delivering specialized palliative care including inpatient palliative care units, inpatient hospices and palliative care consultant teams in hospitals, home care, palliative outpatient services, day care and short-term integrated palliative care<sup>13</sup>. The idea is to operate across all of the settings where patients and their families need support<sup>13</sup>. The way of delivering these services depends largely on the country in question, but some principles and values are common such as a holistic and multidisciplinary approach based on a need<sup>13,82</sup>. A recent review from 2017 concluded that a wide range of different models of providing palliative care are used, but comparing them is difficult mainly because of under-reporting of the components that are included in the interventions and comparator models<sup>83</sup>. However, different models appear to show benefits and can even reduce total healthcare costs<sup>83</sup>. WHO has calculated that approximately 377 adults out of 100 000 will require palliative care at the end-of-life<sup>2,82</sup>.

### 2.1.2.2 Finland

In Finland, the first steps towards palliative care were the publication of guidelines for terminal care by the National Health board in 1982 and the founding of the first hospice in 1988 in Tampere<sup>84</sup>. Today there are four hospices, specialist palliative care units in all five university hospitals and a national guideline for palliative and EOL care (updated in 2018)<sup>80,85</sup>. The Ministry of Social Affairs and Health has recently

published recommendations for providing palliative and EOL care in Finland<sup>79</sup>. In these recommendations, it is stated that palliative care should be equally available to all citizens based on their need<sup>79</sup>. Although specialized palliative care services are needed, the vast majority of dying patients in Finland are cared for by general practitioners (GPs) in wards of the community hospitals, at home or in nursing homes.

In Finland there are two associations that work to promote palliative medicine and care. The Finnish Association for Palliative Medicine (Suomen palliatiivisen lääketieteen yhdistys) founded in 2003 aims to promote physicians' knowledge and education of palliative medicine<sup>86</sup>. The Finnish Association for Palliative Care (Suomen Palliatiivisen Hoidon Yhdistys ry) established in 1995 aims to develop the multi-professional care of people with an incurable disease, as well as terminally ill patients<sup>87</sup>.

### 2.1.3 Ethics in palliative care

The word ethics comes from a Greek word *ēthikós* meaning "relating to one's character". Ethics is a sub-branch of philosophy that examines rights and wrongs and seeks to understand how human beings should behave<sup>88</sup>. Many of the ethical issues that arise in palliative care are similar to issues that also arise in other areas of health care, such as the four main principles: non-maleficence (do no harm), beneficence (doing good), autonomy (the right of self-determination), justice (e.g. appropriate use and allocation of health care resources), as well as truth telling and confidentiality, decision-making authority in the professional–patient relationship, the conduct of research and the focus on ethical responsibility when care is provided by a team<sup>13,15,88,89</sup>. Other ethical issues are more commonly associated with EOL care, such as decision-making for incompetent patients, withholding and withdrawing life sustaining treatments (LSTs), and hastening death<sup>13,88</sup>. Respecting life can be considered as one of the fundamental principles of medicine<sup>62,81,88,90</sup>. This may, however, create an ethical paradigm in EOL care, if interpreted as a synonym for prolonging life as long as possible<sup>81</sup>. On the other hand, respecting life can also be seen as a value that reinforces the relief from suffering in palliative care<sup>81</sup>. In the Finnish ethical guidelines for physicians, six main ethical principles are highlighted: respecting life, respecting human dignity, self-determination, caring (including benevolence, beneficence and non-maleficence), justice and benefit<sup>62</sup>. In the Charter of Fundamental Rights of the European Union, human dignity is called out in the

first article, and in Finland, the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) raised the term human dignity to an important ethical principle especially in EOL situations<sup>54,91,92</sup>. The ethics of decision-making and hastening death are further discussed in the following paragraphs: 2.2.5. Ethics of end-of-life decision-making and 2.3.4. Complexities of hastened death.

A major question in palliative care and especially in EOL care, is how to define a good death, dying well or dying with dignity? There are no right, wrong, universal or all-inclusive answers to this question. People differ in their willingness to face the reality of their death and how they wish to deal with different aspects of dying. For example, how one balances pain relief against alertness and how one desires to talk about feelings with friends, family, or caregivers differs between individuals<sup>13,88</sup>. It can be concluded that a good death, dying well and dying with dignity are all regarded differently by individuals<sup>13,88</sup>. This personal variability requires health care professionals to approach patients and families as individuals in an effort to provide care that is consistent both with the patient's and family's values and with their own conscience<sup>88</sup>.

## 2.1.4 Education in palliative medicine

The growing need for high-quality palliative care due to the world's ageing population and the increasing number of patients suffering from cancer and other diseases leading to death demands systematic education in palliative medicine (PM)<sup>2</sup>. This education of health care professionals is considered to be highly important by the EAPC<sup>93</sup>. Therefore, the EAPC has made recommendations for an undergraduate curriculum (40-hours) in different aspects of PM to be utilized at medical schools in Europe<sup>93</sup>. In addition, palliative medicine has evolved to a medical specialty in some countries, such as in the UK (1987) and the US (2006)<sup>94</sup>.

In Finland, five universities have a faculty of medicine. Tampere University has had a chair in PM since 1999 and University of Helsinki since 2014. Both these universities have also established a curriculum in PM, while the other three universities with a faculty of medicine lack both professorship and a curriculum in PM<sup>95</sup>. In addition to undergraduate education in PM at medical schools, a postgraduate training in PM has been available since 2007 in Finland. This training leads to a certification for a special competency in palliative medicine (cPM) awarded by the Finnish Medical Association<sup>96</sup>. Finnish physicians are allowed to start this postgraduate training after working for at least 2 years as a licensed physician<sup>96</sup>. The

special training consists of a minimum of 150 hours of theoretical education in different aspects of palliative medicine, 200 patient encounters in palliative care, 2 years of clinical practice, including a working period in a specialized palliative care unit for a minimum of 6 months, and a final written examination<sup>96</sup>.

Throughout the world, medical students and junior physicians have been found to lack confidence and to feel underprepared for having discussions about EOL care and for providing this care to a patient and their family<sup>27,30,97-99</sup>. Furthermore, their knowledge about assisted dying, do-not-resuscitate (DNR) orders, advance directives (ADs) and many other aspects of PM is still known to be inadequate<sup>100-103</sup>. On the other hand, undergraduate curricula in PM increases students' knowledge on palliative care and their attitudes towards EOL care change after an observational experience in a hospice<sup>28,95,104,105</sup>. Physicians also report having insufficient knowledge and training in PM<sup>106-109</sup>. Postgraduate education of physicians in palliative and EOL care enhances the knowledge and skills needed to perform high-quality EOL care, including appropriate decision-making<sup>29,31,32,110-113</sup>.

## 2.2 Decision-making in palliative care

### 2.2.1 Principles of decision-making in palliative care

Medical decision-making is a fundamental part of practising medicine, as it occurs at each stage of the diagnostic and therapeutic process<sup>114</sup>. In Goldman's Cecil Medicine the decision-making process is described as a blend of science and art in which the physician must synthesize a variety of concerns including the patient's most likely outcome, various management strategies, the patient's worst possible outcome, and the patient's preferences among these strategies<sup>115</sup>. Decision-making should be evidence-based, but much of the medical decision-making relies on good clinical judgement, as relevant evidence is not always available<sup>114,116</sup>.

Appropriate decision-making is mandatory in high-quality palliative and EOL care to prevent non-beneficial treatments and relieve suffering. Physicians have to strike a balance between the wishes of the patient and family, consider legal and ethical aspects and evaluate the benefit, harm and cost of the care. Paternalism was the previous method of making medical decisions, where a physician made the decision based on the medical evidence and what he or she thought to be best for a patient<sup>117,118</sup>. In an informed (patient-centred) model, the patient makes the decision

based on the information given by a physician<sup>117,118</sup>. Concerns have been raised about the excessive autonomy of patients, which can result in costly, ineffective and even futile treatments<sup>58</sup>. Thus, today, shared decision-making has emerged as the ideal model for complex decision-making<sup>19,117,119-121</sup>. At a minimum a physician and a patient are involved in the decision-making process, but family members, caregivers and other important persons such as friends can all take part, if it is a patient's wish<sup>119</sup>. Before the actual decision-making both the patient and the physician share information and discuss with each other<sup>119</sup>. Thereafter, the patient (and family members, etc.) and the physician take part in the decision-making process and make informed decisions regarding the medical care together<sup>119</sup>. However, it is also possible and allowed for the patient to take a more passive role as the shared decision-making is considered to be a continuum rather than a rigid model<sup>19,119,121</sup>. Today, this shared decision-making is known to be preferred by most physicians and patients<sup>49,51,122</sup>.

Multiple guidelines and frameworks have been established to ease the decision-making process in challenging medical situations<sup>117,123-126</sup>. The purpose of these guidelines and frameworks is to enhance ethical deliberation in the decision-making and to provide practical and educational tools for health care professionals when they are faced with complex decision-making situations. For example, the guide from the Council of Europe gives a practical step-by-step model for decision-making regarding medical treatment in EOL situations<sup>123</sup>. In addition to guidelines, different interventions, such as videos, digital video discs (DVDs) and web-based tools, have been created to support shared decision-making, but the evidence of the benefits of these tools is scarce and inconsistent<sup>127</sup>.

In practice, medical EOL decisions frequently precede dying in Europe, and patients and relatives are generally involved in this decision-making<sup>128</sup>. In a study from Switzerland, 77% of EOL decisions were made through a shared decision-making process in 2013<sup>129</sup>. Patient-related factors are known to influence the decisions about withholding or withdrawing LSTs, with age being the most frequently investigated factor<sup>24,130-133</sup>. In a review article by Frost et al., age was the most commonly identified factor predicting the intensity of the EOL care after adjusting for other variables in cohort studies<sup>24</sup>. Among survey studies, age was the second most commonly identified determinant after patient wishes<sup>24</sup>.

### 2.2.2 Advance care planning

When a patient is faced with a life-threatening illness, it is important to be prepared for the possibility of losing his or her capacity to take part in medical decisions. Advance care planning (ACP) is a way for preparing for situations in which a patient is no longer able to participate in decision-making<sup>134-139</sup>. There was no unified formal definition of ACP until 2017, when two multidisciplinary Delphi panels published consensus definitions for ACP<sup>137,140</sup>. The first definition, approved by the EAPC, defines ACP as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health care providers and to record and review these preferences if appropriate<sup>137</sup>. The second definition states that ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care<sup>140</sup>. The goal of ACP is to ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness<sup>140</sup>. Originally, ACP focused on completing written documents such as ADs but has then evolved into an ongoing social process of also preparing for death and dying, involving not only the patient and healthcare professionals, but also family members and loved ones<sup>139</sup>. One of the most important transitions is the movement from a single discussion about goals of care to an evolving process, which requires constant updating<sup>136,137,139,140</sup>. The ethical grounds for ACP are in patient's self-determination, respect for an individual, and the exercise for control even when a patient loses his or her capacity<sup>138,139,141</sup>. In the US, the amount of ACP among community-dwelling individuals aged 50 and older has steadily risen from 36% to 61% between 2002 and 2010<sup>142</sup>.

Recent reviews show that ACP can positively impact the quality of EOL care and that complex ACP interventions may be more effective in meeting patient preferences than written documents alone<sup>134,135,143-145</sup>. According to the studies, ACP decreases the number of hospitalizations, allowing especially older patients to die in nursing homes, increases the number of DNR orders, improves concordance between preferences for care and delivered care, and increases the use of hospice care<sup>134,135,143-145</sup>. There is some data that ACP could potentially reduce the net costs of care, although this is, in most studies, associated with the reduced demand for hospital care<sup>146,147</sup>. Despite the mounting evidence of the benefits of ACP, implementing it in practice can be challenging. The lack of knowledge among healthcare professionals and the public regarding ACP is an obstacle to implement ACP in practice<sup>148</sup>. Other barriers against taking up ACP include having a diagnosis

of a non-malignant disease, having dependent children, being African American, having uncertainty about ACP and its legal status, and poor documentation<sup>149,150</sup>. Several tools, including electronic health records, games and videos, have been created to facilitate ACP<sup>151-154</sup>. Some of these have a positive impact on the initiation and implementation of ACP to standard, every day practice<sup>151-154</sup>. However, a recent systematic review by Myers et al. concludes that instead of tools, an effective ACP conversation at both the population and the individual level requires provider education and communication skill development, standardized and accessible documentation, quality improvement initiatives, and system-wide coordination to create an impact at the population level<sup>153</sup>.

On the other hand, the effect and utility of ACP has also been under debate in recent years<sup>155-158</sup>. There are studies in which ACP has not improved quality of life or reached other pursued goals<sup>159,160</sup>. It has been proposed that meaningful improvements in EOL care will not result from the institutionalization of ACP, but from more significant changes to the design and delivery of care<sup>155</sup>. At the same time, the risk of routinization and turning ACP into just another protocol, undermines the importance of an open ethical dialogue where no correct answers exist<sup>156,157</sup>.

The Finnish national guideline for palliative and EOL care recommends the following topics to be covered in ACP (“Pitkälle edenneen sairauden hoitosuunnitelma”): 1) Patient (and loved ones) wishes, fears and understanding of the disease trajectory now and in the future; 2) Goals of care; 3) Treatment modalities and needs; 4) Decisions to withhold treatments; and 5) EOL care<sup>80</sup>. A recent article in a national medical journal, *Duodecim*, introduced the same elements of ACP as mentioned above and highlighted the importance of conducting ACP for all patients suffering from an advance disease<sup>161</sup>. A Finnish study showed that even modest investments in resources for palliative care can induce an objective change in the allocation of health care resources and improve the ACP for cancer patients at their EOL<sup>162</sup>. Visits to a palliative outpatient clinic have been shown to correlate with a higher frequency of DNR orders, better connection to primary care and better documented goals of care<sup>162</sup>.

### 2.2.3 Advance directives

The first proposal for ADs was made by the Euthanasia Society of America in 1967, and Luis Kutner, a human rights lawyer from Chicago who represented the society, described this concept in his article published in 1969<sup>163</sup>. He suggested that the



individual should indicate in writing ahead of time the extent to which he or she would consent to treatment<sup>163</sup>. Since 1976, when the first living will statute was adopted in California, the number of living will laws has increased rapidly<sup>163</sup>. In many countries, AD statutes require witnesses or a notary to be legally binding<sup>163-165</sup>. As in the case of ACP, the ethical basis for ADs rests in a patient's autonomy<sup>138,164</sup>.

The prevalence of ADs varies widely. In the US, the prevalence of ADs seems to have increased from approximately 10% up to 21–55% among the elderly in the last 10 years, while a Finnish study from 2004 showed that only 12% of the home-dwelling elderly had a living will<sup>166-168</sup>. In another study from Finland from 2003, only 1.5% of patients suffering from cardiac arrest without resuscitation being initiated had a living will.<sup>169</sup> The place of care also influences the prevalence of ADs. A recent Australian study demonstrated, that the prevalence of ADs was higher in residential aged care facilities (48%) than in hospitals (16%) or in general practices (3%), reflecting differences in the patient cohorts in these facilities<sup>170</sup>.

Although ADs reinforce patient participation in EOL discussions, patients often wish for their physician to initiate the discussion<sup>39,171</sup>. ADs are shown to increase the decision to forgo medical interventions, including in complex situations where the patient's health care proxy disagrees with the statements in the AD<sup>36,37</sup>. This is further supported by a very recent review where twenty-one out of the twenty-eight studies reported that individuals with living wills received significantly less medical management of which the authors meant cardio-pulmonary resuscitation, mechanical ventilation, hospitalization or admissions to an intensive care unit (ICU)<sup>172</sup>.

Concerns have been raised as to whether ADs express the genuine will of a patient at an exact moment<sup>40</sup>. Although the stability of EOL preferences is demonstrated in a recent study by van Wijmen et al., this was not supported by another recent study by Gallo et al., showing that transitions in preferences do happen highlighting the need for reassessments<sup>173,174</sup>. There is also variation in how ADs are implemented in daily practice. In a study made among palliative care physicians in Japan, most of the responders considered ADs to be important, but only one third actually recommended patients to complete their ADs<sup>5</sup>. Health care professionals report positive perceptions of the use of advance care documentation, but it is not clear how ADs are implemented in EOL discussions in daily practice or whether it increases engagement in EOL discussions to have access to previously formulated wishes<sup>175</sup>. Physicians are more likely to follow patient ADs, if the decisions are in line with their own clinical views<sup>176</sup>.



In a Finnish study from 2004, a majority of physicians answering a questionnaire had a positive attitude towards (92%), and respect for (86%), living wills, and 72% reported situations in which such a will would have been helpful<sup>177</sup>. In Finland, ADs are considered legally binding upon physicians and other health care professionals based on the Act on the Status and Rights of Patients which states that a competent person has a right to refuse any planned or ongoing treatment upon receiving adequate information or refusing to take this information<sup>60,62,81,178,179</sup>. All physicians, no matter where they practice medicine, should follow a patient's wishes expressed in an AD (except for wishes regarding futile therapies)<sup>62,81,180</sup>. Thus, ADs ought to be transferred into patient records as clearly as possible<sup>62,81,180</sup>. In Finland, it is also possible for a patient to have a legal representative who has a right to make medical decisions on their behalf<sup>181</sup>.

## 2.2.4 Withholding and withdrawing treatment

Withholding LST is the deliberate decision not to initiate treatment aimed at prolonging life, whereas withdrawing LST involves removing a medical intervention without which life is not expected to continue due to the patient's underlying health status<sup>13,182</sup>. Withholding or withdrawing LST is therefore considered to lead to a patient death due to the natural progression of their underlying illness, not by hastening death<sup>13</sup>. The similar result of both of these decisions has led to the conclusion that from a Western bioethical perspective, there is no moral or ethical reason to differentiate between withholding and withdrawing LST<sup>13,183-185</sup>. However, this perspective has been challenged in several articles in recent decades, reasoning, for example, that withholding is passive and withdrawing is active or that a physician's duty to care for a patient makes it unethical to withdraw a treatment once started<sup>46,184,186-188</sup>.

The legality of withholding or withdrawing LST differs between countries. In most western countries, withholding or withdrawing LST is legal; this is in contrast to the developing world where these actions are either of uncertain status or are illegal<sup>13</sup>. In Finland, the physician is responsible for the medical care of the patient, including medical examination, diagnosis and treatment of disease<sup>179</sup>. Based on the Act on the Status and Rights of Patients, a competent person has a right to refuse any planned or ongoing treatment upon receiving adequate information or refusing to take this information<sup>60,178</sup>. It is stated in the Act on the Status and Rights of Patients and in the main principles of Physician's Ethics, the ethical guideline for

Finnish physicians, that a physician must treat a patient in agreement with and in a mutual understanding<sup>60,62</sup>. However, futile therapies should not be used (even if a patient or families have requested them), as stated by the Finnish National Supervisory Authority for Welfare and Health and the Act on Health Care Professionals<sup>63,179</sup>. As the physician is responsible for the care of a patient, it is legal in Finland to withhold or withdraw life-sustaining treatments, if they are considered futile<sup>63,81,179</sup>. This is a medical decision made by the treating physician, but it should be discussed with the patient<sup>63,81,179</sup>. In cases where the patient is incompetent, decisions should be discussed with relatives, other loved ones or with a legal representative, if the latter is legally defined<sup>63,81,179</sup>. Although it is very important to make sure that decisions concerning withholding treatments are included in the patient record, there is still no uniform way of doing this in Finland due to different electronic health care records and health care keepers across the country. A new electronic national health care data base (Kanta) in Finland is trying to gather information from different sources into one location where important information about patients can be found more easily<sup>189</sup>.

Physicians' knowledge of the law on withholding and withdrawing LST may have significant gaps<sup>22,190,191</sup>. False perceptions, such as forgoing LST for patients without decision-making capacity requires evidence that this was the patient's actual wish or that the withholding or withdrawing of artificial fluids and nutrition from a terminally ill patient is illegal, can impair the delivery of the best possible palliative care for patients at their EOL<sup>22,190,191</sup>.

Although it is generally accepted that the withholding and withdrawing of LST are morally and ethically equivalent, physicians decide to withdraw therapy less frequently than to withhold it, probably because they feel that withdrawal is more difficult and ethically problematic than withholding<sup>42-45,182,186</sup>. The physicians' decisions regarding LST also vary between different treatment modalities; the most common reasons for withholding or withdrawing treatments in EOL care are a poor prognosis and futility of the treatment in question<sup>23,42,47,48,133,192,193</sup>. In a Scandinavian study, 57% of intensive care physicians would continue intravenous hydration, but only 5% of them measured blood glucose during EOL care<sup>48</sup>. Another study conducted with Slovenian ICU physicians had similar results, where 76% of responders reported never having terminated intravenous hydration, but antibiotics were withdrawn by most of the responders (86%) in EOL situations<sup>47</sup>. Almost all of these studies were conducted in an ICU setting and with ICU physicians or intensivists<sup>48,130,133,192-194</sup>. Thus, it is not clear how well these results would translate

to a much larger palliative care patient population who are cared for outside of ICUs and emergency departments.

It is true that some medical interventions such as resuscitation or mechanical ventilation are clearly intended to prolong life when used in EOL care, whereas intravenous hydration, antibiotics and supplementary oxygen can be considered as symptom management rather than just LSTs. Artificial nutrition or medically assisted hydration have not been shown to improve survival, quality of life or symptoms in EOL care, although the evidence about this is scarce<sup>195-199</sup>. However, some studies have raised concerns about the potential harm, such as increased respiratory secretions, related to hydration during EOL care<sup>200</sup>. The use of antibiotics in EOL care is controversial, but there is some evidence that antibiotics might relieve symptoms without having serious side-effects<sup>201,202</sup>. Supplementary oxygen is used in more than 70% of patients in EOL care, although the evidence to support this is lacking<sup>203-209</sup>. The benefits of transfusions in palliative care are experienced briefly and remain controversial<sup>210</sup>. The symptomatic relief gained from treatment such as a red blood cell transfusion is often short-lived, or even absent, if given very near death<sup>210</sup>.

#### 2.2.4.1 Do-not-resuscitate orders

As discussed previously, ACP is a broad entity, but DNR or do not attempt cardiopulmonary resuscitation (DNACPR) orders are in many ways an important part of these discussions<sup>134,136,211,212</sup>. The issue of resuscitation raises fundamental ethical questions about autonomy (a patient's wishes and choices), beneficence (doing good), non-maleficence (harm avoidance) and justice (allocation of limited resources and appropriate decision-making)<sup>213</sup>. Thus, the ethical basis for these orders can be seen as what is in the best interest of the patient, as DNR orders presumably allow dying patients to die with dignity<sup>178,214</sup>.

Multiple studies have shown that the outcomes of cardiopulmonary resuscitation (CPR) are poor, especially in cancer patients, whose overall survival after CPR for hospital discharge is less than 10%<sup>14,214-217</sup>. Despite recent medical advances, CPR survival in the cancer patient population has not changed<sup>14</sup>. The survival from CPR declines towards zero as the cancer spreads and the performance status lowers, resulting in the fact that attempting CPR for a cancer patient with widespread incurable cancer and a low performance status is indeed futile<sup>218</sup>. Although the evidence of poor CPR outcomes among cancer patients is consistent, misconceptions about DNR orders still exist among the public and physicians. In a

small study by Sundar et al., responders significantly overestimated the chance of a successful CPR outcome in a terminally ill cancer patient; 50% believed that CPR has at least a 30% chance of successfully resuscitating a hypothetical 60-year-old patient with widespread cancer, who is in hospice and has exhausted all chemotherapy options<sup>219</sup>. In a Finnish questionnaire study to physicians from 2004, a DNR order was interpreted by one third (30%) of the responders that only palliative (symptom oriented) care was required<sup>177</sup>. ACP and other interventions, such as structured discussions, involving family members, which commonly enable better communication between patients, their loved ones and physicians, increase the prevalence of DNR orders<sup>9,134,220-223</sup>.

In our country, the decision not to resuscitate is a medical decision made by a physician, although there is no legislation regarding DNR orders<sup>178,224</sup>. However, the ethical guidelines of the Finnish Medical Association, the Finnish National Supervisory Authority for Welfare and Health and the Act on the Status and Rights of Patients all oblige physicians to discuss DNR orders with the patient and if the patient is incompetent with his or her loved ones or with a legal representative<sup>60,62,224</sup>. The goal is to achieve an agreement about this decision and a mutual understanding<sup>62,224</sup>. Documentation of both the discussions around the decision and the decision itself is crucial<sup>62,224</sup>.

## 2.2.5 Ethics of end-of-life decision-making

Decision-making at the EOL is a complex process involving many ethical aspects<sup>15,124,225-227</sup>. Guidance on the decision-making process regarding medical treatment in EOL situations published in 2014 by the Council of Europe states that the main principles for the ethical framework regarding the decision-making process are autonomy, beneficence, non-maleficence and justice<sup>123</sup>. Thus, these are again the same ethical principles that, are considered to be the ethical back bone of all medicine<sup>88,90</sup>. According to this guidance, the principle of autonomy is implemented in particular through the exercise of free (without any undue constraints or pressure) and informed (following the provision of information appropriate to the proposed action) consent<sup>123</sup>. The principles of beneficence and non-maleficence include the obligation to deliver only appropriate treatment and the concept of needless or disproportionate treatment is likely to be limited or withdrawn<sup>123</sup>. The principle of justice means equitable access to health care<sup>123</sup>. In addition to these ethical principles, medical professionals have raised other ethical issues concerning decision-making,

including responsibility, integrity, and dignity<sup>227</sup>. As mentioned before, human dignity is considered to be a fundamental value in Europe, as it is included in the first article in the Charter of Fundamental Rights of the European Union<sup>54</sup>.

In a recent article by Forte et al., a bioethical framework introducing alternative ethical principles to guide the decision-making process in the care of seriously ill patients compared to the well-known ones used in the Council of Europe guide<sup>123,124</sup>. In this framework, decision-making is divided into four steps: 1st step: Ethics of accuracy referring to accuracy in the diagnosis, prognosis and success and failure rates of possible treatments; 2nd step: Ethics of comprehension, meaning to comprehend and be empathetic to the patient's values and views of suffering; 3rd step: Ethics of situational awareness, meaning applying scientific evidence to the specific situation of the patient by the healthcare multidisciplinary team; 4th step: Ethics of deliberation, meaning that goals of care are established in a consensual patient-provider relationship, where the patient's values are respected and scientifically acceptable practices are used<sup>124</sup>. These guidelines and other studies focusing on ethical dilemmas in EOL care emphasize individual decision-making, where the needs, preferences, and values of the patient and family are at the core, but acknowledge that medical decisions must also be based on evidence and futile therapies should not be used<sup>123,124,225-228</sup>.

Rapid medical developments have led to a growing gap between treatment possibilities and resources. In Finland, this has led to a situation where society has a growing need to control the medical profession<sup>62</sup>. As a result, medical ethics and medical decision-making can be seen as a part of a larger social discussion trying to balance the medical profession, the patient-physician relationship and equal care for all patients<sup>62</sup>. Finland was the first country in Europe to include the right of the patient to be involved in treatment decisions into law, highlighting the importance of communication<sup>60,62</sup>. Physicians are the experts in medicine, although unambiguously right answers rarely exist, and the patient is the expert of his- or herself<sup>62</sup>. Thus, both information and decision-making must happen in an optimal interaction and under agreement between a patient and a physician<sup>62</sup>.

## 2.2.6 Patient and family preferences

In a review by Chewing et al., 71% of patients preferred shared decision-making in studies performed after 2000 compared to 50% in studies performed before 2000<sup>49</sup>. In another review that, included only cancer patients, almost all patients wished for

full information, but only about two-thirds wished to actively participate in decision-making<sup>229</sup>. Patients' informational needs appear to be consistently high in studies concerning patient preferences towards EOL decision-making, but actual participation in the decision-making and taking part in the final decision varies among individuals, depending, for example, on a patient's openness to EOL discussions<sup>230-232</sup>. However, the preferred and actual participation in the EOL decision-making does not always correspond, as previous studies have shown that patients want to be more involved in the decision-making than they actually are<sup>120,233</sup>.

Most patients want their loved ones to be involved in EOL decision-making, and having discussions with both patients and their family is shown to increase satisfaction with EOL care<sup>33,34</sup>. Despite the fact that family members and caregivers are often involved in the decision-making, discordance between the patient's wishes, caregiver's preferences and caregiver's predictions of the patient's preferences do exist<sup>35,38,234,235</sup>. Hence, discussions about EOL preferences and wishes should be encouraged within families to facilitate a common understanding and to increase the satisfaction with EOL care.

## 2.2.7 Physician-related factors in end-of-life decision-making

Significant differences have been discovered in studies examining the EOL decision-making by physicians<sup>23,128,236</sup>. Many physician-related factors, including age, experience, specialty, education, personal attitudes and values, have been shown to influence EOL decision-making<sup>5,16-18,23,24,237</sup>.

The age of the physician seems to be an incongruous factor in decision-making<sup>24</sup>. In some studies, older age has been associated with more decisions to withhold or withdraw interventions, while in other studies, younger physicians or trainees make less aggressive decisions<sup>17,23,25,45,236,238,239</sup>. Further, there are studies in which the age of a physician was not found to influence the decision to withhold or withdraw LST<sup>26,240</sup>. Younger physicians have less experience in EOL care, but on the other hand, education in PM is currently included in the curriculum of many medical schools, increasing younger colleagues' knowledge of the benefits of palliative care.

Many studies have shown that the physician's gender does not influence their decision-making<sup>23,239,241,242</sup>. However, in some studies, female gender has been found to be associated with more active and intensive treatment decisions<sup>17,25,243</sup>. Female physicians communicate more often and for longer in a patient-centred manner than male physicians, but whether this translates into differences in actual decision-

making remains unclear<sup>244</sup>. In general, gender does not seem to be an important influential factor in EOL care decision-making<sup>24</sup>.

Experience with EOL care, death, dying and making decisions to withhold or withdraw therapy seems to be associated with more decisions to withhold or withdraw therapy in EOL care<sup>23-25,240</sup>. Education in palliative care increases the knowledge and skills needed to provide high-quality EOL care<sup>28,29,31,32,95,112,113</sup>. However, it is not clear how training in PM influences EOL decision-making. Löfmark et al. reported that having had training in palliative care resulted in more experience with EOL decisions including decisions about withholding or withdrawing potentially life-prolonging treatment and more acceptance for alleviating pain or other symptoms with a concomitant possible life-shortening effect<sup>25</sup>. The specialty of a physician impacts decision-making<sup>18,25,236</sup>. Oncologists have been shown to be more willing to withhold or withdraw futile treatments in EOL care and to choose a palliative care approach more often than other specialists<sup>17,18,25</sup>. In a study by Alemayehu et al., family physicians were more likely than specialists to choose more conservative treatment options<sup>236</sup>.

It has been shown that religion is associated with the unwillingness to withdraw life-supportive care<sup>23-26,45,245,246</sup>. Although religion has an enormous effect on decisions to forgo LST, religiousness did not influence physicians' decisions to choose palliative care approaches over active or intensive care approaches in a study by Hinkka et al.<sup>17</sup>. This finding was suggested to be due to the uniform religious background of Finnish physicians, as approximately 90% of Finnish people belonged to the Lutheran Church at the time of the study in the end of 1990<sup>17</sup>.

ADs and a health care proxy or a family's opinion have been shown to have marked influence on physicians' decision-making<sup>17,18,36,37,40,45</sup>. A patient's AD or a proxy opinion to forgo medical intervention significantly increased the odds of forgoing these interventions in a randomized vignette trial<sup>36</sup>. This result is well in line with the previous studies by Hinkka et al., where after finding a patient's AD, physicians' decisions to withhold and withdraw medical treatments increased and choosing active or intensive care decreased<sup>17,18</sup>. In another study by Escher et al., the patient's AD had more influence on physicians' decisions to forgo medical intervention than did the proxy opinion when the AD and proxy opinion disagreed with each other<sup>37</sup>. In a study by Vincent et al., a family's wish for everything to be done was more influential to physicians' decisions than their request to withhold and withdraw treatment<sup>45</sup>. A similar influence of a family's appeal in choosing aggressive treatment options has also been shown in the studies by Hinkka et al.<sup>17,18</sup>.



Physicians', patients' and families' attitudes regarding EOL decisions concerning themselves differ from each other<sup>247</sup>. In a European study conducted with ICU physicians, patients surviving ICU and families of ICU patients found that physicians held quality of life to be more important and valued life as less important for themselves in their own EOL decisions than did the patients and families answering a similar questionnaire<sup>247</sup>. If diagnosed with a terminal illness, physicians reported that they would prefer fewer ICU admissions and less use of CPR and mechanical ventilation for themselves than did the patients and families<sup>247</sup>. Physicians also preferred being at home or in a hospice significantly more often than the patients and the families if they had a short life-expectancy<sup>247</sup>.

### 2.2.8 Decision-making among medical students

EOL decision-making among medical students is poorly described and studied compared to physicians' EOL decision-making. In a large Brazilian study, 46% of the students responding to a controversial ethical questionnaire reported that they did not have object to the withdrawal of artificial life support<sup>248</sup>. In that study, student age had only a small influence on this decision, but religious beliefs significantly increased the objection to withdrawal of LSTs<sup>248</sup>. In another study from Puerto Rico, 68% of the medical students said that they would support withholding or withdrawing life-sustaining treatments for dying patients with an informed consent<sup>249</sup>. Gruber et al. studied changes in medical students' attitudes towards EOL decisions and found that the fifth-year students accepted forgoing of CPR and discontinuation of LST more often than the first-year students<sup>250</sup>. One third of the medical students from Germany and France classified withdrawal of medical measures as "active euthanasia", while 65% of the students from Germany and 47% from France knew that forgoing or limiting life-sustaining therapy could be legal<sup>251</sup>. Almost all responders knew that ending a patient's life on request was illegal<sup>251</sup>. In many studies, medical students report feeling unprepared and lack confidence in EOL decision-making<sup>27,30,252</sup>. Therefore, medical students generally desire more support and role modelling from residents and attendings<sup>252</sup>.



## 2.3 Hastened death

### 2.3.1 Definitions

The word euthanasia (εὐθανασία) is a combination of two Greek words: eu (εὖ) meaning well or good and thanatos (θάνατος) meaning death. Thus, literally and etymologically euthanasia means “good death”. Today, it is understood as killing a person after an explicit request<sup>81,253</sup>. Clear definitions have been specified for euthanasia and PAS, which lead to a clearly assisted death whereas hastened death lack a specific definition<sup>253</sup>. Definitions used in this thesis are summarized in Table 2.

**Table 2.** Definitions for different aspect of hastened death in this thesis.

Euthanasia <sup>253</sup>	A physician (or other person) intentionally kills a person by the administration of drugs, at that person's voluntary and competent request.
(Physician-) assisted suicide <sup>253</sup>	A person (or a physician) intentionally helps another person to terminate his or her life (by providing drugs for self-administration), at that person's voluntary and competent request.
Assisted death <sup>13</sup>	Euthanasia and (physician-) assisted suicide.
Hastened death	Assisted death or causing a patient's death unintentionally, but by acknowledging/accepting the risk of death through a certain treatment.

### 2.3.2 Current practices and legislation

Euthanasia is legal in five countries worldwide: the Netherlands, Belgium, Luxembourg, Canada and Colombia<sup>64</sup>. In addition to these countries, PAS is legal in Switzerland and in five states in the USA (Oregon, Washington, Montana, Vermont, and California)<sup>64</sup>. In Switzerland, assisted suicide may be legally performed by persons other than physicians and that practice is also available for Swiss nonresidents<sup>64</sup>. In most of the other countries assisted suicide not performed by a physician is illegal<sup>13,64</sup>. According to Finnish Criminal law, taking someone else's life is a punishable criminal act<sup>254</sup>. Thus, euthanasia is illegal in Finland. However, the

Ministry of Social Affairs and Health has currently set up an expert group to consider legal options for euthanasia and EOL care after a citizen initiative demanding the legalization of euthanasia. In contrast to euthanasia, aiding in a suicide is not specifically stated as a criminal act in Finnish law<sup>254</sup>. However, this type of action has not been tested in a court of law in Finland and a physician performing this type of procedure might be prosecuted and convicted for a criminal deviation of good clinical practice<sup>62,81</sup>.

The World Medical Association (WMA) considers euthanasia to be unethical<sup>255</sup>. The Finnish Medical Association is in line with the WMA and objects to the legalization of euthanasia<sup>255</sup>. It is stated in the national ethical guideline for physicians that to kill a patient deliberately is a violation of medical ethics<sup>62</sup>. After the civil motion demanding the legalization of euthanasia, the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) published a statement on euthanasia in Finland concluding that only after reaching high quality and equal EOL care offered for all citizens based on their needs, it is possible to consider if changes in the Finnish legislation are needed to allow euthanasia<sup>91</sup>. The IAHCP and the EAPC have recently stated that euthanasia and PAS should not be included as part of the clinical practice of palliative care<sup>253,256</sup>.

The procedure of euthanasia involves injecting the patient with barbiturates to induce coma, followed by neuromuscular blockers which cause respiratory muscle paralysis<sup>13</sup>. Death occurs quickly as a consequent anoxia and cardiac arrest<sup>13</sup>. In PAS, a physician provides medication for the patient to self-administer an overdose of barbiturates that suppresses respiration, causing a patient's death<sup>13</sup>.

### 2.3.3 Attitudes towards euthanasia and physician-assisted suicide

Public support for euthanasia and PAS is mounting across Western Europe, while some decline has been observed in the USA and Eastern Europe<sup>64,257</sup>. Public acceptance towards euthanasia in Finland was moderate, with a slight increase during the past decade according to an international study published in 2013<sup>257</sup>. In national studies, public acceptance has increased from 50% to 82% between 1998 and 2014<sup>258,259</sup>. Although the methods and results differ between the studies, a clear trend towards a more accepting atmosphere is apparent<sup>258,259</sup>.

Several surveys demonstrate a lower amount of support from physicians for euthanasia and PAS when compared to support from the general public<sup>64</sup>. In our country, physicians' attitudes towards euthanasia have become more accepting. In a

study conducted with a random sample of Finnish physicians in 2013, 46% of the participants answering a questionnaire supported the legalization of euthanasia compared with only 29% in 2003<sup>260</sup>. In another study, conducted in 2007, the support for euthanasia among Finnish GPs, internists and geriatrics from Southern Finland was only 19%<sup>261</sup>. In other Scandinavian countries, the number of physicians who are in favour of euthanasia ranges from 17% in Norway to 39% in Sweden, but these results were obtained already in 2002<sup>262</sup>. Although the attitudes have become more permissible, the proportion of Finnish physicians willing to perform euthanasia remains low (approximately 20%), which is in line with the results from other studies showing physicians' reluctance to perform euthanasia or PAS<sup>260,263</sup>. In contrast to most European countries, a majority of physicians from Belgium, Switzerland and the Netherlands (77–90%) consider euthanasia and PAS to be justified in certain situations<sup>64</sup>. There are also studies showing that the most experienced physicians in palliative care have the strongest opinions in their opposition to hastening death<sup>264,265</sup>. The wide range of attitudes towards euthanasia and PAS is probably due to large social, cultural and religious variations throughout the world<sup>64,257</sup>.

Medical students seem to accept euthanasia and PAS more frequently than physicians. In a study from Puerto Rico, 40% of the medical students and 20% of members of the medical faculty accepted euthanasia<sup>249</sup>. In another study from Poland, 26% of students and 17% of the physicians were in favour of legalization of euthanasia, but only 5% of physicians and 12% of students were willing to perform euthanasia or PAS<sup>266</sup>. Overall, medical students' attitudes towards euthanasia and PAS vary depending on the country. Acceptance of assisted death ranges from 26 to 88% in recent studies<sup>100,248,266-270</sup>.

## 2.3.4 Complexities of hastened death

Questions about hastening death in EOL care are complex and include ethical concerns that are broader than in euthanasia or PAS. The term "hastened death" is unspecified and has many interpretations. The termination of life-sustaining treatments may be confused with euthanasia and PAS among the public and physicians, as well as among medical students<sup>65,100</sup>. When palliative care physicians were asked, over half of them had experienced that palliative treatments, such as palliative sedation or stopping artificial hydration/nutrition, were being characterized as euthanasia, murder or killing by the families of patients, other physicians or another health care professionals<sup>271</sup>. Of these physicians, 4% had been

formally accused due to such decisions, but none had been convicted of homicide in a court of law<sup>271</sup>.

Withholding or withdrawing treatments is commonly regarded as a part of EOL care, not hastening death, as previously discussed (see paragraph 2.2.3. Withholding and withdrawing treatment). However, these practices are often referred to as hastening death, even in medical literature<sup>272</sup>. European physicians have reported to have had an explicit intention of hastening death in 45% of all treatments that were withheld or withdrawn<sup>272</sup>. Alleviating symptoms with a possible life-shortening treatment can be seen as a more complex and ethically challenging question. In a large multinational study by Miccinesi et al., there was general approval for alleviating symptoms with a possibly life-shortening treatment<sup>26</sup>. Similar findings were discovered in a study by Löfmark et al., where 57–95% of physicians were willing to intensify the drug therapy to alleviate pain and/or other symptoms, taking into account the probability or certainty that this would shorten a patient's life<sup>25</sup>. On the other hand, in countries where euthanasia is illegal only 1–14% of physicians compared to 19–56% of physicians in Belgium and the Netherlands, would administer, prescribe or supply drugs with the explicit intention of hastening the EOL on the explicit request of a patient<sup>25</sup>. In a study from the UK, physicians reported that they had at least some intention to hasten death in 7.4% of the deaths evaluated<sup>273</sup>. In a study by Sprung et al., 73% of patients dying in ICUs across Europe forgone LSTs, but 2% underwent active shortening of the dying process via the administration of drugs, including opiates, benzodiazepines, muscle relaxants or barbiturates, as reported by the attending physician<sup>274</sup>. In another study from Germany, 78% of the physicians reported that they would alleviate symptoms with the possibility of shortening life, but only 1% would assist dying<sup>275</sup>. The use of medications to deliberately hasten death was found in only 0.8% of deaths in a survey from France<sup>276</sup>.

The principle of double effect has been used when the act intended to do good (for example relief of suffering) justifies the danger of harm (e.g., hastened death). It is applicable in a situation in which a person is not able to avoid all harmful actions<sup>66,277,278</sup>. The principle is considered morally permissible if four conditions are met: 1) the action is not immoral in itself, 2) the action is undertaken with the intention of achieving the possible good effect and the possible bad effects may be foreseen, but must not be intended, 3) the bad effect must not be a means to the good effect and 4) the good effect must outweigh the bad effect (the rule of proportionality: the bad effect can be permitted only when there is proportionally grave reason for it)<sup>66,277,278</sup>. The use and dosing of opioids during EOL care is a

commonly used example when talking about the double effect: does the intent to treat pain or breathlessness outweigh the risk of potentially hastening death<sup>279,280</sup>? Criticism has been expressed towards using the principle of double effect as a justification for hastening death due to its simplicity, narrow focus and often ambiguity of the intension behind the action<sup>66,277,281</sup>.

To further enhance the complexities of discussions around hastening death, it has been shown that the patient's wish to hasten death does not always imply a genuine wish to die, but might be the result of overwhelming physical, psychological, social and existential suffering, all of which impacts the patient's sense of self, dignity and meaning in life<sup>282,283</sup>.

### 3 AIMS OF THE STUDY

This study was conducted to evaluate the decision-making and attitudes of physicians and medical students concerning the end-of-life care of cancer patients, and whether there have been changes in these issues over the past sixteen years.

The specific aims were:

1. To study whether medical specialty or special competency in palliative medicine influences end-of-life decision-making and whether other background factors or values affect these decisions.
2. To evaluate whether, attitudes and values towards different aspects of end-of-life care or hastened death have changed over the past sixteen years among Finnish physicians.
3. To reveal whether there have been changes in the decision-making relating to end-of-life care between 1999 and 2015.
4. To assess whether the attitudes and values towards different aspects of end-of-life care differ between medical students and experienced general practitioners.
5. To examine differences between medical students and experienced general practitioners in decision-making in end-of-life care and in factors influencing their decision-making.

## 4 PARTICIPANTS AND METHODS

### 4.1 Participants

The study sample consisted of three cohorts. The first cohort was a sample of Finnish physicians included in the 1999 survey<sup>16-18,178,284</sup>. This sample consisted of 500 GPs, 300 surgeons, and 300 internists randomly selected from the register of the Finnish Medical Association and all Finnish oncologists (n=82). The second cohort was formed in 2015 by selecting Finnish physicians in the same way as in the first cohort in 1999 and enlarged with all Finnish physicians with special competency in palliative medicine (n=82), excluding those with a mailing proscription (n=23). In this second cohort, the number of oncologists rose to 158, and 13 of them also had cPM. The third cohort included all graduating medical students (n=639) from five universities in Finland (Helsinki, Kuopio, Tampere, Turku and Oulu) who answered the survey during the autumn of 2015 and the spring of 2016 depending on the graduation date at each university. Altogether, 3 148 physicians and medical students were asked to participate in the study.

The survey was mailed to the physicians by post and given to the students during a teaching session and returned to the teacher either personally or by post. Non-responders were reminded twice.

In the comparison between 1999 and 2015, physicians with cPM were excluded from the respondents in 2015 unless they were oncologists (n=13). This was done because none of the physicians answering in 1999 had cPM, as it has been available only since 2007 in Finland. When comparing students and GPs we included only experienced GPs who had graduated from medical school a minimum of five years ago (n=222) to further improve the validity of this comparison.

### 4.2 Questionnaire

The original, complete questionnaire used as a basis for this study is presented in the appendix<sup>16-18,178,284</sup>. It consists of seven hypothetical patient scenarios, six of which were cancer patients at their EOL and one was a patient with advanced dementia.

For the current study, five of the cancer patient scenarios were included (patient scenarios 1 and 4-7 from the original questionnaire). The responders were instructed to answer the questions in the given order and to not change their answers once given.

#### 4.2.1 Patient scenarios

Patient scenario 1 (numbered as scenario 1 in the publications III and IV) presented an 82-year-old retired forest worker, who had received a diagnosis of prostatic cancer 3 years ago. During the past year he has received treatments for bone metastases. He has now been in a hospital for one month, almost totally bedridden, and needs help with all functions. His mental condition has been normal. His general condition has weakened over the past week, he is now totally bedridden, and he has received large doses of pain medication. Today, he has become comatose. His haemoglobin count has decreased to 68 g/l, while the week before it was 118 g/l. His blood pressure is 80/40 mmHg. There is no verbal or written advance directive. The patient's wife has previously said that she expects the doctor to make all treatment decisions according to his/her best understanding. After the patient scenario, the doctors were asked to choose one of the given treatment options. The concepts used in the treatment options were explained as follows: 1) palliative care: good nursing, sufficient medications for pain and other symptoms, intravenous hydration only when it is considered to relieve the patient's symptoms; 2) active care: use of antibiotics, intravenous hydration or blood transfusions aimed at saving the patient's life in a life-threatening condition; 3) intensive care: moving the patient to an intensive care unit. After the initial question for the patient scenario 1, four additional alternatives were presented, each ending with the same treatment options: a) It has been discovered that the patient's faeces are black. You remember having prescribed ketoprofen for pain a week ago; b) The patient's son is coming from America the day after tomorrow to see his father while he is still alive; c) The patient has had spiritual anxiety and there is a planned appointment with a minister and the Lord's Supper tomorrow; d) The patient's written advance directive has been found, in which the patient has expressed that all active interventions should be withheld if there is no hope for recovery. After asking for the treatment decisions, a Likert-type scale was presented to evaluate the influence of different factors (patient's benefit, family's benefit, patient's legal protection, physician's legal protection, ethical values,



patient's age, cost of care, patient's social status) on the decisions (from 1—very little influence to 5—very much influence).

In patient scenario 4 (numbered as scenario 2 in the publication III), a 68-year-old patient suffers from breast cancer with bone metastases. She is bedridden, and her general condition has rapidly collapsed. She is in a community hospital ward and is receiving adequate pain treatment with which she is pleased. She is depressed and wants to transfer to a hospice for her last days. She feels that the atmosphere on the ward is very restless and “institutional”. You have the right to issue a voucher for the costs of hospice care (290 euros per day) to be paid by the community hospital. The costs would be approximately double compared to those in a community hospital, and the chief doctor has advised you to use great discretion in issuing vouchers. Your solution: a) to accept the transfer b) to accept the transfer, provided that the patient pays the extra costs herself c) not to accept, because according to normal practice the patient's care belongs to the community hospital ward, and there are no special problems in her care d) I don't know e) other solution:\_\_\_\_\_.

Patient scenario 5 (numbered as scenario 1 in the publication II), presented a 60-year-old male patient suffering from prostate cancer with metastases. Metastases in the thoracic spine led to total paraparesis one month earlier. There is no hope for a cure. The patient is well aware of the situation. He has totally lost his will to live. When you are together with him alone, he asks for a sufficient dose of morphine to “get away”. You have denied the overdose, explaining that it is against your ethical principles. During the following days, you notice that the patient asks you to double his morphine dose because of unbearable pain. The anti-inflammatory pain medication is at its maximum dose and you suspect if the pain is real (this sentence was removed from the scenario in 2015 as it did not comply with current treatment guidelines for cancer pain). You suspect that increasing the dose in such a way would lead to the patient's death. Your decision is which of the following: a) to raise the dose because the patient has the right to sufficient pain relief in this end-of-life (terminal) care situation; b) to try to help the patient in other ways, such as with antidepressants, thus continuing with morphine dosing according to given guidelines; c) I can't say; or d) give another solution:\_\_\_\_\_.

In patient scenario 6 (numbered as scenario 2 in the publication II and scenario 2 in the publication IV), a 32-year-old female patient is brought by an ambulance to the emergency unit. She is accompanied by her husband who says his wife has inoperable brain cancer. She has been receiving maximum radiotherapy, but this was discontinued three weeks ago. She has deteriorated considerably during the past week. The patient has now had an epileptic seizure and has been unconscious since

the attack. After 20 minutes at the hospital, the patient stops breathing, and there is no pulse. Your treatment decision as a doctor on call is which of the following: a) to start cardiopulmonary resuscitation or b) to withhold cardiopulmonary resuscitation.

Patient scenario 7 (numbered as scenario 1 in the publication I and scenario 3 in the publication IV), presented a 62-year-old male patient with lung cancer and metastases, who was admitted to the hospital ward and received high-dose morphine medication. Due to respiratory weakening, he had become comatose the night before. He also suffered from severe anaemia and had abundant pleural effusion and fever. There is no possibility of discussing the matter with the family and there is no advance directive. After the presentation of the patient scenario, there was a question about the treatment decision: Which of the following treatments already started (\*) or planned would you withhold or withdraw? The decision responses were expressed on a scale from 1 (I definitely would not) to 5 (I definitely would). The treatments were a) antibiotics (\*); b) mechanical ventilation (\*); c) blood transfusion; d) pleural drainage; e) chest X-ray examination; f) laboratory tests; g) intravenous hydration (\*); h) nasogastric tube (\*); i) thrombosis prophylaxis (\*); and j) supplementary oxygen (\*). After the original patient scenario, two alternatives with extra information were provided: 1) the patient's daughters come to you distressed and crying, expressing their hope that everything possible will be done to save their father's life; 2) there is a written advance directive in the patient's medical chart in which he expresses his wish that all active treatment should be withdrawn if there is no hope for recovery. After each of these alternatives the same questions (with the same treatment options as in the original scenario) were asked.

#### 4.2.2 Fear-of-death index

After the patient scenarios, the questionnaire continued with questions concerning the responders' fear-of-death (set of 11 questions, Likert 1-5). A fear-of-death index was calculated by summing up the responses to four questions which maximized Cronbach's alpha in 1999; g: I fear death, h: I'm afraid that someone close to me dies, i: I'm worried about the sadness brought to my family by my own death and k: I'm distressed to think that someday I shall not exist (range 4-20, cut point 16). Although, the fear-of-death index did not play an important part in the present study, it was included to the questionnaire with the intention to keep the questionnaire as similar as possible in 2015 as in 1999.

### 4.2.3 Attitudes and background factors

Attitudes regarding several moral and ethical aspects were assessed with a 100-mm visual analogue scale (VAS) from “definitely agree” (0 mm) to “definitely disagree” (100 mm). These included statements concerning euthanasia, withdrawal of life-sustaining treatments, assisted suicide, palliative and end-of-life care, the role of religion in ethical decisions, advanced care directives and health care economics together with physicians’ satisfaction with their own health, work and salary. Physicians’ personal conceptions of professional status, their own health and family, length of life, religion, nature and standard of living were assessed using a four-point Likert scale. Sociodemographic data was collected as well.

### 4.2.4 Validation of the questionnaire

The questionnaire has been previously used and validated by Hinkka et al.<sup>16-18,178,284</sup>. In the validation process, the questionnaire was sent to 45 physicians (health care practitioners and specialists) twice at two-week intervals in order to test the reliability of the responses to patient scenarios and the questions on attitudes and values<sup>16-18,178,284</sup>. Thirty physicians returned two acceptable questionnaires<sup>16-18,178,284</sup>. The value of kappa coefficient for an acceptable scenarios or questions was determined to be more than 0.40, which is a commonly accepted limit for reliability<sup>16-18,178,284</sup>.

## 4.3 Statistical analysis

The answers to the hypothetical patient scenarios were re-categorized dichotomously for the statistical analysis. The conversion was conducted as follows (responses shown in brackets): In patient scenario 1 of the original questionnaire, “choosing palliative care” (a) and “not choosing palliative care” (b and c); In patient scenario 4, “willing to issue a voucher for hospice” (a) or “not willing to issue a voucher” (b-e); in patient scenario 6, “accept” (a) and “not to accept” (b, c and d), and in patient scenario 7, “to withhold or withdraw” (4 and 5) and “not to withhold or withdraw or I don’t know” (1, 2 and 3). The answers on the 4-point Likert scale concerning values were converted to the following 2-point scale: 1-2 for “not important” and 3-4 for “important”. The answers on the 5-point Likert scale concerning the influence of different factors were converted to the following 2-point scale: 1-3 for “not much influence” and 4-5 for “much influence”.

Dichotomous variables were tested by using the Pearson chi-squared test or Fisher's exact test when appropriate. Continuous variables were tested by using an independent-variables t-test or the Mann-Whitney U-test if the data were not normally distributed. Two-sided p-values of less than 0.05 were accepted as statistically significant.

From patient scenario 7, measured mean distributions of the chronological original scenario, family's appeal and advance directive values were clustered by trajectory analysis<sup>285</sup>. The trajectories were created according to the measurements of mean values in each responder as a continuous outcome measure. The analyses undertaken were latent class mixture models of quadratic trajectories including a random intercept and concomitant variables. Models were fitted by using the flexmix package of the statistical program R, version 3.3.0, from the R Foundation for Statistical Computing (R Development Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria, 2008, ISBN 3-900051-07-0, URL)<sup>286</sup>. Relative goodness of fit was assessed using Bayesian information criteria. Factors affecting the willingness to continue or start therapy (belonging to the trajectory groups 3 or 4) compared withholding or withdrawing therapy (belonging to the trajectory groups 1 or 2) were examined by univariate and age-adjusted logistic regression models results shown by odds ratios (OR) with 95% confidence intervals (CIs). Additionally, a multivariable model, where variables were added simultaneously into the model, was performed for variables with statistical significance under 0.20 in the age-adjusted model.

A forward stepwise logistic regression was used to create models explaining the decision to choose palliative care in patient scenario 1, willingness to issue a voucher for hospice in patient scenario 4 and to increase the morphine dose in patient scenario 6. Background factors, life values, and attitudes, were all tested in the models. The p-value limit for significance was set at 0.10 to enter and 0.15 to be removed from the model.

The data analysis was performed using IBM SPSS Statistics for Windows, version 23.0 (publication I and II) and version 24.0 (publications III and IV) (Armonk, NY, USA, IBM Corp).

## 4.4 Ethical considerations

A cover letter including an introduction to the study and an assurance of anonymity and voluntariness was provided together with the questionnaire. This study was

approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101).

## 5 SUMMARY OF RESULTS

### 5.1 Characteristics of the responders (publications I-IV)

In total, 1 763 valid responses were received, giving an overall response rate of 56%. Characteristics of the participants are shown in Table 3. A majority of the responders were women, except in the groups of surgeons in both study years and internists in 1999. Medical students were younger than the physicians and were less often married. Most of the GPs worked in outpatient clinics in both years (78% in 1999 and 85% in 2015), while the other physicians mainly worked in hospitals (66–88%).

**Table 3.** Characteristics of the responders.

	Surgeons			Internists			GPs			Oncologists			Physicians with cPM <sup>†</sup>	Physicians total	Medical students 2015-2016
	1999	2015	1999	2015	1999	2015	1999	2015	2015 <sup>‡</sup>	1999	2015 <sup>‡</sup>	2015 <sup>‡</sup>	2015		
Number (% of total)	175 (10)	142 (8)	184 (10)	153 (9)	316 (18)	245 (14)	54 (3)	104 (6)		54 (3)	104 (6)		67 (4)	1 361 (77)	402 (23)
Response rate, %	58	47	61	47	63	49				51	66		82	54	63
Female, n (%)	33 (19)	47 (33)	60 (33)	81 (53)	170 (55)	173 (71)	30 (56)	85 (82)		30 (56)	85 (82)		57 (85)	711 (52)	248 (62)
Mean age (range)	48 (33-66)	51 (33-64)	48 (32-70)	52 (33-65)	42 (25-63)	47 (25-65)	46 (35-61)	48 (32-67)		46 (35-61)	48 (32-67)		53 (35-66)	48 (25-70)	27 (23-46)
Working place*															
Outpatient unit	1 (1)	2 (1)	15 (9)	15 (10)	242 (78)	208 (85)	2 (4)	4 (4)		2 (4)	4 (4)		12 (18)	501 (37)	
Hospital	146 (85)	124 (88)	123 (71)	122 (82)	33 (11)	24 (10)	44 (83)	91 (88)		44 (83)	91 (88)		44 (66)	740 (54)	
Other	24 (14)	15 (11)	35 (20)	12 (8)	35 (11)	10 (4)	7 (13)	8 (8)		7 (13)	8 (8)		11 (16)	156 (11)	
Years from graduation, median (range)**	22 (2-42)	26 (7-42)	21 (7-41)	26 (8-42)	16 (1-35)	21 (0-40)	18 (9-34)	22 (7-40)		18 (9-34)	22 (7-40)		27 (9-42)	21 (0-42)	
Married, n (%)	140 (81)	119 (84)	142 (79)	124 (81)	228 (73)	198 (81)	45 (83)	71 (71)		45 (83)	71 (71)		54 (81)	1 091 (80)	206 (51)

\*For 32 responders working place was not available

\*\*For 20 responders year of graduation was not available

<sup>‡</sup>12 oncologists in 2015 had also cPM and are included in both of these groups in this table

GP: General Practitioners, cPM: Special competency in Palliative Medicine

## 5.2 Decision-making at the end-of-life

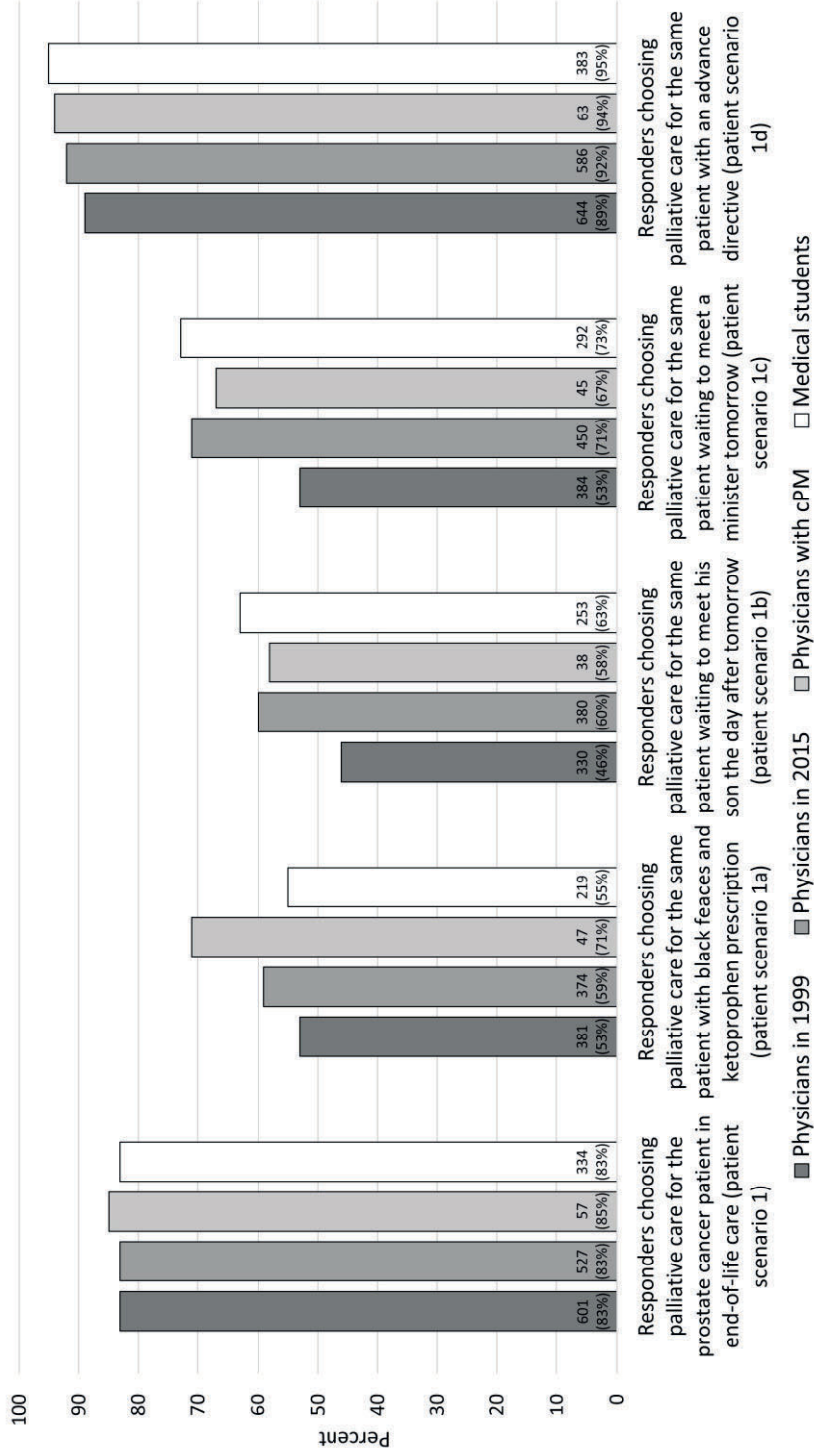
### 5.2.1 Choosing palliative care over life prolongation at the end-of-life (publications II and IV)

Responders' answers for the hypothetical patient scenario representing the prostate cancer patient in EOL care with deteriorating overall condition (patient scenario 1) are summarized in Figure 1.

Most responders (83–85%) chose a palliative care approach in the original scenario with no significant differences between the groups. In the alternative situation where the same patient probably had iatrogenic gastrointestinal (GI)-bleeding (patient scenario 1a), the amount of palliative care approaches decreased. A palliative care approach was chosen significantly more often by the physicians in 2015 than in 1999 ( $p=0.014$ ) and by those with cPM than the others ( $p=0.049$ ), whereas no significant difference between the students and the experienced GPs was found (55% vs 60% of the responders chose a palliative approach,  $p=0.230$ ). Physicians answering in 1999 chose active or intensive care more frequently than in 2015 when the patient was waiting to see his son (patient scenario 1b) or a minister to have a Lord's Supper (patient scenario 1c) ( $p<0.001$  in both). No significant difference was found between the answers of the experienced GPs and the students when the son was coming (60% vs 63% of the responders chose a palliative approach,  $p=0.406$ ) and when an appointment with a minister was planned (71% vs 73% of the responders chose a palliative approach,  $p=0.598$ ). When an AD was found, almost all responders (89–95%) chose a palliative care approach.

Some of the physicians' opinions influencing their decisions regarding the prostate cancer patient in patient scenario 1 changed from 1999 to 2015. In 2015, patient's benefit (96% vs 99%,  $p=0.001$ ), ethical values (83% vs 93%,  $p<0.001$ ) and patient's (68 vs 86%,  $p<0.001$ ) or physician's legal protection (44% vs 63%,  $p<0.001$ ) were considered more influential on the decision-making, while the family's benefit (37% vs 25%,  $p<0.001$ ) and patient's age (46% vs 40%,  $p=0.023$ ) were regarded as less influential than in 1999.





**Figure 1.** The number and proportion (%) of the physicians and the medical students choosing palliative care approach for the patient with prostate cancer and deteriorating overall condition (patient scenario 1). Numbers and proportions are marked inside the bars. cPM: Special competency in Palliative Medicine.

Logistic regression analysis from the cohorts of physicians answering in 1999 and 2015 (excluding physicians with cPM except if they were oncologists) was carried out to explore the factors associated with physicians' decisions concerning the prostate cancer patient with probable iatrogenic GI-bleeding and waiting to meet his son or a minister (patient scenarios 1a–c). The year of the survey remained as a significant independent factor explaining the physicians' decision in these patient scenarios (patient scenario 1a OR 0.65 (CI 95% 0.48, 0.88), patient scenario 1b OR 0.41 (95% CI 0.30, 0.56), and patient scenario 1c OR 0.47 (95% CI 0.36, 0.63)). In general, physicians answering in 2015 were less eager to choose active or intensive care. Willingness to withdraw LSTs (patient scenario 1a OR 0.92 (95% CI 0.87, 0.97), patient scenario 1b OR 0.94 (95% CI 0.90, 0.99), patient scenario 1c OR 0.91 (95% CI 0.86, 0.96)) and having postgraduate EOL training (patient scenario 1a OR 0.54 (95% CI 0.39, 0.73), patient scenario 1b OR 0.60 (95% CI 0.45, 0.80), patient scenario 1c OR 0.68 (95% CI 0.51, 0.92)) were also significantly associated with a decreased likelihood of choosing active or intensive care in all of these scenarios. In addition, men more often chose a palliative care approach for the seriously ill prostate cancer patient even when the GI-bleeding was detected (patient scenario 1a OR 0.67 (95% CI 0.51, 0.88)) and when the son was coming (patient scenario 1b OR 0.65 (95% CI 0.50, 0.84)).

All the responders were influenced by the probable iatrogenic GI-bleeding, the possibility of the son seeing his father while he was still alive, and the spiritual anxiety of the prostate cancer patient, as active and intensive care approaches increased in these situations, although there were variations between the specialty groups. On the other hand, a discovery of a written AD clearly shifted the answers towards a palliative care approach.

## 5.2.2 Willingness to withdraw or withhold therapies (publications I and IV)

When the responders were asked to evaluate their willingness to withdraw or withhold different therapies, it was discovered that the experienced GPs were more willing to forgo therapies compared to the medical students. Similarly, the physicians with cPM were more willing to forgo therapies compared to the other physicians in 2015. However, these differences varied between the therapies. These results are shown in Tables 4 and 5.

**Table 4.** Number and proportion (%) of the physicians answering in 2015 and the medical students answering in 2015 and 2016 deciding to withdraw a treatment in the scenario representing the patient with an end-stage lung cancer (patient scenario 7).

<i>Treatment</i>	<i>Patient scenario</i>	<i>Physicians with cPM</i>	<i>Surgeons</i>	<i>Internist</i>	<i>GPs</i>	<i>Oncologists</i>	<i>Students<sup>1</sup></i>
Antibiotic	Original scenario	41 (65)	72 (51)	78 (51)	128 (53)	45 (54)	150 (37)
	Family's appeal	33 (50)	55 (39)	55 (36)	89 (37)*	34 (37)	91 (23)
	AD	58 (87)	116 (83)	122 (82)	204 (84)	82 (89)	320 (80)
Mechanical ventilation	Original scenario	63 (96)	119 (85)*	135 (89)	195 (81)*	83 (91)	300 (75)
	Family's appeal	59 (92)	113 (80)*	126 (83)	175 (72)*	76 (84)	263 (66)
	AD	67 (100)	130 (92)*	147 (98)	228 (94)*	90 (99)	373 (93)
Intravenous hydration	Original scenario	43 (65)	31 (22)**	39 (26)**	85 (35)**	42 (46)*	128 (32)
	Family's appeal	26 (40)	21 (15)**	19 (13)**	58 (24)*	34 (37)	93 (23)
	AD	58 (88)	64 (46)**	84 (56)**	162 (67)*	75 (82)	267 (67)
Nasogastric tube	Original scenario	62 (95)	85 (60)**	98 (65)**	161 (67)**	63 (69)**	225 (56)
	Family's appeal	60 (92)	76 (54)**	87 (58)**	126 (53)**	64 (70)*	192 (48)
	AD	64 (97)	105 (75)**	126 (84)*	203 (84)*	82 (89)	306 (77)
Thrombos prophylaxis	Original scenario	55 (85)	108 (76)	105 (69)*	151 (62)*	73 (80)	219 (55)
	Family's appeal	52 (80)	104 (74)	95 (64)*	128 (53)**	67 (73)	191 (48)
	AD	63 (96)	121 (88)	127 (85)*	199 (82)*	86 (94)	322 (80)
Supplementary oxygen	Original scenario	11 (16)	16 (11)	23 (15)	14 (6)*	11 (12)	18 (5)
	Family's appeal	12 (18)	14 (10)	13 (9)*	12 (5)	6 (7)*	8 (2)
	AD	20 (30)	40 (28)	46 (31)	51 (21)	27 (29)	70 (18)

<sup>1</sup>Statistical comparison between physicians and students not shown in the table (see text for the comparison between experienced GPs and the students)

\*p < 0.05 and \*\*p < 0.001 compared to physicians with cPM

cPM: Special competency in Palliative Medicine, GP: General Practitioner, AD: Advance Directive

**Table 5.** Number and proportion (%) of the physicians answering in 2015 and the medical students answering in 2015 and 2016 deciding to withhold a treatment in the scenario representing the patient with an end-stage lung cancer (patient scenario 7)

<i>Treatment</i>	<i>Patient scenario</i>	<i>Physicians with cPM</i>		<i>Surgeons</i>		<i>Internists</i>		<i>GPs</i>		<i>Oncologists</i>		<i>Students<sup>1</sup></i>	
Blood transfusion	Original scenario	60	(91)	98	(70)*	108	(72)*	185	(76)*	72	(78)*	265	(67)
	Family's appeal	55	(85)	90	(64)*	85	(56)**	153	(64)*	67	(76)	225	(56)
	AD	66	(99)	132	(94)	136	(91)	227	(94)	90	(98)	367	(92)
Pleural drainage	Original scenario	43	(65)	59	(42)*	85	(56)	99	(41)**	58	(64)	84	(21)
	Family's appeal	41	(63)	57	(40)*	73	(49)	89	(37)**	51	(56)	72	(18)
	AD	53	(79)	103	(73)	119	(80)	179	(74)	82	(89)	208	(52)
Chest X-ray	Original scenario	51	(77)	66	(47)**	88	(58)*	119	(60)**	67	(73)	162	(41)
	Family's appeal	44	(67)	61	(43)*	74	(49)*	29	(38)**	59	(65)	144	(36)
	AD	59	(88)	111	(79)	124	(83)	194	(81)	90	(98)*	280	(70)
Laboratory tests	Original scenario	49	(74)	70	(59)*	87	(57)*	121	(50)*	59	(64)	178	(45)
	Family's appeal	40	(61)	60	(43)*	67	(45)*	85	(35)**	51	(56)	144	(36)
	AD	58	(87)	115	(81)	119	(78)	190	(78)	88	(96)*	299	(75)

<sup>1</sup>Statistical comparison between physicians and students not shown in the table (see text for the comparison between experienced GPs and the students)

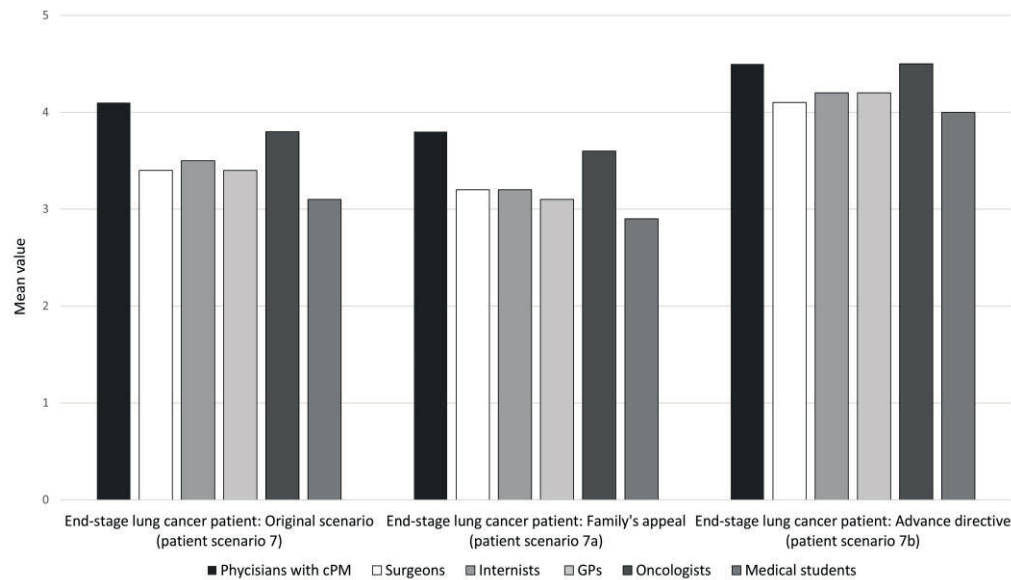
\*p < 0.05 and \*\*p < 0.001 compared to physicians with cPM

cPM: Special competency in Palliative Medicine, GP: General Practitioner, AD: Advance Directive

In the original patient scenario of the lung cancer patient, experienced GPs withdrew antibiotics (55% vs 37%, p<0.001) and the nasogastric tube (67% vs 56%, p=0.007) more often than the medical students, and they withheld blood transfusion (79% vs 67%, p=0.002), pleural drainage (42% vs 21%, p<0.001) and avoided a chest X-ray (52% vs 41%, p=0.006) more frequently as well. Supplementary oxygen was

continued (94–95%), and mechanical ventilation was withdrawn (75–81%) by most of the responders, without significant differences between the students and the GPs.

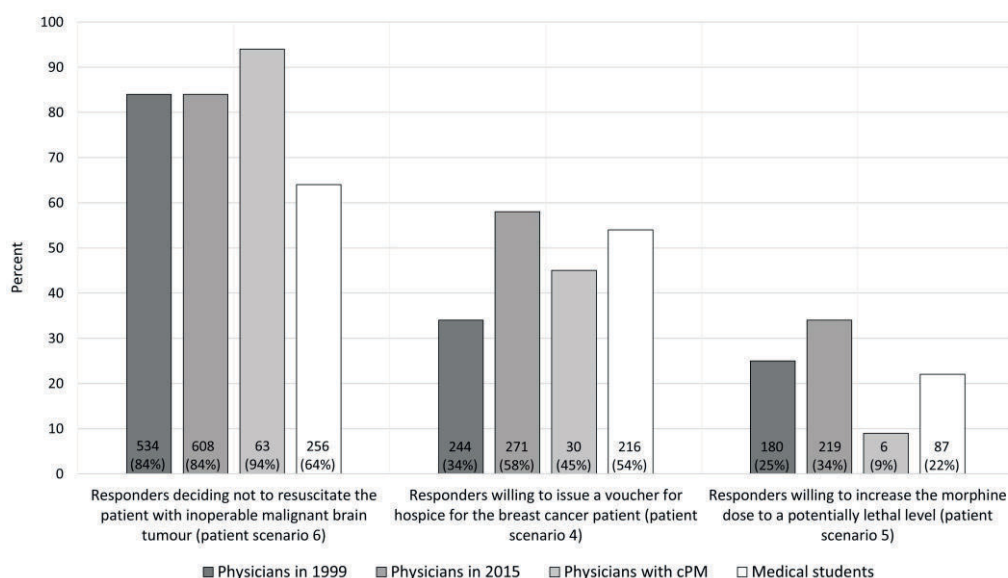
General willingness to withhold or withdraw therapies according to responder groups in 2015 is shown in Figure 2. In the original scenario, the physicians with cPM were significantly more willing to withhold or withdraw therapies compared to the other physicians in 2015 ( $p<0.001$ ). The family's appeal for everything to be done significantly decreased ( $p<0.001$ ) and an advance directive increased ( $p<0.001$ ) the willingness to forgo therapies, but the difference between the physicians with cPM and the other physicians remained ( $p<0.001$  and  $p=0.010$ , respectively). As it is presented in the Tables 4 and 5, the difference in decision-making regarding individual treatments between the physicians with and without cPM was most striking in withdrawing intravenous hydration, removing the nasogastric tube and withholding blood transfusions. In contrast, some decisions (e.g., withdrawing oxygen or antibiotics) varied only slightly. Mechanical ventilation was withdrawn by most of the physicians, while supplementary oxygen was frequently continued by all of the physicians answering in 2015.



**Figure 2.** Mean values (scale from 1 to 5) of all the ten answers in the end-stage lung cancer patient scenario (patient scenario 7) according to responder groups. cPM: Special competency in Palliative Medicine, GP: General Practitioner.

When responses of the physicians answering in 2015 were fitted with a trajectory analysis, four differently behaving groups were found. In trajectory group 1, responders were consistently willing to withdraw and withhold therapies, and in trajectory group 2, responders would probably withdraw and withhold therapies, but their decisions were influenced by the family's appeal and the AD. In contrast, responders in trajectory group 3 were either uncertain or chose an aggressive approach in about half of their decisions, and they were more influenced by the AD, while physicians in trajectory group 4 were most hesitant to withdraw and withhold therapies. Factors associated with the physicians' willingness to continue or start LSTs during EOL care (belonging to trajectory groups 3 or 4) were tested with logistic regression analysis. Younger age (OR 3.19 (95% CI 1.54–6.57)) and being an internist (OR 4.27 (95% CI 2.13–8.56)), a surgeon (OR 4.51 (95% CI 2.25–9.07)) or a GP (OR 5.60 (95% CI 2.85–11.0)) were independent factors behind the decision not to withhold—or to withdraw—different interventions.

Figure 3 presents overall results concerning a patient with an inoperable malignant brain tumor (patient scenario 6). The proportion of the physicians choosing to forgo resuscitation did not change from 1999 to 2015, remaining at 84%. In 2015, physicians with cPM decided not to resuscitate more often than other physicians ( $p=0.025$ ), and the experienced GPs were more willing to forgo resuscitation than the students (82% vs 64%,  $p<0.001$ ).



**Figure 3.** Number and proportion (%) of the responders deciding not to resuscitate the patient with an inoperable malignant brain tumour (patient scenario 6), willing to issue a voucher for hospice for the breast cancer patient (patient scenario 4) and willing to increase the morphine dose to a potentially lethal level (patient scenario 5). Numbers and proportions are marked inside the bars. cPM: Special competency in Palliative Medicine.

### 5.2.3 Complying with patient's wish for the hospice care (publication III)

Patient scenario 4 presented a patient with advanced breast cancer who asked for a hospice voucher. In 1999, physicians were more reluctant to issue a voucher than physicians in 2015 ( $p < 0.001$ ). Among physicians answering in 2015, those with cPM were more unwilling to issue a voucher than the others ( $p = 0.038$ ), while there was no significant difference between the students and the experienced GPs (54% vs 48%,  $p = 0.156$ ). Summary of these results is presented in Figure 3.

A logistic regression analysis from the cohorts of physicians answering in 1999 and 2015 (excluding physicians with cPM, except if they were oncologists), was done to study the factors associated with the willingness to issue a voucher. The responders in 2015 still remained independently more willing to issue a voucher than the responders in 1999 (OR 2.62 (95% CI 1.96–3.50)).

## 5.2.4 Accepting morphine dosing with probable risk of hastened death (publication II)

Most of the responders refused (66-91%) to increase a morphine dose to a potentially lethal level when the prostate cancer patient requested for it (patient scenario 5). However, there were clear variations between the groups as shown in Figure 3. The students were more reluctant than the experienced GPs (22% vs 32%,  $p=0.004$ ), the physicians with cPM were more reluctant than the other physicians in 2015 ( $p<0.001$ ) and the physicians answering in 1999 were more reluctant than the physicians answering in 2015 ( $p<0.001$ ).

In 1999, leniency towards euthanasia (median VAS 37 (interquartile range (IQR) 11-69) vs 14 (IQR 5–39),  $p<0.001$ ) and assisted suicide (median VAS 27 (IQR 9–61) vs 11 (IQR 4–28),  $p<0.001$ ) were significantly greater among those who agreed to increase the morphine dose, while this was true only for assisted suicide in 2015 (median VAS 28 (IQR 2–68) vs 10 (IQR 1–49),  $p<0.001$ ). Religion had a significantly greater influence on decision-making for those physicians who did not agree to double the morphine dose in 1999 (median VAS 57 (IQR 30–92) vs 77 (IQR 44–94),  $p=0.040$ ), but not in 2015 (median VAS 78 (IQR 45–98) vs 86 (IQR 49–98),  $p=0.130$ ). From the logistic regression analysis, the most important factor that independently influenced physicians' willingness to increase the morphine dose in the cohorts of physicians answering in 1999 and 2015 (excluding physicians with cPM except if they were oncologists) was not being an oncologist—OR 2.50 (95% CI 1.40, 4.46) for surgeons, OR 2.37 (95% CI 1.34, 4.20) for internists, and OR 2.30 (95% CI 1.33, 3.97) for GPs. In addition, male physicians (OR 1.51 (95% CI 1.11, 2.05)), those who were older (OR 1.02 (95% CI 1.01, 1.04)), did not believe in God (OR 1.64 (95% CI 1.23, 2.19)), accepted assisted suicide (OR 1.13 (95% CI 1.08, 1.19)), had doubts about physicians' ability to assess cancer pain (OR 0.94 (95% CI 0.89, 0.99)), and responded in 2015 (OR 1.40 (95% CI 1.05, 1.88)) were also more likely to be willing to increase the morphine dose.



## 5.3 Attitudes, values and background factors

Summary of the responders' attitudes, values and background factors is shown in Tables 6 and 7.

**Table 6.** Attitudes of the physicians in 1999 or 2015, the physicians with cPM and the medical students. Attitudes are expressed on a visual analogue scale (VAS) from 0 mm (definitely agree) to 100 mm (definitely disagree).

	<i>Physicians answering in 1999</i>		<i>Physicians answering in 2015<sup>1</sup></i>		<i>Physicians with cPM<sup>1</sup> 2015</i>		<i>Medical students 2015-2016</i>	
<b>Attitudes, median VAS (IQR)</b>								
Active euthanasia is reprehensible	17	(6-51)	25	(5-66)	12	(2-57)	58	(20-77)
Withdrawal of life-sustaining treatments is reprehensible	89	(76-95)	93	(76-99)	98	(83-99)	93	(80-98)
Assisted suicide is reprehensible	14	(5-38)	13	(2-52)	46	(4-68)	38	(10-69)
End-of-life care is satisfying	36	(19-52)	15	(3-35)	2	(0-7)	26	(12-49)
People should pay costs of factitious diseases by themselves	44	(27-72)	78	(46-93)	93	(80-99)	66	(40-84)
Advance directives have been helpful in my decisions	35	(14-54)	10	(2-29)	5	(1-23)	14	(3-30)
Good palliative care enables good death	17	(9-28)	4	(1-12)	5	(1-12)	4	(1-11)
Physicians can't estimate cancer pain	40	(25-70)	47	(27-72)	49	(29-75)	46	(28-65)
Religion has influence when I make ethical decisions	65	(31-93)	81	(47-98)	82	(45-98)	88	(50-98)
Being a doctor gives me satisfaction	20	(11-30)	7	(2-18)	4	(1-14)	15	(4-28)
My health is excellent	20	(10-32)	14	(6-26)	17	(3-33)	13	(6-25)
I feel burn out, tired to work	84	(63-94)	89	(71-97)	92	(73-98)	85	(59-94)
I am pleased with my salary	72	(37-87)	22	(7-50)	15	(2-42)	13	(3-29)
It is waste of resources to treat patients > 80 years in ICU	73	(49-86)	77	(54-93)	79	(66-98)	70	(50-85)

<sup>1</sup>13 oncologists in 2015 had also cPM and are included in both of these groups in this table

cPM: Special competency in Palliative Medicine, VAS: Visual Analogue Scale, IQR: Interquartile Range, ICU: Intensive Care Unit

### 5.3.1 Background factors and attitudes of the responders (publications I-IV)

Advance directives were most frequent among the physicians with cPM ( $p<0.001$  compared with all other physicians in 2015). Although the physicians in 2015 considered advance directives to be more helpful than in 1999 ( $p<0.001$ ), the number of physicians' own advance directives did not change between 1999 and 2015 ( $p=0.668$ ). All the physicians with cPM had taken care of EOL patients in practice during the last two years. The medical students and the experienced GPs did not differ statistically (64% vs 63%,  $p=0.878$ ) when asked about caring for EOL patients in practice but the experienced GPs had taken care of a family member at the EOL significantly more often (32% vs 50%,  $p<0.001$ ).

The physicians with cPM considered withdrawal of LSTs as less reprehensible ( $p=0.041$ ) and EOL care as more satisfying ( $p<0.001$ ) compared to other physicians. When the experienced GPs and the medical students were compared, EOL care was considered more satisfying by the GPs (median VAS 17 vs 26,  $p<0.001$ ), but there was no difference regarding the attitudes towards withdrawal of LSTs (median VAS 93 vs 93,  $p=0.588$ ). Believing that good palliative care enables a good death increased from 1999 to 2015 ( $p<0.001$ ), whereas there were no differences between the physicians with cPM vs the others ( $p=0.967$ ) and the students vs the experienced GPs (median VAS 4 vs 4,  $p=0.372$ ). The impact of ADs on ethical decisions increased ( $p<0.001$ ), while the influence of religion decreased ( $p<0.001$ ) from 1999 to 2015. The experienced GPs thought ADs were more helpful than students, and religion had more influence on the decisions of the experienced GPs than on the decisions of the students (median VAS 5 vs 14,  $p<0.001$  and median VAS 74 vs 88,  $p=0.001$ , respectively).

**Table 7.** Background factors and life values of the physicians in 1999 or 2015, the physicians with cPM and the medical students.

	<i>Physicians answering in 1999</i>		<i>Physicians answering in 2015<sup>1</sup></i>		<i>Physicians with cPM<sup>1</sup> 2015</i>		<i>Medical students 2015-2016</i>	
<b>Background factors and life values, n (%)</b>								
Having children	600	(85)	555	(88)	59	(86)	51	(13)
Having own advance directive	38	(5)	38	(6)	12	(18)	31	(8)
Taking care of end-of-life patients in practice (last 2 years)	529	(75)	418	(65)	67	(100)	256	(64)
Taking care of a family member in end-of-life	513	(73)	314	(49)	47	(49)	128	(32)
Length of life is important	412	(59)	524	(87)	52	(80)	330	(85)
Health is important	711	(99)	610	(99)	65	(100)	389	(100)
Family is important	686	(95)	607	(99)	65	(100)	386	(99)
Clean environment is important	666	(93)	599	(98)	64	(99)	360	(93)
High standard of living is important	358	(50)	398	(65)	34	(52)	262	(68)
Faith in God is important	338	(48)	253	(42)	25	(39)	84	(22)
Success in professional career is important	639	(89)	377	(62)	37	(57)	235	(60)

<sup>1</sup>13 oncologists in 2015 had also in cPM and are included in both of these groups in this table  
cPM: Special competency in Palliative Medicine

### 5.3.2 Values of the responders (publications I-IV)

All of the physicians and students considered health to be an important life value (99–100%). The importance of family and a high standard of living both increased from 1999 to 2015 ( $p < 0.001$  for both), whereas the importance of success in professional career and faith in God decreased between 1999 and 2015 ( $p < 0.001$  and  $p = 0.024$ , respectively). The most significant difference between the medical students and the experienced GPs concerning life values was the lower importance of faith in God among the students (51% vs 22%,  $p < 0.001$ ).

### 5.3.3 Attitudes on assisted death (publications II and IV)

The medical students considered euthanasia (median VAS 58 vs 24) and assisted suicide (median VAS 38 vs 10) to be significantly less reprehensible than the experienced GPs ( $p < 0.001$  for both). Euthanasia was considered more reprehensible in 1999 than in 2015 ( $p = 0.008$ ), but there was no difference concerning assisted suicide between these years ( $p = 0.480$ ). The physicians with cPM considered assisted suicide to be less reprehensible than the other physicians in 2015 ( $p = 0.013$ ), but there was no difference concerning euthanasia ( $p = 0.102$ ).

## 6 DISCUSSION

In this thesis, EOL decisions concerning hypothetical cancer patients, possible changes in these decisions over time, and factors influencing them were evaluated among Finnish physicians and medical students. Many aspects of the decision-making were influenced by the year of the survey (1999 vs 2015), whether physician had cPM or not and by the clinical experience of the responders.

### 6.1 Factors influencing end-of-life decision-making

#### 6.1.1 Willingness to choose palliative care or to forgo treatment at the end-of-life

When responders were asked to choose between palliative, active or intensive care for the prostate cancer patient with a deteriorating overall condition (patient scenario 1), most of them chose a palliative care approach. In the following scenarios, where the same patient probably had iatrogenic GI-bleeding (patient scenario 1a) and when the patient was waiting to see his son (patient scenario 1b) or a minister to have a Lord's Supper (patient scenario 1c), the number of physicians choosing a palliative care approach decreased. When willingness to withhold or withdraw treatments concerning the metastatic end-stage lung cancer patient (patient scenario 7) was asked, responders were highly influenced by the family's request for everything to be done. Compared to the experienced GPs, the medical students were similarly influenced without significant differences by the family's appeal in the case of the end-stage lung cancer patient (patient scenario 7) or the presence of an AD for the prostate cancer patient with a deteriorating overall condition (patient scenario 1) and in the case of the end-stage lung cancer patient (patient scenario 7).

A family's opinion has been shown to have marked influence on physicians' decision-making<sup>36,37,232</sup>. The findings in this thesis are in line with previous studies, since the family's request for aggressive treatment significantly increased the physicians' willingness to continue or start LSTs. However, in 2015, physicians

reported to be less influenced by the family's benefit, which probably influenced their unwillingness to choose active and intensive care when the son of the seriously ill prostate cancer patient was coming (patient scenario 1b). This lower influence of the family's benefit may be related to the rising individualism and to the increase in human and patient rights in Western countries<sup>50,52,53,56,57,287</sup>.

Guilt has been shown to be one of the reasons that futile treatments are maintained in EOL care<sup>288</sup>. This could explain, at least to some extent, why approximately half of the physicians chose an active approach upon discovery of the GI-bleeding that was likely caused by the previously prescribed ketoprophen, although this shift to life-sustaining treatment was slightly less common in 2015. This tendency to correct possible complications of previous therapies is understandable. On the other hand, the principal justification for treatment should be the patient's benefit rather than the feelings of guilt experienced by the physician.

It is not surprising that an appointment with a minister shifted the treatment decisions to life-prolonging modalities less often in 2015 than in 1999 because religion was considered less influential in decision-making and fewer physicians had faith in God in 2015 than in 1999. Religion has also been shown to have significant effects on EOL decisions in general by shifting decisions towards continuing LSTs<sup>23-25,42</sup>.

After finding the prostate cancer patient's AD in patient scenario 1d, almost all physicians chose a palliative care approach. Similarly, the presence of an AD detected in the case of the lung cancer patient (patient scenario 7) significantly decreased the willingness to start or continue LSTs. This is well in line with earlier studies showing that ADs help the decision-making process in EOL care, although physicians are concerned whether ADs genuinely express a patient's own will<sup>36,39,40,171</sup>.

## 6.1.2 Education and experience of a physician

The medical students were less willing to withhold blood transfusions, pleural drainage and chest X-rays than the experienced GPs (79% vs 67%, 42% vs 21% and 52% vs 41%, respectively). Mechanical ventilation was withdrawn, and supplementary oxygen continued, by most of the students and GPs alike (75% vs 81% and 95% vs 94%, respectively). In contrast to our findings, 41% of medical students objected to withdrawing artificial life-support in a large Brazilian study<sup>248</sup>. This difference might be because the practice of withdrawing mechanical ventilation varies largely depending on the country and culture<sup>193</sup>. Blood transfusions have been

shown to be the most frequently withdrawn treatments in EOL care, both in survey studies and in prospective clinical studies<sup>289,290</sup>. The benefit of blood transfusions in EOL care is often brief and adverse effects are a risk for the patient, although they rarely occur<sup>210</sup>. Dyspnoea can sometimes be alleviated by pleural drainage, but the procedure is invasive and has a risk of a pneumothorax<sup>291</sup>. We suggest that the main reason why GPs are more willing to withhold these procedures is because they have experience with the risks and inconveniences of these interventions among frail patients. Further, many conditions, such as pulmonary oedema, can be detected by clinical examination without X-rays in EOL care and GPs might have had better knowledge of this.

Students were twice as likely as the GPs to attempt resuscitation on the patient with an advanced brain tumour (patient scenario 6). Cancer patient survival from CPR declines towards zero as the cancer advances and performance status declines<sup>218</sup>. Thus, in the case of an advanced brain tumour patient, resuscitation can be considered to be futile<sup>218</sup>. The growing clinical experience of a physician probably offers more insight into whether CPR may or may not be futile, explaining the difference between GPs and students.

Over 80% of both the students and the GPs chose palliative care for a patient clearly approaching death (a comatose patient with prostate cancer in patient scenario 1). Although the palliative care approach in this scenario could be regarded as obvious, our result shows that medical schools in Finland seem to offer a basic understanding of EOL care. This is highlighted by the similar compliance of students and experienced GPs to issue a voucher for hospice for the advanced breast cancer patient (patient scenario 4).

GPs accepted the potential risk of hastening death by giving a high morphine dose more often than the students in the case of the paralyzed prostate cancer patient (patient scenario 5), although less than one third accepted this in both groups. In a study from Puerto Rico, 50% of the students and 80% of the faculty members considered that prescribing drugs to alleviate pain despite the risk of hastening death was ethical<sup>249</sup>. In another study from Poland, only 12% of the physicians, but 51% of the medical students, regarded that it was always wrong to exceed a defined dosage of morphine<sup>266</sup>. Although opioids may cause respiratory depression, even high doses of opioids used for symptom control do not seem to shorten the life of patients in EOL care<sup>292-296</sup>. Thus, the willingness of the GPs to increase the morphine dose might be due to an enhanced understanding of the effects of opioids. However, the actual acceptance of hastening death cannot be ruled out.

The physicians with cPM were more willing to withdraw and withhold LSTs, especially intravenous hydration and a nasogastric tube, compared to the other physician groups in a patient scenario representing end-stage lung cancer (patient scenario 7). We suggest that this willingness is related to the cPM itself, because its influence remained after multivariate analysis which took into account important background factors. Physicians with cPM also forwent resuscitation more often than the others (patient scenario 6) but were less willing to issue a voucher to a hospice for a breast cancer patient who wished for it (patient scenario 4). The influence of education is further supported by the results from the logistic regression analysis in which having post-graduate EOL training was significantly associated with a decreased likelihood of choosing active and intensive care in patient scenarios 1a, b and c concerning the prostate cancer patient with a deteriorating overall condition. Although education in palliative care increases the knowledge and skills needed to perform high-quality EOL care, the effectiveness of special training in palliative medicine on different aspects of decision-making in EOL care have been unknown<sup>29,31,32,112,113</sup>. It can be argued that formal training in PM endows one with a good ability to consider and communicate EOL decisions, probably leading to both more decisions to withdraw or withhold treatments and to better confidence in symptom control and care for the breast cancer patient in a community hospital ward. However, the latter issue could be criticized as taking care of a patient at the EOL should be multidisciplinary<sup>72</sup>. Thus, having a physician who is specialized in palliative and EOL care does not necessary mean that the holistic view of palliative care is achieved, if other professionals of the team are not familiar with the principles of palliative care, which could be the case in community hospitals.

The physicians with cPM were more reluctant than the other physicians to increase the morphine dose to a potentially lethal level when the paralyzed prostate cancer patient requested it (patient scenario 5). This finding might be due to the better knowledge of adjacent drug therapies and other treatment modalities for pain control, more practical experience in the use of opioids during EOL care and perhaps a better awareness that a patient's wish to hasten death does not always imply a genuine wish to die, but might be the result of overwhelming emotional suffering<sup>282,283</sup>.

The age of a physician is a contradictory factor in decision-making<sup>24</sup>. In this thesis, younger age was an independent factor behind the decision not to withhold or to withdraw different interventions in EOL care. This is in line with multiple studies where older age has been associated with more decisions to withhold or withdraw interventions, but does not agree with the few studies where younger



physicians made less aggressive decisions<sup>18,23,45,236,238,239,242</sup>. Reasons behind these different results can only be speculated by the authors; they have not been investigated as part of these studies<sup>18,23,45,236,238,239,242</sup>.

### 6.1.3 Changes between 1999 and 2015

The year of the survey was an important factor explaining physicians' decisions during the EOL care in this thesis. In 2015, the physicians accepted the risk of hastened death from increasing the morphine dose more frequently than in 1999. The physicians' decisions to choose palliative care approaches significantly increased from 1999 to 2015, and physicians were also more willing to issue a voucher for hospice in 2015. Our findings may reflect increasing support of patient's preferences, a decreased importance of family and religion among our responders, and better knowledge of the principles of palliative care<sup>49,51,82,85,120,297</sup>. Today, patient-centred care and shared decision-making are preferred by most physicians and patients<sup>49,51,120,121</sup>. Advances and benefits of palliative care are more evident and better known today than in the late 1990s<sup>4,6-8,10,11,298-300</sup>.

In general, physicians accepted potentially lethal morphine dosing more frequently today than in 1999, although approximately two-thirds of the doctors were still unwilling to provide this. As discussed above, this result might be due to the actual acceptance of hastening death at the EOL, better knowledge regarding the use of opioids, or both. It is now known that clinically relevant respiratory failure is not a problem when opioids are titrated against cancer pain<sup>301</sup>. Since 1999, there has been growing evidence that the use of opioids for symptom control in advanced diseases has no effect on survival, and even high doses of opioids do not seem to shorten life during EOL care<sup>294,296</sup>. However, the potential of opioids to hasten death during EOL care is almost impossible to study in prospective randomized trial settings. In a study conducted in the Netherlands, physicians administered similar dosages of opioids in 1995, 2001 and 2005, but in 2005 they thought that life was shortened by the opioids or that their intention was to hasten death by administering opioids less frequently than in previous years<sup>280</sup>. Although we did not ask the intention behind physicians' willingness to increase the morphine dose, it was clearly stated in the patient scenario that the increased dose might lead to the patient's death. Therefore, we cannot rule out the possibility that this result reflects an increased acceptance of hastening death, while taking into account the previous studies showing an increased acceptance of euthanasia in Finland<sup>258-260</sup>. The oncologists

were most reluctant to increase the morphine dosing, and their opinion did not change between 1999 and 2015. This might be due to the fact that they were probably most familiar with the influences of opioids in clinical practice, as well as with the studies on this issue. These results are in line with the study by Miccinesi et al. in which oncologists were the least in favour of using drugs in lethal doses<sup>26</sup>. In the current study, the difference between the oncologists and the other physician groups remained in the results of the logistic regression analysis accounted for relevant confounding factors.

The influence of patient's benefit on the physicians' decision-making rose between the years studied. The rise of individualism and the well-established status of patient's rights today in western parts of the world might reflect to this change, as well as the fact that today respecting patient's wishes is one of the main principles in the ethical guideline of the Finnish Medical Association<sup>50,52,53,56,57,62,287</sup>. Both patient's and physician's legal protection was considered more influential today than sixteen years ago. In Finland, patient's rights regarding treatment decisions were incorporated into Finnish law in 1992, which has obviously emphasized the importance of the patient's legal protection<sup>60</sup>. These results also raise the question as to whether physicians are more concerned about malpractice claims at present than they were sixteen years ago. The data from malpractice claims from other countries is conflicting, as some studies show an increasing amount of malpractice claims, while others show a clear decrease<sup>302,303</sup>. In contrast to these results, the law appeared to play a limited role in medical EOL decision-making, as doctors prioritized patient-related clinical and ethical considerations over law in a recent study from Australia<sup>304</sup>. On the other hand, that study is partly in line with the current study, as ethical values were considered to be highly influential by our responders as well. Our findings emphasize the complexity of EOL decision-making and the different factors that affect it, as physicians consider both legal and ethical aspects to be important, and one does not exclude the other.

## 6.2 Differences in attitudes and values

Euthanasia was considered to be less reprehensible by the medical students compared to the experienced GPs and among the physicians in 2015 than in 1999. These findings are in agreement with previous studies showing an increased acceptance of euthanasia among physicians worldwide and in Finland and that students tend to be more in favour of euthanasia than practising

physicians<sup>64,249,258,260,266,305</sup>. Although we found a trend towards a lesser acceptance of euthanasia among physicians with cPM than without this training, this difference was not statistically significant, and PAS was, surprisingly, considered less reprehensible by the physicians with cPM compared to others. Thus, our results do not fully comply with earlier international studies showing that physicians who have the most experience in palliative care are strongest in their opposition to hastening death<sup>264,265,306</sup>. Finnish physicians without cPM considered PAS slightly more reprehensible than euthanasia and this did not change at all during the past 16 years. This result differs from previous studies where physicians' acceptance of PAS exceeds the acceptance of euthanasia but is in line with our finding on physicians with cPM, as they considered PAS less reprehensible than euthanasia<sup>64</sup>. One aim for future research could be to determine whether these somewhat conflicting results are due to a true difference in the attitudes towards these two procedures or just to less knowledge about the process of PAS in Finland. Public attitudes towards assisted death have changed since the 1990s to become more permissible, leading to the legalization of assisted death in some countries and increased political support for it in Finland<sup>64,257-259</sup>. These changes in the surrounding society and general attitudes might have had a substantial influence on these results. Finally, when comparing these results to previous studies, it has to be taken into account, that we asked whether the responder considered euthanasia or PAS "reprehensible" or not on a VAS scale. This differs from surveys asking "yes or no" questions regarding the acceptance of legislation or the practice of assisted death. Keeping this in mind, it must be said that even though attitudes have become more permissible, euthanasia was still considered reprehensible by physicians in 2015, as the median VAS was only 25 mm on a scale 0 (definitely agree) to 100 mm (definitely disagree).

Religion has been confirmed to have a tremendous effect on EOL decisions and attitudes towards euthanasia and PAS<sup>23,25,26,248,269</sup>. This complies with our results, as experienced GPs had faith in God and considered religion to influence their decision-making in EOL care more often than did the students, whereas students had a greater acceptance of euthanasia and PAS. Faith in God and the influence of religion on decision-making also decreased during the study years. This might have influenced the physicians' decision to accept the increase of the morphine dose more frequently in 2015 than in 1999, as faith in God was found to decrease physicians' willingness to administer a potentially lethal morphine dose. Löfmark et al. concluded that a non-religious philosophy of life increased physicians' willingness to perform euthanasia and PAS, possibly by emphasizing patient autonomy<sup>25</sup>.

In 2015, a clear majority of physicians and medical students thought that palliative care enables a good death. There was a significant increase in this opinion compared to the answers in 1999. This finding is not surprising because knowledge about the benefits of palliative care has grown in recent decades, and today it is considered a part of everyday care in life-threatening illnesses and a human right<sup>1,3,4,6-11,298-300</sup>. However, in another international study, only 51–70% of the physicians believed that palliative care was able to prevent the need for euthanasia and PAS<sup>26</sup>. The physicians with cPM considered the withdrawal of LSTs less reprehensible and EOL care more satisfying compared to the other physicians. This is understandable when taking into account the nature of palliative care in which considering the withdrawal of LSTs to be reprehensible could be problematic.

## 6.3 Methodological considerations

This study included physicians mainly from four specialties: general practice, internal medicine, surgery and oncology. In addition, physicians with cPM had different underlying specialties. These physician groups were selected because they are known to take care of cancer patients throughout the disease trajectory and especially during EOL care. Graduating medical students were also invited to participate in order to explore differences between them and the more experienced physicians.

The overall response rate was 56%. This is a limitation of the study, although it is higher than in many recent studies conducted among physicians<sup>5,37,190</sup>. Response rates in studies conducted among medical students vary widely, from 44% in a study from Sweden to over 90% in studies from Poland and Austria, which places our response rate of 63% among students as average<sup>269,270,307</sup>. Some responder bias may have occurred, as it is possible that physicians who consider EOL care to be meaningful may have appreciated this survey, leading them to answer more frequently than the others. However, the study population is large and can be seen as a representative sample of Finnish physicians because it reflects the overall distribution of specialties and gender among Finnish physicians<sup>308</sup>. The latest statistics of Finnish physicians are from 2016, when there were approximately 29 000 licensed physicians, of whom 21 000 were currently practising medicine<sup>308</sup>. Approximately 60% of all the Finnish physicians were female<sup>308</sup>.

The follow-up period of sixteen years is long enough to detect relevant changes in attitudes and decision-making. In studies investigating changes in attitudes towards euthanasia, a time period of around ten years is the most commonly

used<sup>257,260,270</sup>. Some of the language used in the questionnaire was old fashioned, e.g., the use of the term terminal, but in order to make the comparison between the study years as valid as possible, we chose not to change the language. Instead, we explained the background of the questionnaire in the cover letter, making a remark about the language and terms used in the survey.

Answers to the hypothetical patient scenarios might differ from physicians' real life decision-making in clinical practice. In addition, the scenarios forced the responders to give simple answers without the possibility to discuss with the patient or family to achieve a shared decision. Thus, interactions between a patient or family and the physician were missing, which might influence the decisions made. We suggest, however, that the factors behind decision-making remain similar in real life situations compared with these hypothetical patient scenarios, and this is also supported by previous studies<sup>289,290</sup>. A survey study by Christakis et al. and an actual prospective study by Asch et al. both showed that blood products and haemodialysis were the most frequently withdrawn treatments, whereas tube feeding and intravenous fluids were often continued in EOL care<sup>289,290</sup>.

The reliability of the questionnaire is highly important, as physicians' answers may vary due to confounding factors that are not measured. The questionnaire was previously tested in a pilot study at a two-week interval, and the reliability was found to be sufficient (kappa coefficient 0.40 or greater)<sup>16-18,178,284</sup>.

Although using a VAS scale to measure attitudes might have caused some confusion, physicians are generally familiar with its use because it is widely used to measure different symptoms. The VAS scale has been demonstrated to be useful in statistical analysis under a variety of conditions, especially when VAS responses are skewed to either end of the scale, as they were in many of the responses in this study<sup>309</sup>. This type of assessment might provide more appropriate insights into the complex ethical questions than simply answering yes or no.

The study population was previously determined, as explained earlier in this chapter, so no power calculations were performed. In addition to conventional statistical analysis, a trajectory analysis was used in patient scenario 7 to take into account all of the optional sub scenarios in the given order (original, family's appeal and advance directive). This analysis, together with the multivariable analysis from the most hesitant group, further supported our finding that in 2015 physicians with cPM were more willing to withdraw and withhold treatments compared to other physician groups.

Five of the six cancer patient scenarios from the original questionnaire were selected to be part of this thesis. The patient scenario concerning a dementia patient

was not included in this thesis in order to keep the content coherent; therefore, only the cancer patient scenarios were incorporated into the thesis. Patient scenario 3, representing a patient with an advanced pancreatic cancer planning to receive immunization treatment, was not selected to be part of this thesis, because immunological treatments are currently a part of everyday practice in some cancer types, and the original idea of an unorthodox therapy was no longer clear in 2015<sup>310,311</sup>.

In this study, only cancer patients were included, hence the results can be generalized only to cancer patients. However, it can be argued that in EOL care the underlying diagnosis is not as important as the symptoms, values and wishes of the patient, as it has been shown that symptom burden at the EOL is quite similar across different illnesses<sup>312</sup>. Thus, the results from this thesis regarding the decision-making in EOL care may be at least partly broadened to other diagnoses beyond cancer.

## 6.4 Practical suggestions and recommendations for the future

The results from this thesis demonstrate that EOL decision-making varies between physicians and medical students depending on their background factors, personal values, experience and education. The decision-making of physicians also changes over time, constantly reflecting the changing social surroundings and medical atmosphere.

Discussions among the public, policy makers and physicians are ongoing about the ethical justification of hastened death due to unbearable suffering. Instead of asking simple yes or no questions, it is important to try to understand different aspects and attitudes towards hastened death and EOL decision-making in a more complex way, as was done in this thesis. Although most of the responders believed that palliative care enables good death, not every physician seems to be convinced that palliative care could prevent the need for euthanasia and PAS worldwide. More studies, especially with in-depth methods, are needed to further explore hastened death in years to come to enable societies to build a solid and consistent foundation for legislation around the multilateral and ethically challenging subject of hastened death.

The attitudes, experience and education of a physician seems to play an important part in their EOL decision-making. Self-reflection and acknowledging one's own attitudes and values influencing medical decision-making is crucial. These findings

call for continuous education about palliative care and decision-making from the beginning of medical school and continuing in the post-graduate training of different specialties who face dying patients in their everyday practice. In this education, it is of utmost important to include different medical, ethical and legal aspects of EOL decision-making to ensure that equal access to high-quality EOL care is achievable for every patient and their family. However, palliative care consultations might be needed for complex cases of decision-making in EOL care. Palliative care is a holistic and interdisciplinary approach where different professionals work together as a team. Therefore, these educational aspects should be thought of a larger perspective than just for physicians. For example, nurses and social workers should be incorporated into multidisciplinary education about EOL decision-making. In Finland, the Ministry of Education and Culture has founded a project to develop education in palliative care in both the under- and post-graduate training of nurses and physicians<sup>313</sup>. The results of this thesis could be useful when describing educational needs and planning palliative medicine education for all stages in the trajectory of becoming and being a physician.

## 7 SUMMARY AND CONCLUSIONS

This study was carried out to evaluate end-of-life decisions and the factors influencing these decisions among Finnish physicians and medical students (publications I-IV) as well as the possible changes in these decisions and influencing factors over the past sixteen years (publications II and III). The evaluation was based on a survey consisting of five hypothetical cancer patient scenarios concerning end-of-life care together with questions on attitudes towards different aspects of end-of-life care, sociodemographic characteristics and professional factors.

The main findings are as follow:

1. The physicians with special competency in palliative medicine made less aggressive decisions in end-of-life care compared to other physicians in general. The difference varied between therapies but was most striking with regard to the use of intravenous hydration, nasogastric tubes and blood transfusions. All of the physicians were influenced by the family's request and an advance directive.
2. The physicians considered euthanasia, but not assisted suicide, to be less reprehensible in 2015 than in 1999, and physicians in 2015 stated more often that palliative care enables a good death. When making end-of-life decisions, the physicians regarded the patient's benefit, ethical values and the legal protection of the patient or physician to be more influential, while the family's benefit was regarded as less influential in 2015 than in 1999.
3. In 2015, the physicians accepted the risk of hastened death from an increased morphine dose more frequently than in 1999. Physicians' decisions to choose palliative care approaches in end-of-life care and their willingness to issue a voucher for hospice significantly increased from 1999 to 2015.
4. The medical students considered euthanasia and assisted suicide to be less reprehensible than the experienced GPs, whereas religion had a



stronger influence on the decisions among the GPs. Both the medical students and the experienced GPs frequently thought that withdrawal of life-sustaining treatments was not reprehensible and that good palliative care can enable a good death.

5. The experienced GPs were more willing to accept the risk of hastened death and withheld or withdrew different therapies in end-of-life care more often than the medical students. There was no difference between the students and the experienced GPs when choosing a palliative care approach in EOL situations or in the willingness to issue a voucher for hospice.

The characteristics, attitudes, values, experience and education of physicians and medical students play a significant part in their end-of-life decision-making; therefore, it is of the utmost importance to include ethical, medical and juridical aspects of decision-making, end-of-life care and palliative medicine in the under- and postgraduate medical education and to study these aspects in prospective clinical trials in the future.

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## 9 APPENDIX

### The questionnaire

Answer the questions based on the following patient scenarios in the given order. Choose one of the three treatment options given (palliative, active intensive). Circle the right option. Do not change your answer once decided.

**Palliative care:** good nursing, sufficient medications for pain and other symptoms, intravenous hydration only when it is considered to relieve patient's symptoms

**Active care:** use of antibiotics, intravenous hydration or blood transfusions aimed at saving the patient's life in a life-threatening condition

**Intensive care:** moving the patient to intensive care unit (ICU)

**Patient scenario1:** An 82-year-old retired forest worker, who had received a diagnosis of prostatic cancer 3 years ago. During the past year he received treatments for bone metastases. He has now been in hospital for one month, almost totally bedridden, and needs help with all functions. His mental condition has been normal. His general condition has weakened over the past week, he is now totally bedridden, and he has received large doses of pain medication. Today, he has become comatose. His haemoglobin count has decreased to 68 g/l, while the week before it was 118 g/l. His blood pressure is 80/40 mmHg. There is no verbal or written advance directive. The patient's wife has previously said that she expects the doctor to make all treatment decisions according to his/her best understanding. Is your treatment decision

a) palliative care

b) active care

c) intensive care

There are four alternative hypothetical situations linked to the previous scenario

A) You are told by the nurse that it has been discovered that the patient's faeces are black. You remember having started ketoprofen for pain a week ago. Is your treatment decision

- a) palliative care                      b) active care                      c) intensive care

B) You are told by the nurse that the patient's son is coming from America the day after tomorrow to see his father while he is still alive. Is your treatment decision

- a) palliative care                      b) active care                      c) intensive care

C) You are told by the nurse that the patient has had spiritual anxiety and there is a planned appointment with a minister and the Lord's Supper tomorrow. Is your treatment decision

- a) palliative care                      b) active care                      c) intensive care

D) You are told by a family member that there is a written advance directive in which patient has expressed that all active interventions should be withheld if there is no hope for recovery. Is your treatment decision

- a) palliative care                      b) active care                      c) intensive care

Evaluate the influence of the following factors on your decision on a scale 1-5

	very little influence				very much influence
Family's benefit	1	2	3	4	5
Patient's benefit	1	2	3	4	5
Patient's legal rights	1	2	3	4	5
Physician's legal rights	1	2	3	4	5
Ethical values	1	2	3	4	5
Patient's age	1	2	3	4	5
Costs of care	1	2	3	4	5
Patient's social status	1	2	3	4	5



**Patient scenario 2:** An 82-year-old man has suffered from progressive dementia for three years. He has been diagnosed as suffering from Alzheimer’s disease. He is brought to the emergency department at 2 am with life-threatening gastrointestinal bleeding. He lives in a nursing home, has urinary and faecal incontinence, needs help washing and dressing and does not recognize his daughter. His blood pressure is 70/40 mm Hg and his heart rate 120 beats/min. The patient cannot communicate, and his family and physician cannot be reached. The nurse’s aide who accompanied him to the emergency department is not familiar with the patient. There is no information available as to his wishes or those of his family concerning treatment in this situation. Is your treatment decision

- b) palliative care
- b) active care
- c) intensive care

Evaluate the influence of the following factors on your decision on a scale 1-5

	very little influence				very much influence
Family’s benefit	1	2	3	4	5
Patient’s benefit	1	2	3	4	5
Patient’s legal rights	1	2	3	4	5
Physician’s legal rights	1	2	3	4	5
Ethical values	1	2	3	4	5
Patient’s age	1	2	3	4	5
Costs of care	1	2	3	4	5
Patient’s social status	1	2	3	4	5

**Patient scenario 3:** A 45-year-old woman suffers from pancreatic cancer with multiple metastases in the liver. There are no possibilities for active treatment. In three months she has become cachectic. Now she is in your ward in end-of-life (terminal) care. Her friends are planning to take her to another city (distance 300 km) to consult a private doctor to get immunization treatment. The patient and

her friends have expressed criticism of the official medical treatment and made accusations of a delay in diagnosis.

As the doctor responsible for her care you

- a) accept the plan (as the last glimmer of hope) without criticizing it, because there is no medical treatment which you can order her
- b) you have a negative attitude to the plan and tell this to the patient properly and justify your opinion with medical facts
- c) I don't know
- d) other solution: \_\_\_\_\_

The same patient is in any case in your ward and is receiving immunization therapy ordered by another physician. The therapy includes a special diet, which incurs about 20 euros additional cost per day.

- a) you refuse to carry through the diet
- b) the patient can have the diet, but she has to pay the extra costs
- c) the patient can have the diet, because her presumed life expectation is very short
- d) other decision: \_\_\_\_\_

**Patient scenario 4:** A 68-year-old patient suffers from breast cancer with bone metastases. She is bedridden and her general condition has rapidly collapsed. She is in a community hospital ward and is receiving adequate pain treatment with which she is pleased. She is depressed and wants to transfer to a hospice for her last days. She feels that the atmosphere on the ward is very restless and "institutional". You have the right to issue a voucher for the costs of hospice care (290 euros per day) to be paid by the community hospital. The costs would be approximately double compared to those in a community hospital, and the chief doctor has advised you to use great discretion in issuing vouchers. Your solution:

- a) to accept the transfer
- b) to accept the transfer, provided that the patient pays the extra costs herself
- c) not to accept, because according to normal practice the patient's care belongs to the community hospital ward and there are no special problems in her care
- d) I don't know
- e) other solution: \_\_\_\_\_

**Patient scenario 5:** A 60-year-old male patient is suffering from prostatic cancer with metastases. Metastases in the thoracic spine led to total paraparesis 1 month earlier. There is no hope for a cure. The patient is well aware of the situation. He has totally lost his will to live. When you are together with him alone, he asks for a sufficient dose of morphine to “get away”. You have denied the overdose, explaining that it is against your ethical principles. During the following days, you notice that the patient asks you to double his morphine dose because of unbearable pain. The anti-inflammatory pain medication is at its maximum dose and you suspect if the pain is real (this sentence was removed from the scenario in 2015 as it did not comply with current treatment guidelines for cancer pain). You suppose that increasing the dose in such a way would lead to the patient’s death. Your decision is which of the following:

- a) to raise the dose because the patient has the right to sufficient pain relief in this end-of-life (terminal) care situation
- b) to try to help the patient in other ways, such as with antidepressants, thus continuing with morphine dosing according to given guidelines
- c) I can’t say
- d) give another solution: \_\_\_\_\_

**Patient scenario 6:** A 32-year-old female patient is brought by ambulance to the emergency unit. She is accompanied by her husband who says his wife has inoperable brain cancer. She has been receiving maximum radiotherapy, but this was discontinued 3 weeks ago. She has deteriorated considerably during the past week. The patient has now had an epileptic seizure and has been unconscious since the attack. After 20 min at the hospital the patient stops breathing, and there is no pulse. Your treatment decision is which of the following:

- a) to start cardiopulmonary resuscitation
- b) to withhold cardiopulmonary resuscitation

**Patient scenario 7:** A 62-year-old male patient with pulmonary cancer and metastases. He was admitted to hospital ward and received high-dose morphine medication. Due to respiratory weakening, he had become comatose the night before. He also suffered from severe anaemia and had abundant pleural effusion and fever. Which of the following treatments already started (\*) or planned would you withhold or withdraw? You have no possibility of discussing the matter with the family and there is no advance directive.

Would you withhold or withdraw the following treatments; express your decision on a scale 1-5

	I definitely would not withhold or withdraw*				I definitely would withhold or withdraw*
a) antibiotics (*)	1	2	3	4	5
b) mechanical ventilation (*)	1	2	3	4	5
c) blood transfusion	1	2	3	4	5
d) pleural drainage	1	2	3	4	5
e) chest x-ray examination	1	2	3	4	5
f) laboratory tests	1	2	3	4	5
g) intravenous hydration (*)	1	2	3	4	5
h) nasogastric tube (*)	1	2	3	4	5
i) nasogastric tube (*)	1	2	3	4	5
j) supplementary oxygen (*)	1	2	3	4	5

Next there is two alternatives with extra information for the scenario above:

- A) the patient's daughters come to you distressed and crying, expressing their hope that everything possible will be done to save their father's life. Which of the following treatments already started (\*) or planned would you withhold or withdraw?

		I definitely would not withhold or withdraw*				I definitely would withhold or withdraw*
a)	antibiotics (*)	1	2	3	4	5
b)	mechanical ventilation (*)	1	2	3	4	5
c)	blood transfusion	1	2	3	4	5
d)	pleural drainage	1	2	3	4	5
e)	chest x-ray examination	1	2	3	4	5
f)	laboratory tests	1	2	3	4	5
g)	intravenous hydration (*)	1	2	3	4	5
h)	nasogastric tube (*)	1	2	3	4	5
i)	nasogastric tube (*)	1	2	3	4	5
j)	supplementa ry oxygen (*)	1	2	3	4	5

- B) there is a written advance directive in the patient's medical chart in which he expresses his wish that all active treatment should be withdrawn if there is no hope for recovery. Which of the following treatments already started (\*) or planned would you withhold or withdraw?

	I definitely would not withhold or withdraw*				I definitely would withhold or withdraw*
a) antibiotics (*)	1	2	3	4	5
b) mechanical ventilation (*)	1	2	3	4	5
c) blood transfusion	1	2	3	4	5
d) pleural drainage	1	2	3	4	5
e) chest x-ray examination	1	2	3	4	5
f) laboratory tests	1	2	3	4	5
g) intravenous hydration (*)	1	2	3	4	5
h) nasogastric tube (*)	1	2	3	4	5
i) nasogastric tube (*)	1	2	3	4	5
j) supplementary oxygen (*)	1	2	3	4	5

Next there are questions regarding your opinions. Assess your opinion with a straight line to the scale on the place which describes your opinion best.

- 1) Euthanasia is reprehensible  
I definitely agree I definitely disagree  
|-----|
- 2) Withdrawal of life-sustaining treatments is reprehensible  
I definitely agree I definitely disagree  
|-----|
- 3) Assisted suicide is reprehensible  
I definitely agree I definitely disagree  
|-----|
- 4) End-of-life care is satisfying  
I definitely agree I definitely disagree  
|-----|
- 5) People should pay costs of factitious diseases by themselves  
I definitely agree I definitely disagree  
|-----|
- 6) Advance directives have been helpful in my decisions  
I definitely agree I definitely disagree  
|-----|
- 7) Good palliative care enables good death  
I definitely agree I definitely disagree  
|-----|
- 8) Physicians can't estimate cancer pain  
I definitely agree I definitely disagree  
|-----|
- 9) Religion has influence when I make ethical decisions  
I definitely agree I definitely disagree  
|-----|
- 10) Being a doctor gives me satisfaction  
I definitely agree I definitely disagree  
|-----|
- 11) My health is excellent  
I definitely agree I definitely disagree  
|-----|
- 12) I feel burn out, tired to work  
I definitely agree I definitely disagree  
|-----|

13) I'm pleased with my salary

I definitely agree

I definitely disagree

|-----|

14) It is waste of resources to treat patients > 80 years in ICU

I definitely agree

I definitely disagree

|-----|



Here some opinions and views towards death is presented. Choose the alternative that is closest to your own thinking. (A five point Likert: 1=definitely agree, 2=agree to some extent, 3=I don't know, 4=I don't quite agree, 5= definitely disagree)

	I definitely agree				I definitely disagree
A) Death is like a long dream	1	2	3	4	5
B) Dying means suffering	1	2	3	4	5
C) Dying is not tragic for the one dying but for those who remain	1	2	3	4	5
D) Death comes always too soon	1	2	3	4	5
E) Our existence does not end at death	1	2	3	4	5
F) Death is always in "higher hands"	1	2	3	4	5
G) I fear death	1	2	3	4	5
H) I'm afraid that someone close to me dies	1	2	3	4	5
I) I'm worried about the sadness brought to my family by my own death	1	2	3	4	5
J) Sometimes I imagine what it would be like at my own funeral	1	2	3	4	5
K) I'm distressed to think that someday I shall not exist	1	2	3	4	5



Finally same life values. Choose an option that best describes your own thinking.

	not important at all	not so important	quite important	very important
Lenght of life	1	2	3	4
Health	1	2	3	4
Family	1	2	3	4
Clean environment	1	2	3	4
Hight standart of living	1	2	3	4
Faith in God	1	2	3	4
Success in professional career	1	2	3	4



## PUBLICATIONS



# PUBLICATION

I

**Does special education in palliative medicine make a difference in end-of-life decision-making?**

Piili Reetta P, Lehto Juho T, Luukkaala Tiina, Hinkka Heikki, Kellokumpu-Lehtinen Pirkko-Liisa I

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RESEARCH ARTICLE

Open Access



# Does special education in palliative medicine make a difference in end-of-life decision-making?

Reetta P. Piili<sup>1,2,3\*</sup> , Juho T. Lehto<sup>1,2</sup>, Tiina Luukkaala<sup>4,5</sup>, Heikki Hinkka<sup>6</sup> and Pirkko-Liisa I. Kellokumpu-Lehtinen<sup>1,2</sup>

## Abstract

**Background:** Characteristics of the physician influence the essential decision-making in end-of-life care. However, the effect of special education in palliative medicine on different aspects of decision-making in end-of-life care remains unknown. The aim of this study was to explore the decision-making in end-of-life care among physicians with or without special competency in palliative medicine (cPM).

**Methods:** A questionnaire including an advanced lung cancer patient-scenario with multiple decision options in end-of-life care situation was sent to 1327 Finnish physicians. Decisions to withdraw or withhold ten life-prolonging interventions were asked on a scale from 1 (definitely would not) to 5 (definitely would) – first, without additional information and then after the family's request for aggressive treatment and the availability of an advance directive. Values from chronological original scenario, family's appeal and advance directive were clustered by trajectory analysis.

**Results:** We received 699 (53%) responses. The mean values of the ten answers in the original scenario were 4.1 in physicians with cPM, 3.4 in general practitioners, 3.4 in surgeons, 3.5 in internists and 3.8 in oncologists ( $p < 0.05$  for physicians with cPM vs. oncologists and  $p < 0.001$  for physicians with cPM vs. others). Younger age and not being an oncologist or not having cPM increased aggressive treatment decisions in multivariable logistic regression analysis. The less aggressive approach of physicians with cPM differed between therapies, being most striking concerning intravenous hydration, nasogastric tube and blood transfusions. The aggressive approach increased by the family's request ( $p < 0.001$ ) and decreased by an advance directive ( $p < 0.001$ ) in all physicians, regardless of special education in palliative medicine.

**Conclusion:** Physicians with special education in palliative medicine make less aggressive decisions in end-of-life care. The impact of specialty on decision-making varies among treatment options. Education in end-of-life care decision-making should be mandatory for young physicians and those in specialty training.

**Keywords:** Decision-making, Terminal care, Education, Palliative medicine, Life support care

## Background

Rapid developments in medicine have allowed many interventions for patients with very advanced diseases. At the same time, the difficulty of choosing worthwhile therapies for each patient has led to the use of

non-beneficial treatments among dying patients at their end-of-life (EOL) [1]. In contrast, well-timed palliative care improves patients' quality of life and symptom control and reduces invasive procedures and costs [2–8].

Appropriate decision-making is mandatory in high-quality EOL-care to prevent non-beneficial treatments and relieve suffering. The decisions include, but are not limited to, statements on cardiopulmonary resuscitation, parenteral fluids, and diagnostic tests. This decision-making is a challenging process involving many ethical, legal, medical and psychological aspects [9–16].

\* Correspondence: [piili.reetta.p@student.uta.fi](mailto:piili.reetta.p@student.uta.fi)

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<sup>1</sup>Faculty of Medicine and Life Sciences, University of Tampere, Tampere, Finland

<sup>2</sup>Department of Oncology, Tampere University Hospital, Tampere, Finland  
Full list of author information is available at the end of the article



Physicians' decisions vary concerning different interventions. In a Scandinavian study, 57% of intensive care physicians would continue intravenous hydration, but only 5% of them measured blood glucose during EOL-care [17]. Physicians also decide to withdraw therapies less frequently than to withhold them, probably because they feel withdrawal is more difficult and ethically problematic [18–21].

In addition to medical facts and personal characteristics, education and specialty of the physician influence the complex decision-making in EOL [11]. Although education in palliative care increases the knowledge and skills needed to perform high-quality EOL-care [22–27], the effectiveness of special training in palliative medicine (PM) on different aspects of decision-making in EOL-care remains unknown.

Most patients wish their closest ones to be involved in EOL decision-making, and discussions with the family are essential [28–30]. The families' opinions are also shown to influence physicians' decisions [12, 31, 32], although discordance between patients' wishes, caregivers' preferences and caregivers' predictions of patients' preferences may exist [28, 33]. Advance directives reinforce patients' participation and help with decision-making [31, 32, 34]. However, there are variations in how advance directives are understood and taken into account [12, 35–37].

The aim of our study was to examine whether special education in PM affects decision-making in EOL-care, as evaluated by a hypothetical patient scenario with different alternatives. The impact of family requests, written advance directives, and physicians' background factors on their decisions were analysed.

## Methods

### Participants

A postal survey with a questionnaire was provided to 1327 Finnish physicians in autumn 2015. The sample consisted of 500 general health care practitioners (GPs), 300 surgeons, and 300 internists randomly selected from the register of the Finnish Medical Association. The sample size is similar to our previous studies done sixteen years ago and is based on the distribution of different specialties in Finland, which has remained largely unchanged over the years studied [10–12, 38, 39]. In addition, the questionnaire was sent to all Finnish oncologists ( $n = 158$ ) and all physicians with a special competency in PM ( $n = 82$ ), excluding those with a mailing proscription ( $n = 23$ ). Two reminders were sent to nonrespondents.

A cover letter including an introduction to the study and an assurance of anonymity and voluntariness was mailed together with the questionnaire. This study was

approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101).

### Special competency in palliative medicine

In Finland, postgraduate training in PM leads to a certification for special competency in PM (cPM) awarded by the Finnish Medical Association [40]. Finnish physicians are allowed to start this postgraduate training after working at least 2 years as a physician. This special training consists of 150 h of theoretical education in different aspects of PM, 200 patient interactions in palliative care, 2 years of clinical practice including a working period in a specialized palliative care unit for a minimum of 3 months, and a final written examination.

### Questionnaire

The questionnaire has been previously used and validated with Finnish physicians. A pilot study was done in January 1999. The questionnaire was sent to 45 physicians (health care practitioners and specialists) twice at two-week intervals in order to test the reliability of the responses to patient scenarios and the questions on attitudes and values. Thirty physicians returned two acceptable questionnaires. The value of kappa coefficient for an acceptable scenarios or questions was determined to be more than 0.40, which is a commonly accepted limit for reliability. [10–12, 38]

The questionnaire includes seven hypothetical patient scenarios together with questions concerning responders' background, personal features, and attitudes. In this study, we included one of the patient scenarios designed to study doctors' treatment decisions in the EOL-care. In addition, questions about the responders' own advance directives, experience in EOL-care among relatives, treatment of EOL patients within 2 years, availability of professional supervision, chief position and financial responsibility at work together with age and sex were used as background factors. The parts of the questionnaire used in this study are available as an Additional file 1.

### Case scenario

The scenario presented a 62-year-old male patient with pulmonary cancer and metastases. He was admitted to hospital ward and received high-dose morphine medication. Due to respiratory weakening, he had become comatose the night before.

He also suffered from severe anaemia and had abundant pleural effusion and fever.

After the presentation of the patient scenario, there was a question about the treatment decision: Which of the following treatments already started (\*) or planned would you withhold or withdraw? In the first situation, there was no possibility of discussing the matter with

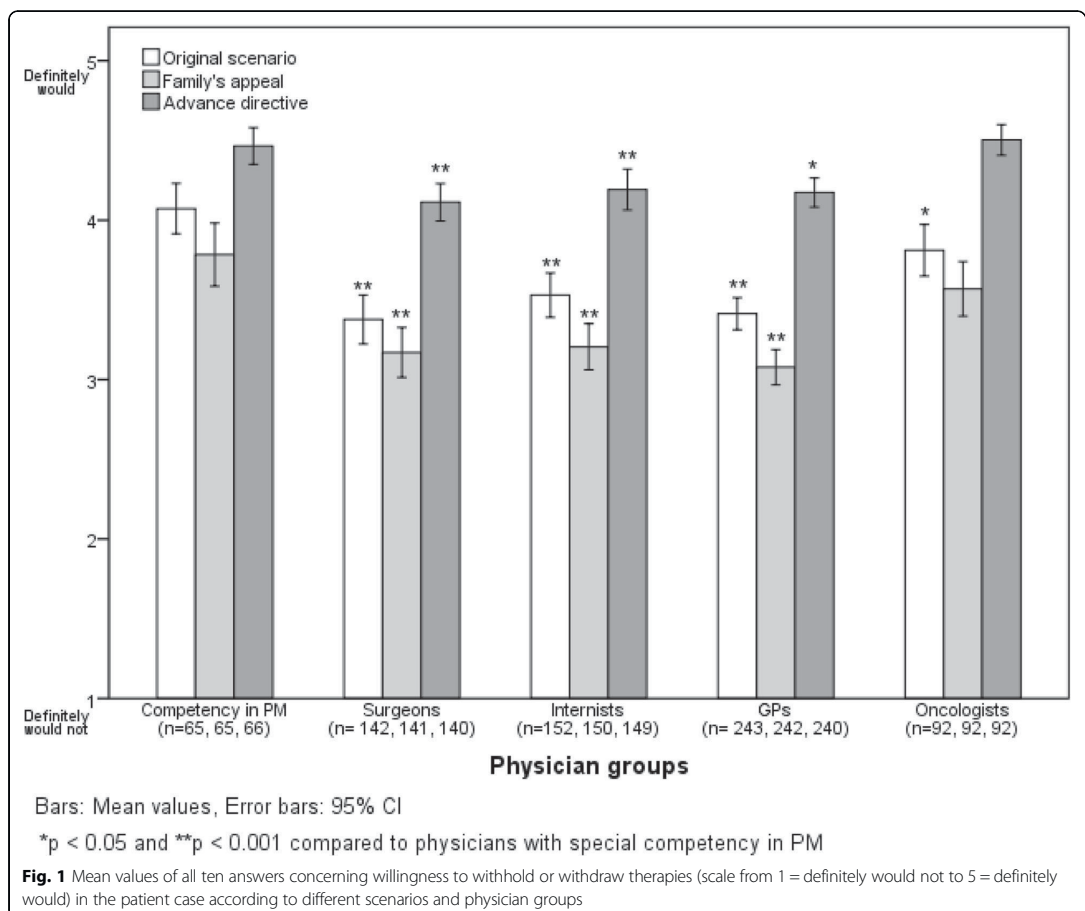
the family and there was no advance directive. The decision responses were expressed on a scale from 1 (I definitely would not) to 5 (I definitely would). The treatments were a) antibiotics (\*); b) mechanical ventilation (\*); c) blood transfusion; d) pleural drainage; e) chest x-ray examination; f) laboratory tests; g) intravenous hydration (\*); h) nasogastric tube (\*); i) thrombosis prophylaxis (\*); and j) supplementary oxygen (\*).

After the original patient scenario, two alternatives with extra information were provided: 1) the patient's daughters come to you distressed and crying, expressing their hope that everything possible will be done to save their father's life; 2) there is a written advance directive in the patient's medical chart in which he expresses his wish that all active treatment should be withdrawn if there is no hope for recovery. After each of these alternatives the same questions (with the same treatment options as in the original scenario) were asked. Questions were asked to be answered in

the given order and not to change answers once decided.

### Statistical analysis

Different responder groups were compared by t-test for normally distributed continuous variables (Fig. 1) and by chi-square or Fisher's exact tests when appropriate for categorical variables (Tables 2 and 3). The answers on the 5-step Likert scale in the scenarios were converted to a 2-step scale: 1–3, “would not withdraw or withhold and don't know” and 4–5, “would withdraw or withhold”. Measured mean distributions of the chronological original scenario, family's appeal and advance directive values were clustered by trajectory analysis [41]. The trajectories were created according to the measurements of mean values in each responder as a continuous outcome measure. The analyses undertaken were latent class mixture models of quadratic trajectories including a random intercept and concomitant variables. Models were fitted



by using the flexmix package [42] of the statistical program R, version 3.3.0, from the R Foundation for Statistical Computing (R Development Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria, 2008, ISBN 3–900,051–07-0, URL). Relative goodness of fit was assessed using Bayesian information Criteria.

Factors (Table 4) affecting the willingness to continue or start therapies (belonging to trajectory groups 3 or 4) compared to withhold or withdraw therapies (belonging to trajectory groups 1 or 2) were examined by univariate and age-adjusted logistic regression models results shown by odds ratios (OR) with 95% confidence intervals (CI). Additionally, a multivariable model, where variables were added simultaneously into the model, was performed for variables with statistical significance under 0.20 in age-adjusted model. Two-sided *p*-values of less than 0.05 were accepted as statistically significant. Data-analyses were performed using IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp. Released 2014.

Results  
Responders

Altogether, 699 valid responses were achieved (response rate 53%). The response rate ranged from 82% among physicians with cPM to 47% among surgeons. Characteristics of the responders are presented in Table 1. A majority of the responders were women, except in the group of surgeons. The median age of the responders was 52 years (interquartile range 43–58), with slight variations between the groups. Most of the GPs worked at out-patient clinics (85%), while the others mainly worked at hospitals (66–87%).

Overall willingness to withhold or withdraw therapies

The mean values of all ten answers according to the three alternatives in the case scenario are shown in Fig. 1. Physicians with cPM were most willing to

withhold and withdraw interventions, especially compared to GPs, internists and surgeons. The family's appeal significantly increased the willingness to start or continue life-prolonging therapies in all physician groups, whereas the advance directive decreased it (*p* < 0.001 compared to the original scenario).

Decisions concerning individual treatments

Physicians with cPM were more willing to withdraw and withhold most of the individual interventions, compared to the others (Tables 2 and 3). This difference in decision-making was most striking in withdrawing intravenous hydration, removing nasogastric tube and withholding blood transfusions. In contrast, some decisions (e.g., withdrawing oxygen or antibiotics) varied only slightly between the physicians with cPM and others. Mechanical ventilation was withdrawn by most of the physicians, while supplementary oxygen was frequently continued by all responders.

The daughters' request for "everything to be done" (the family's appeal) increased the willingness to continue or start each life-prolonging treatment, with the only exception the use of oxygen among cPMs. The daughters' request had the largest influence on the decisions concerning intravenous hydration and diagnostic tests (Table 2).

The availability of the advance directive markedly moved decisions towards withdrawing and withholding treatments. Although the differences between responder groups diminished, the physicians with cPM and the oncologists still had the least aggressive approach. Nearly all physicians withdrew mechanical ventilation, discontinued thrombosis prophylaxis and withheld blood transfusion. However, over one third of the physicians without cPM continued intravenous hydration, and supplementary oxygen was frequently continued by all physicians.

Table 1 Characteristics of the participants

	Competency in PM		Surgeons		Internists		GPs		Oncologists		Total
Number (% of total)	67	(10)	142	(20)	153	(22)	245	(35)	92	(13)	699 (100)
Response rate, %	82		47		51		49		63		53
Female, n (%)	57	(85)	47	(33)	81	(53)	173	(71)	73	(79)	431 (62)
Median age (IQR)	55	(49–58)	52	(44–59)	53	(46–59)	49	(38–57)	49	(41–56)	52 (43–58)
Age distribution, n (%)											
< 35	0	(0)	4	(3)	4	(3)	42	(17)	2	(2)	52 (7)
35–49	20	(30)	52	(37)	51	(33)	84	(34)	46	(50)	253 (36)
> 49	47	(70)	86	(61)	98	(64)	119	(49)	44	(48)	394 (56)
Years from graduation, median (IQR) <sup>a</sup>	27	(21–32)	26	(17–34)	26	(20–32)	21	(9–31)	22	(14–29)	25 (15–32)

PM, Palliative Medicine, GP, General Practitioner, IQR, Interquartile Range  
<sup>a</sup>For nine participants year of graduation was not available

**Table 2** Number and proportion (%) of physicians deciding to withdraw a treatment in the patient scenario according to physician groups

Treatment	Scenario	Competency in PM		Surgeons		Internist		GPs		Oncologists		P-value <sup>a</sup>
Antibiotic	Original scenario	41	(65)	72	(51)	78	(51)	128	(53)	45	(54)	0.399
	Family's appeal	33	(50)	55	(39)	55	(36)	89	(37)*	34	(37)	0.353
	Advance directive	58	(87)	116	(83)	122	(82)	204	(84)	82	(89)	0.641
Mechanical ventilation	Original scenario	63	(96)	119	(85)*	135	(89)	195	(81)*	83	(91)	0.008
	Family's appeal	59	(92)	113	(80)*	126	(83)	175	(72)*	76	(84)	0.002
	Advance directive	67	(100)	130	(92)*	147	(98)	228	(94)*	90	(99)	0.011
Intravenous hydration	Original scenario	43	(65)	31	(22)**	39	(26)**	85	(35)**	42	(46)*	< 0.001
	Family's appeal	26	(40)	21	(15)**	19	(13)**	58	(24)*	34	(37)	< 0.001
	Advance directive	58	(88)	64	(46)**	84	(56)**	162	(67)*	75	(82)	< 0.001
Nasogastric tube	Original scenario	62	(95)	85	(60)**	98	(65)**	161	(67)**	63	(69)**	< 0.001
	Family's appeal	60	(92)	76	(54)**	87	(58)**	126	(53)**	64	(70)*	< 0.001
	Advance directive	64	(97)	105	(75)**	126	(84)*	203	(84)*	82	(89)	0.001
Thrombos prophylaxis	Original scenario	55	(85)	108	(76)	105	(69)*	151	(62)*	73	(80)	< 0.001
	Family's appeal	52	(80)	104	(74)	95	(64)*	128	(53)**	67	(73)	< 0.001
	Advance directive	63	(96)	121	(88)	127	(85)*	199	(82)*	86	(94)	0.013
Supplementary oxygen	Original scenario	11	(16)	16	(11)	23	(15)	14	(6)*	11	(12)	0.019
	Family's appeal	12	(18)	14	(10)	13	(9)*	12	(5)	6	(7)*	0.011
	Advance directive	20	(30)	40	(28)	46	(31)	51	(21)	27	(29)	0.189

PM, Palliative Medicine, GP, General Practitioner

<sup>a</sup>Global p-value across all physician groups\* $p < 0.05$  and \*\* $p < 0.001$  pair-wise comparison to physicians with special competency in PM

### Trajectory analysis and factors associated with aggressive treatment decisions

When answers were fitted with a trajectory analysis, four differently behaving groups were found (Fig. 2). In the trajectory group 1, responders were consistently willing to withdraw and withhold therapies, and in the trajectory group 2, physicians would probably withdraw and withhold

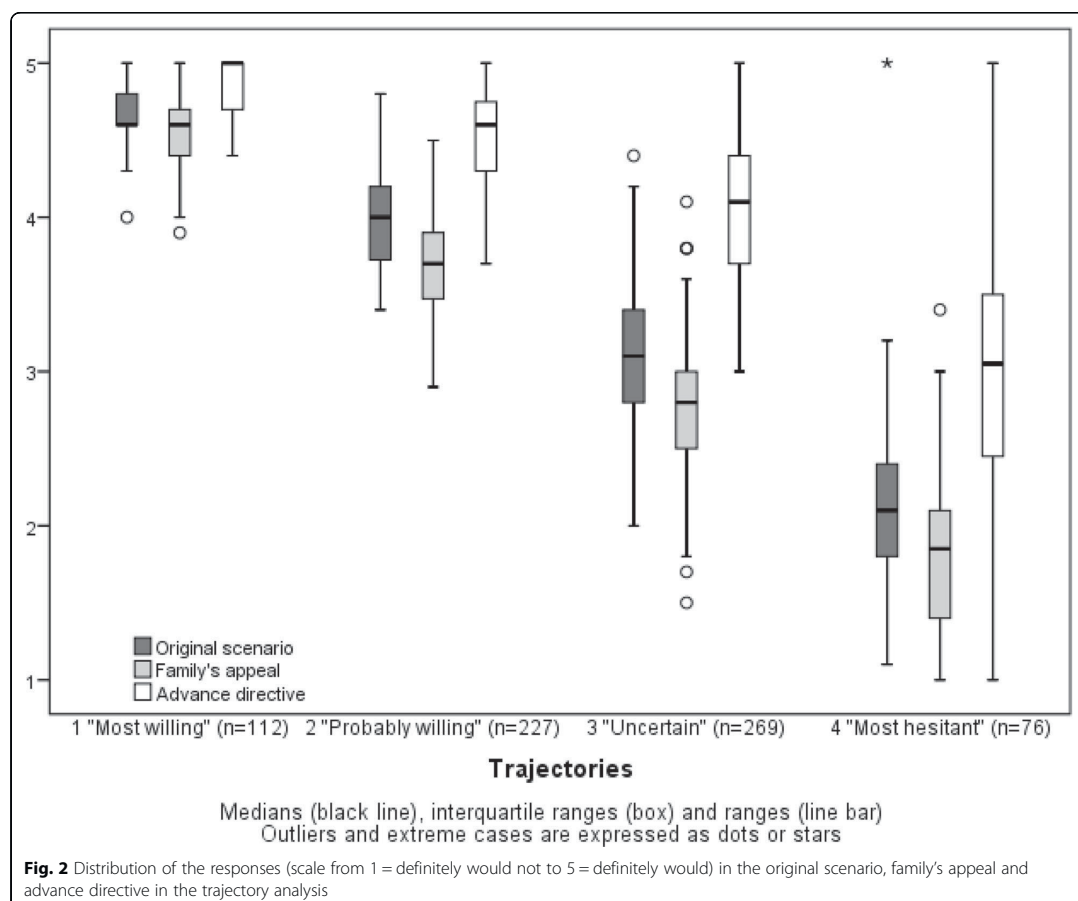
therapies, but their decisions were influenced by the family's appeal and the advance directive. In contrast, responders encompassed in the trajectory group 3 were either uncertain or chose an aggressive approach in about half of their decisions, and they were more influenced by the advance directive, while physicians in the trajectory group 4 were most hesitant to withdraw and withhold therapies.

**Table 3** Number and proportion (%) of physicians deciding to withhold an intervention in the patient scenario according to physician groups

Treatment	Scenario	Competency in PM		Surgeons		Internists		GPs		Oncologists		P-value <sup>a</sup>
Blood transfusion	Original scenario	60	(91)	98	(70)*	108	(72)*	185	(76)*	72	(78)*	0.011
	Family's appeal	55	(85)	90	(64)*	85	(56)**	153	(64)*	67	(76)	< 0.001
	Advance directive	66	(99)	132	(94)	136	(91)	227	(94)	90	(98)	0.134
Pleural drainage	Original scenario	43	(65)	59	(42)*	85	(56)	99	(41)**	58	(64)	< 0.001
	Family's appeal	41	(63)	57	(40)*	73	(49)	89	(37)**	51	(56)	< 0.001
	Advance directive	53	(79)	103	(73)	119	(80)	179	(74)	82	(89)	0.030
Chest X-ray	Original scenario	51	(77)	66	(47)**	88	(58)*	119	(60)**	67	(73)	< 0.001
	Family's appeal	44	(67)	61	(43)*	74	(49)*	29	(38)**	59	(65)	< 0.001
	Advance directive	59	(88)	111	(79)	124	(83)	194	(81)	90	(98)*	0.001
Laboratory tests	Original scenario	49	(74)	70	(59)*	87	(57)*	121	(50)*	59	(64)	0.002
	Family's appeal	40	(61)	60	(43)*	67	(45)*	85	(35)**	51	(56)	< 0.001
	Advance directive	58	(87)	115	(81)	119	(78)	190	(78)	88	(96)*	0.006

PM, Palliative Medicine, GP, General Practitioner

<sup>a</sup>Global p-value across all physician groups\* $p < 0.05$  and \*\* $p < 0.001$  pair-wise comparison to physicians with special competency in PM



Factors associated with the physicians' willingness to continue or start life-prolonging therapies during EOL-care (belonging to trajectory groups 3 or 4) compared to withhold or withdraw therapies (belonging to trajectory groups 1 or 2) are shown in Table 4. By multivariable analysis, younger age and being an internist, surgeon or GP were independent factors behind the decisions not to withhold - or to withdraw - different interventions. In contrast, gender, being in chief-position, having financial responsibility, or a physician's own advance directive and experience in EOL-care among relatives did not have independent influence.

## Discussion

We found that physicians with cPM were more willing to withdraw and withhold life-prolonging therapies, especially intravenous hydration and a nasogastric tube, in a patient scenario representing EOL-care. The family's request increased the aggressive approach in all physicians,

whereas the availability of an advance directive decreased this. Younger age and being an internist, surgeon or GP without cPM were independent factors for responses reflecting willingness to start or continue life-prolonging treatments in multivariable regression analysis.

In this study, the overall willingness to withhold and withdraw therapies in EOL-care was higher in physicians with cPM, measured by mean values of all the answers and in a multivariable regression analysis, although oncologists and cPMs differed only slightly. We used trajectory analysis to take into account all the scenarios in the given order and found a similar pattern across all four groups. Therefore, the groups starting from a low willingness to withhold or withdraw therapies in the original scenario were finally chosen to be presented in the multivariable analysis. In light of previous studies [43–45], it is understandable that physicians with formal training in PM have good ability to consider and communicate the EOL decisions, probably leading to more decisions to withdraw and

**Table 4** Factors associated with the willingness to continue or start life prolonging therapies (belonging to trajectories 3 or 4) compared to withhold or withdraw therapies (belonging to trajectories 1 or 2) in the patient scenario presented by univariate, age-adjusted and multivariate analysis

	n	Univariate		p	Age-adjusted		p	Multivariate		p
		OR	(95% CI)		OR	(95% CI)		OR	(95% CI)	
Age continuous, years	692	<b>0.96</b>	<b>(0.95–0.98)</b>	< 0.001						
Age				< 0.001						0.002
25–35	52	<b>4.71</b>	<b>(2.35–9.44)</b>					<b>3.19</b>	<b>(1.54–6.57)</b>	
35–49	253	<b>1.49</b>	<b>(1.08–2.05)</b>					<b>1.46</b>	<b>(1.03–2.06)</b>	
50–67	387	1.00						1.00		
Sex				0.796			0.433			
Female	425	1.04	(0.77–1.41)		0.88	(0.64–1.21)				
Male	267	1.00			1.00					
Chief-position				0.013			0.208			
No	480	<b>1.51</b>	<b>(1.09–2.11)</b>		1.25	(0.88–1.76)				
Yes	205	1.00			1.00					
Financial responsibility				0.006			0.083			0.183
No	562	<b>1.75</b>	<b>(1.17–2.62)</b>		1.44	(0.95–2.19)		1.35	(0.87–2.08)	
Yes	120	1.00			1.00			1.00		
Own advance directive				0.604			0.932			
No	638	1.17	(0.65–2.09)		1.03	(0.57–1.86)				
Yes	49	1.00			1.00					
End-of-life care among relatives				0.066			0.322			
No	336	1.32	(0.98–1.79)		1.17	(0.86–1.59)				
Yes	352	1.00			1.00					
Physician group				< 0.001			< 0.001			< 0.001
Competency in PM	66	1.00			1.00			1.00		
Oncologists	92	1.63	(0.78–3.40)		1.39	(0.66–2.93)		1.61	(0.75–3.46)	
Internists	150	<b>3.92</b>	<b>(2.00–7.67)</b>		<b>3.85</b>	<b>(1.96–7.57)</b>		<b>4.27</b>	<b>(2.13–8.56)</b>	
Surgeons	142	<b>4.53</b>	<b>(2.30–8.90)</b>		<b>4.37</b>	<b>(2.21–8.64)</b>		<b>4.51</b>	<b>(2.25–9.07)</b>	
GPs	242	<b>6.27</b>	<b>(3.29–12.0)</b>		<b>5.34</b>	<b>(2.78–10.3)</b>		<b>5.60</b>	<b>(2.85–11.0)</b>	

Significant results ( $p < 0.05$ ) bolded and nearly significant ( $p < 0.10$ ) shown by italic fontAge-adjusted significant ( $p < 0.05$ ) or nearly significant ( $p < 0.10$ ) variables included into the multivariate model. Missing values were not analyzed  
PM, Palliative Medicine, GP, General Practitioner

withhold treatments. We suggest that this willingness is related to the cPM itself as its influence remained also after multivariate analysis taking into account some important background factors in our study. We have to state, however, that we don't know all the attitudes, which might drive physicians to special education in PM and whether these factors also predispose to withholding and withdrawing life-sustaining treatments.

As our case represented a cancer patient, it is not surprising that responses among physicians with cPM and oncologists were quite similar, although there were differences concerning individual interventions. The relative unwillingness of GPs to make decisions for a palliative approach is a bit concerning, since a vast majority of dying patients in Finland are cared for by GPs.

This result was independent of the GPs' younger age. Our results highlight the need for education in PM starting from medical school and continuing throughout specialty training. In addition, palliative care consultations have shown to be beneficial and they should be offered to all specialties to help complex decision-making in EOL-care [6, 46–48].

Younger age was associated with unwillingness to withhold and withdraw therapies in our study. Age seems to be a contradictory factor in decision-making [49]. In some studies, including our own, older age has been associated with more decisions to withhold or withdraw interventions [50, 51], while in others, younger physicians or trainees make less aggressive decisions [52–54]. Younger physicians have less experience in



EOL-care, but on the other hand, PM is currently included in the curriculum of many medical schools, increasing younger colleagues' awareness of the benefits of palliative care. After 1999 two out of the five medical schools in Finland has included an undergraduate curriculum in PM fulfilling the European recommendations [55, 56]. Our results are in line with other studies showing that gender does not influence the decision-making [51, 54]. Some of the other background factors (such as experience in EOL-care with loved ones or a physician's own advance directive) did not influence the decision-making in our study, but are not included in previous studies.

Our results imply, that decisions to withhold or withdraw therapies in a clinical practise is mainly driven by medical education and clinical experience of a physician and preferences of a patient rather than doctor's personal life experience or attitudes.

Advance directive and a healthcare proxy or the family's opinion have been shown to have marked influence on physicians' decision-making [12, 31, 35, 57, 58], but there are no earlier studies about this for palliative care physicians. Our study is in line with previous ones [31, 32], since the family's request for aggressive treatments significantly increased physicians' willingness to continue or start life-prolonging therapies, and advance directive decreased this. This finding was constant through different physician groups including physicians with cPM. Communication and shared decision-making are very important in EOL-care [20, 49–54, 57, 58], but futile therapies should not be used (even if families have requested them), as stated by the Finnish National Supervisory Authority for Welfare and Health [59]. Therefore, this clear influence of family requests on decision-making is controversial and perhaps an issue needing more attention in the education of PM, which should also introduce legal aspects and official recommendations on decision-making. Knowing a patient's own will helps in decision-making [31, 32], and an advance directive naturally moves the decisions towards a palliative approach. However, the content of an advance directive presented here did not describe the patient's will in detail, which is often the case in the real world as well. The understanding of "active treatments" probably influenced the decisions concerning individual therapies in the present study and calls for more detailed advanced care planning and advance directives in clinical practice.

The differences in decision-making between physicians with cPM and others were most striking for nasogastric tube and intravenous hydration. Surgeons, internists and to a lesser extent GPs were unwilling to withdraw hydration, even when an advance directive was found. Artificial nutrition or medically assisted hydration has not been shown to improve survival, quality of life or symptoms in

EOL-care, although the evidence about this is scarce [60–64]. There are studies, however, raising concerns about the potential harms, such as increased respiratory secretions, related to hydration during EOL [65]. Although the use of artificial nutrition or intravenous hydration in EOL-care remains controversial, the case scenario in our study represented a dying patient in which these therapies can be considered non-beneficial. The pros and cons of these therapies are included in the formal training in PM, but are probably quite unfamiliar to other physicians.

Supplementary oxygen was the least withdrawn treatment in our study, even among physicians with cPM. This result is in line with reports showing that oxygen is used in more than 70% of patients in EOL-care [66, 67], although the evidence to support this is lacking [68–70]. Perhaps this unwillingness to withdraw oxygen is related to the presumption of its benefit and harmlessness, although it may cause dryness of the mouth and aggravate communication.

In our study antibiotics were withdrawn by about half of the physicians. Use of antibiotics in EOL is controversial, but there is some evidence that antibiotics might relieve symptoms without serious side-effects, which might explain the unwillingness to withdraw them [71, 72]. Internists and GPs were more unwilling to withdraw thrombosis prophylaxis compared to others, probably due to their familiarity with the indications of anticoagulation in the general population. There are no controlled studies to guide when to stop anticoagulation in palliative care, but as our case represented a dying person, withdrawing it can be considered reasonable [73].

The benefits of transfusions in palliative care are experienced briefly and remain controversial [74]. In our study, the physicians with cPM withheld blood transfusions more frequently than others, although the availability of an advance directive increased the willingness to over 90% in all groups.

Pleural drainage can alleviate dyspnoea, but this is an invasive procedure including some risks in EOL-care [75]. Surgeons and GPs were most eager to perform this procedure, which probably reflects their willingness to perform chest X-rays as well. In a Scandinavian study, intensive care physicians withheld laboratory tests [17] more often than all the physicians in our study, which is somewhat surprising. Changing from cure to care might be more complex in a common hospital ward compared to an intensive care unit (ICU), where withdrawing life-supporting treatments commonly leads to relatively rapid patient death.

### Limitations

Some limitations of this study need to be acknowledged. Our response rate (53%) is higher than in many of the recent surveys [31, 37, 76], but still sets a limitation.



Although there might be some nonresponse bias, our responders can be considered a representative sample of Finnish physicians providing insight into their decision-making. The distribution of physician groups in the study equals the distribution of different specialities in Finland [39]. Similarly, the high proportion of female respondents in our study is understandable, since 60% of physicians in Finland are women and female dominance is true among all the specialities studied excluding surgeons [39]. Answers to hypothetical scenarios might differ from physicians' decision-making in real life situations. In addition, the scenario forced the responder to give simple "yes" or "no" answer without the possibility for example to discuss with the family to achieve shared decision. Further studies on physicians' decision-making in clinical practice are needed, although this might be difficult to study in large physician groups, as each clinical circumstance is very different. We suggest, however, that the factors behind decision-making remain similar in real life situations and in our hypothetical scenarios. Finally, most of the treatments in our case clearly intend to prolong life (e.g., mechanical ventilation), while some of them may be partly considered as supporting ones (e.g., pleural drainage). Similarly, oxygen or transfusions may be given for symptom relief only or to prolong life, which should be distinguished.

Therefore, "palliative" or "life-prolonging" intent may be questioned in some decisions, but we suggest that the overall tendency to withdraw or withhold therapies in our study reflects reasonable decision-making in EOL-care. The intention itself behind these decisions is an interesting subject for future studies.

## Conclusions

Physicians with special education in palliative medicine are more willing to withdraw and withhold life-prolonging therapies in EOL-care. This is especially true concerning decisions on hydration, artificial nutrition and transfusions. Families' request and advance directives have a significant influence on decision-making in all physicians.

Younger age and specialty of a physician are main factors influencing the willingness to start or continue life-prolonging treatments. Therefore, education about decision-making in EOL-care should be mandatory at medical schools and in the training of all the specialities facing dying patients. Palliative care consultations might be needed for complex cases of decision-making in EOL-care.

## Additional file

**Additional file 1:** The parts of the questionnaire reported in this study. (DOCX 23 kb)

## Abbreviations

cPM: Special competency in palliative medicine; EOL: End-of-life; GP: General health care practitioner; ICU: Intensive care unit; IQR: Interquartile range; PM: Palliative medicine

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## Availability of data and materials

The datasets used and analysed during the study are available from the corresponding author on reasonable request.

## Authors' contributions

RP, JL, HH and PLKL designed the study outline and the questionnaire. RP, JL and PLKL collected the data. RP, JL, PLKL and TL analysed the data. RP and TL did the final statistical analysis. All the authors contributed to the writing and reviewing of the manuscript and approved the final manuscript.

## Ethics approval and consent to participate

The study was approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101) and participation was voluntary and anonymous. A cover letter including full information about the study and contact details of the authors for any additional questions were mailed together with the questionnaires. Answering the questionnaire and sending it to the authors was regarded as a written informed consent to participate to the study. This was approved by the ethics committee.

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

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## Author details

<sup>1</sup>Faculty of Medicine and Life Sciences, University of Tampere, Tampere, Finland. <sup>2</sup>Department of Oncology, Tampere University Hospital, Tampere, Finland. <sup>3</sup>Department of Oncology, Tampere University Hospital, Palliative Care Unit, Teiskontie 35, R-building, 33520 Tampere, Finland. <sup>4</sup>Research and Innovation Center, Tampere University Hospital, Tampere, Finland. <sup>5</sup>Health Sciences, Faculty of Social Sciences, University of Tampere, Tampere, Finland. <sup>6</sup>Rehabilitation Center Apila, Kangasala, Finland.

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# **PUBLICATION**

## **II**

**Changes in attitudes towards hastened death among Finnish physicians  
over the past sixteen years.**

Piili Reetta P, Metsänoja Riina, Hinkka Heikki, Kellokumpu-Lehtinen Pirkko-Liisa  
I, Lehto Juho T

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RESEARCH ARTICLE

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# Changes in attitudes towards hastened death among Finnish physicians over the past sixteen years

Reetta P. Piili<sup>1,2\*</sup> , Riina Metsänoja<sup>3</sup>, Heikki Hinkka<sup>4</sup>, Pirkko-Liisa I. Kellokumpu-Lehtinen<sup>1,2</sup> and Juho T. Lehto<sup>1,2</sup>

## Abstract

**Background:** The ethics of hastened death are complex. Studies on physicians' opinions about assisted dying (euthanasia or assisted suicide) exist, but changes in physicians' attitudes towards hastened death in clinical decision-making and the background factors explaining this remain unclear.

The aim of this study was to explore the changes in these attitudes among Finnish physicians.

**Methods:** A questionnaire including hypothetical patient scenarios was sent to 1182 and 1258 Finnish physicians in 1999 and 2015, respectively. Two scenarios of patients with advanced cancer were presented: one requesting an increase in his morphine dose to a potentially lethal level and another suffering a cardiac arrest. Physicians' attitudes towards assisted death, life values and other background factors were queried as well. The response rate was 56%.

**Results:** The morphine dose was increased by 25% and 34% of the physicians in 1999 and 2015, respectively ( $p < 0.001$ ). Oncologists approved the increase most infrequently without a significant change between the study years (15% vs. 17%,  $p = 0.689$ ). Oncological specialty, faith in God, female gender and younger age were independent factors associated with the reluctance to increase the morphine dose. Euthanasia, but not assisted suicide, was considered less reprehensible in 2015 ( $p = 0.008$ ). In both years, most physicians (84%) withheld cardiopulmonary resuscitation.

**Conclusion:** Finnish physicians accepted the risk of hastening death more often in 2015 than in 1999. The physicians' specialty and many other background factors influenced this acceptance. They also regarded euthanasia as less reprehensible now than they did 16 years ago.

**Keywords:** Clinical ethics, Decision-making, End-of-life care, Euthanasia

## Background

Discussions about the ethical justification of hastened death due to unbearable suffering are ongoing. Assisted death through euthanasia or physician-assisted suicide (PAS) has been legalized in seven countries (five states in the United States of America) thus far [1]. In addition, public support for euthanasia and PAS is mounting all over Western Europe, while some decline has been observed in the United States of America and Eastern Europe [1, 2]. Today, there are debates about the legalization of euthanasia in many countries, including Finland, where the

government is currently considering options after a civil motion demanding the legalization of euthanasia. At the same time, the importance of palliative care and patient-centred decision-making has been increasingly recognized among health care professionals and the general public in European countries including Finland [3–9].

Palliative care, by definition, intends to neither hasten nor postpone death [10]. The International Association for Hospice and Palliative Care and the European Association for Palliative Care have recently stated that euthanasia and PAS should not be included as part of the clinical practice of palliative care [11, 12]. Attitudes among physicians towards assisted death are not widely studied, but several surveys do demonstrate a lower amount of support from physicians for euthanasia and PAS when compared to support from the general public [1].

\* Correspondence: [piili.reetta.p@student.uta.fi](mailto:piili.reetta.p@student.uta.fi)

<sup>1</sup>Faculty of Medicine and Life Sciences, University of Tampere, Tampere, Finland

<sup>2</sup>Department of Oncology, Palliative Care Unit, Tampere University Hospital, Teiskontie 35, R-building, 33520 Tampere, Finland

Full list of author information is available at the end of the article



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Questions about hastening death in end-of-life care are complex and may include ethical concerns broader than just euthanasia or PAS. Although clear definitions have been specified for euthanasia and PAS [12], which lead to a clearly assisted death, the term “hastened death” is unspecified and has many interpretations. The termination of life-sustaining treatments may be confused with euthanasia and PAS among the public and physicians [13]. The term “double effect” has been used when the act intended to do good (e.g., relief of suffering) justifies the foreseeable danger of harm (e.g., hastened death) [14]. The use and dosing of opioids during end-of-life care is a commonly used example when talking about the double effect: does the intent to treat pain or breathlessness outweigh the risk of potentially hastening death [15, 16]?

However, there is growing evidence that even though high doses of opioids may cause respiratory depression [17–19], they do not seem to hasten death during end-of-life care [20, 21]. In a large multinational study by Miccinesi et al., there was general approval for alleviating symptoms with a possibly life-shortening treatment [22]. In another study from the United Kingdom (UK), physicians reported that they had at least some intention to hasten death in 7.4% of the deaths evaluated [23]. Physicians’ attitudes towards hastened death through a dual effect and the background factors influencing these decisions remain largely unknown.

The aims of our study were to elucidate how, if at all, the attitudes and values towards assisted death among Finnish physicians have changed over the past 16 years and to determine the attitudes and background factors affecting physicians’ willingness to accept hastened death in a hypothetical patient scenario.

## Methods

### Participants

A postal survey was conducted in spring 1999 and in autumn 2015. In both years, the questionnaire was sent to 500 general practitioners (GPs), 300 surgeons, and 300 internists randomly selected from the register of the Finnish Medical Association and to all Finnish oncologists ( $n = 82$  in 1999 and  $n = 158$  in 2015). Reminders were sent twice to non-respondents. A cover letter including an introduction to the study and an assurance of anonymity was mailed together with the questionnaire. It was also stated in the cover letter, that answering to the questionnaire was completely voluntary. This study was approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101).

### Questionnaire

The questionnaire included seven hypothetical patient scenarios. Following the patient scenarios, attitudes regarding several moral and ethical aspects were assessed

with a 100-mm visual analogue scale (VAS) from “definitely agree” (0 mm) to “definitely disagree” (100 mm). These included, for example, statements concerning euthanasia, palliative care, the role of religion in ethical decisions, advanced care directives and health care economics together with physicians’ satisfaction with their own health, work and salary (Tables 2 and 3). Physicians’ personal conceptions of professional status and their own health, family life, religion, and nature and standard of living were assessed using a four-point Likert scale (Table 2). The questionnaire has been previously used and validated with Finnish physicians [24–26].

### Patient scenarios

In this study, we included two patient scenarios:

In scenario 1, a 60-year-old male patient is suffering from prostatic cancer with metastases. Metastases in the thoracic spine led to total paraparesis 1 month earlier. There is no hope for a cure. The patient is well aware of the situation. He has totally lost his will to live. When you are together with him alone, he asks for a sufficient dose of morphine to “get away”. You have denied the overdose, explaining that it is against your ethical principles. During the following days, you notice that the patient asks you to double his morphine dose because of unbearable pain. The anti-inflammatory pain medication is at its maximum dose and you suspect if the pain is real (this sentence was removed from the scenario in 2015 as it did not comply with current treatment guidelines for cancer pain). You suppose that increasing the dose in such a way would lead to the patient’s death. Your decision is which of the following: a) to raise the dose because the patient has the right to sufficient pain relief in this end-of-life (terminal) care situation; b) to try to help the patient in other ways, such as with antidepressants, thus continuing with morphine dosing according to given guidelines; c) I can’t say; or d) give another solution:\_\_\_\_\_.

In scenario 2, a 32-year-old female patient is brought by ambulance to the emergency unit. She is accompanied by her husband who says his wife has inoperable brain cancer. She has been receiving maximum radiotherapy, but this was discontinued 3 weeks ago. She has deteriorated considerably during the past week. The patient has now had an epileptic seizure and has been unconscious since the attack. After 20 min at the hospital the patient stops breathing, and there is no pulse. Your treatment decision is which of the following: a) to start cardiopulmonary resuscitation (CPR) or b) to withhold CPR.



### Statistical analysis

The answers concerning the doubling of the morphine dose in scenario 1 were converted to two options: “I accept” (response a) and “I do not accept” (other solutions). The answers on the 4-point Likert scale concerning values were converted to the following 2-point scale: 1–2 for “not important” and 3–4 for “important”.

Two-scale background factors and values were tested using the Pearson chi-square test.

Continuous variables were tested using an independent-variables *t*-test or the Mann-Whitney U-test if the data were not normally distributed. Two-sided *p*-values less than 0.05 were considered as statistically significant.

### Logistic regression analysis

A forward stepwise logistic regression was used to create a model explaining the decision to increase the morphine dose. Background factors, life values, and attitudes, shown in Table 2, were all included in the model. The *p*-value limit for significance was set at 0.10 to enter and 0.15 to remove from the model.

Data analyses were performed using IBM SPSS Statistics for Windows, Version 23.0 (Armonk, NY: IBM Corp. Released 2014).

## Results

In total, 1373 valid responses were received (response rate 56%). Characteristics of the physicians according to the year of response are shown in Table 1. Compared to respondents in 1999, respondents in 2015 were older ( $p < 0.001$ ), had longer working experience ( $p < 0.001$ ) and were more often women ( $p < 0.001$ ).

### Change in attitudes

The attitudes, personal factors and life values of the responding physicians in 1999 and 2015 are shown in Table 2.

Euthanasia and withdrawal of life-sustaining treatments were considered slightly less reprehensible in 2015 than in 1999, whereas attitudes towards assisted suicide did not change significantly. In 2015, physicians more often believed that good palliative care enables a good death and found end-of-life care satisfying, although they were less often actually involved in end-of-life care than the respondents in 1999. Advance directives were considered more helpful in 2015, although physicians still rarely had their own advance directives. The impact of physicians' background factors, faith in God, and religion on ethical decisions decreased between 1999 and 2015. The length of life, family, and cleanliness of environment were thought to be more important in 2015, while success in their professional career was less important.

### Change in decision-making

In the case in scenario 1, physicians were significantly more willing to increase the morphine dose in 2015 ( $n = 219$ , 34%) than in 1999 ( $n = 180$ , 25%) ( $p < 0.001$ ). This willingness increased in all groups of physicians, except among oncologists, who were also the most unwilling to do this in both years (Fig. 1). In contrast, 84% of the physicians decided to withhold CPR in case scenario 2 in both years. There were no significant changes regarding this decision about CPR among the different physician groups between the study years.

### Factors associated with physicians' willingness to increase the morphine dose

Difference in the attitudes of physicians who accepted and those who did not accept the doubling of the morphine dose in both years studied are shown in Table 3.

In 1999, leniency towards euthanasia and assisted suicide was significantly greater in those who accepted the dose increase, while this was true only for assisted suicide in 2015.

Religion had a significantly larger influence on decision-making in physicians who accepted the morphine dose increase in 1999 but not in 2015.

Factors and attitudes that independently influenced physicians' willingness to increase the morphine dose from the logistic regression analysis are shown in Table 4.

Not being an oncologist was the most striking factor associated with physicians' willingness to increase the morphine dose. In addition, physicians who were male, were older, did not believe in God, accepted assisted suicide, had doubts about physicians' ability to assess cancer pain, and responded in 2015 were also more likely to be willing to increase the morphine dose. However, physicians' decisions about CPR for the patient in scenario 2 and their attitudes towards euthanasia or withdrawal of life-sustaining treatments did not influence their decision to accept the escalation of the morphine dose.

## Discussion

Our study shows that some Finnish physicians' attitudes and life values have changed substantially during the last 16 years. Their approval of euthanasia has slightly increased, whereas their acceptance of physician-assisted suicide (PAS) has remained low. In an end-of-life patient case scenario, physicians show an increasing willingness to give a high morphine dose, which might potentially hasten death. In logistic regression analysis, not being an oncologist, being male, and not believing in God were the most important background factors associated with physicians' willingness to increase the morphine dose.

In our study Finnish physicians were less opposed to euthanasia now than they were 16 years ago. This finding is in agreement with previous studies showing

**Table 1** Characteristics of the participants

	Surgeons			Internists			GPs			Oncologists			Total		
	1999	2015		1999	2015		1999	2015		1999	2015		1999	2015	
Number (% of total)	175 (24)	142 (22)		184 (25)	153 (24)		316 (43)	245 (38)		54 (7)	104 (16)		729 (100)	644 (100)	
Response rate, %	58	47		61	47		63	49		51	66		62	51	
Female, n (%)	33 (19)	47 (33)		60 (33)	81 (53)		170 (55)	173 (71)		30 (56)	85 (82)		293 (41)	386 (60)	
Mean age (range)	48 (33–66)	51 (33–64)		48 (32–70)	52 (33–65)		42 (25–63)	47 (25–65)		46 (35–61)	48 (32–67)		45 (25–70)	50 (25–67)	
Working place <sup>a</sup>															
Outpatient unit	1 (1)	2 (1)		15 (9)	15 (10)		242 (78)	208 (86)		2 (4)	4 (4)		260 (37)	229 (36)	
Hospital	146 (85)	124 (88)		123 (71)	122 (82)		33 (11)	24 (10)		44 (83)	91 (88)		346 (49)	361 (57)	
Other	24 (14)	15 (11)		35 (20)	12 (8)		35 (11)	10 (4)		7 (13)	8 (8)		101 (14)	45 (7)	
Years from graduation, median (range) <sup>b</sup>	22 (2–42)	26 (7–42)		21 (7–41)	26 (8–42)		16 (1–35)	21 (0–40)		18 (9–34)	22 (7–40)		19 (1–42)	23 (0–42)	
Married, n (%)	140 (81)	119 (84)		142 (79)	124 (81)		228 (73)	198 (81)		45 (83)	71 (71)		555 (77)	512 (80)	

<sup>a</sup>For 32 participants working place was not available

<sup>b</sup>For 19 participants year of graduation was not available  
GP general practitioner

**Table 2** Attitudes, background factors and life values of the physicians in 1999 and 2015

	1999		2015		P-values*
Attitudes, median VAS (IQR)					
Active euthanasia is reprehensible	17	(6–51)	25	(5–66)	0.008
Withdrawal of life-sustaining treatments is reprehensible	89	(76–95)	93	(76–99)	< 0.001
Assisted suicide is reprehensible	14	(5–38)	13	(2–52)	0.480
End-of-life care is satisfying	36	(19–52)	15	(3–35)	< 0.001
People should pay costs of factitious diseases by themselves	44	(27–72)	78	(46–93)	< 0.001
Advance directives have been helpful in my decisions	35	(14–54)	10	(2–29)	< 0.001
Good palliative care enables good death	17	(9–28)	4	(1–12)	< 0.001
Physicians can't estimate cancer pain	40	(25–70)	47	(27–72)	0.042
Religion has influence when I make ethical decisions	65	(31–93)	81	(47–98)	< 0.001
Being a doctor gives me satisfaction	20	(11–30)	7	(2–18)	< 0.001
My health is excellent	20	(10–32)	14	(6–26)	< 0.001
I feel burn out, tired to work	84	(63–94)	89	(71–97)	< 0.001
I'm pleased with my salary	72	(37–87)	22	(7–50)	< 0.001
It is waste of resources to treat patients > 80 years in ICU	73	(49–86)	77	(54–93)	< 0.001
Background factors and life values, n (%)					
Having children	600	(85)	555	(88)	0.057
Having own advance directive	38	(5)	38	(6)	0.668
Taking care of end-of-life patients in practice (last 2 years)	529	(75)	418	(65)	< 0.001
Taking care of a family member in end-of-life	513	(73)	314	(49)	< 0.001
Being afraid of death (Fear-of-death index)	580	(80)	544	(86)	0.006
Length of life is important	412	(59)	524	(87)	< 0.001
Health is important	711	(99)	610	(99)	0.027
Family is important	686	(95)	607	(99)	< 0.001
Clean environment is important	666	(93)	599	(98)	< 0.001
High standard of living is important	358	(50)	398	(65)	< 0.001
Faith in God is important	338	(48)	253	(42)	0.024
Success in professional career is important	639	(89)	377	(62)	< 0.001

VAS visual analogue scale

IQR interquartile range

ICU intensive care unit

\*Mann-Whitney u-test for attitudes and Pearson Chi-Square for background factors and life values

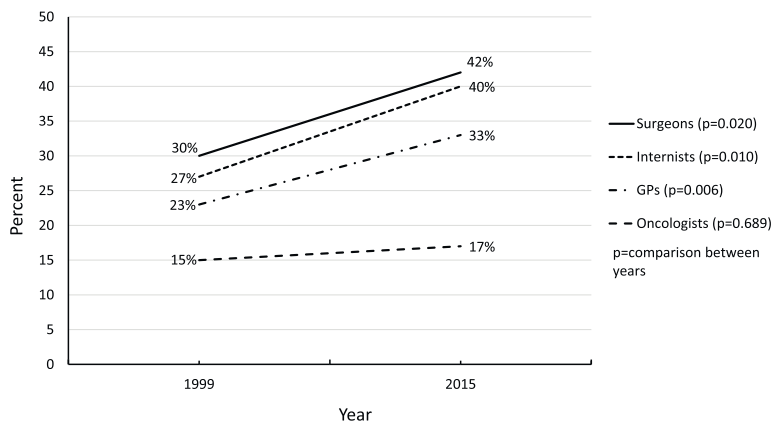
Attitudes are expressed on a visual analogue scale (VAS) from 0 mm (definitely agree) to 100 mm (definitely disagree)

increased acceptance of euthanasia in Europe as well as in Finland [1, 2]. However, attitudes towards euthanasia were measured with a continuous visual analogue scale (VAS) on a scale from 0 mm (reprehensible) to 100 mm (not reprehensible) in our study rather than with a dichotomous question (i.e., if the physician accepts or does not accept euthanasia).

Although using a VAS scale might have caused some confusion, doctors are generally familiar with its use. This type of assessment might provide more appropriate insight into this complex ethical question. Of note, the VAS median value in 2015 was still only 25 mm and the absolute difference compared to the value in 1999 was

8 mm. Thus, our results highlight the controversial attitude towards euthanasia, which might not be found in earlier studies; for example, a previous study showed that 46% of Finnish physicians supported legalization of euthanasia [2].

In contrast to other studies [1], Finnish physicians considered PAS even more reprehensible than euthanasia and this has not changed at all during the past 16 years. Determining whether this somewhat conflicting result is due to a true difference in the attitudes towards these two procedures or just less knowledge about the process of PAS in Finland could be an aim of future research.



**Fig. 1** Proportion of respondents who were willing to increase the morphine dose among different physician groups in 1999 and 2015

We asked if euthanasia or assisted suicide were reprehensible or not with a VAS scale to evaluate the personal ethical attitudes of the physicians rather than their opinions on the general justification of these issues. Therefore, our results represent somewhat different aspect of these issues compared to the findings of studies that inquired about physicians' opinions on the legalization of euthanasia or PAS. This might partly explain the differences in the results of the present and previous studies [1, 2].

According to this study, Finnish physicians do not consider withdrawal of life-supporting treatments reprehensible. Although there was a statistically significant change between the study years, the absolute difference was only 4 mm. Our results are in line with the results from a large, international study by Löfmark et al. where 72–86% of the physicians surveyed reported experiencing foregoing life-supporting treatment and only 1–6% reported never being willing to do so [27].

**Table 3** Attitudes of physicians who were willing or unwilling to increase the morphine dose in 1999 and 2015

Attitudes, median VAS (IQR)	1999 Increasing the morphine dose			2015 Increasing the morphine dose		
	Yes	No	P-value*	Yes	No	P-value*
Active euthanasia is reprehensible	37 (11–69)	14 (5–39)	< 0.001	33 (5–72)	24 (4–64)	0.162
Withdrawal of life-sustaining treatments is reprehensible	92 (83–96)	88 (72–95)	0.003	95 (80–99)	93 (75–98)	0.133
Assisted suicide is reprehensible	27 (9–61)	11 (4–28)	< 0.001	28 (2–68)	10 (1–49)	< 0.001
End-of-life care is satisfying	38 (19–51)	34 (18–52)	0.683	16 (2–30)	14 (3–45)	0.363
People should pay costs of factitious diseases by themselves	40 (23–65)	47 (29–75)	0.047	78 (49–94)	77 (47–93)	0.341
Advance directives have been helpful in my decisions	31 (10–55)	36 (15–54)	0.199	12 (2–29)	10 (2–28)	0.723
Good palliative care enables good death	19 (10–25)	16 (9–29)	0.833	4 (1–13)	4 (1–13)	0.869
Physicians can't estimate cancer pain	35 (22–70)	41 (27–71)	0.056	44 (23–69)	50 (29–74)	0.006
Religion has influence when I make ethical decisions	77 (44–94)	57 (30–92)	0.040	86 (49–98)	78 (45–98)	0.130
Being a doctor gives me satisfaction	21 (11–29)	19 (11–30)	0.456	7 (1–19)	7 (2–18)	0.928
My health is excellent	21 (10–35)	20 (10–31)	0.273	15 (5–27)	14 (06–25)	0.751
I feel burn out, tired to work	84 (68–93)	84 (62–94)	0.701	88 (75–96)	89 (70–97)	0.843
I'm pleased with my salary	77 (51–90)	70 (35–87)	0.082	22 (8–50)	22 (7–51)	0.759
It is waste of resources to treat patients over 80 years of age in ICU	70 (48–86)	73 (49–87)	0.262	82 (54–94)	75 (54–91)	0.107

VAS visual analogue scale

IQR interquartile range

ICU intensive care unit

\*Mann-Whitney U-test

Attitudes expressed on a visual analogue scale (VAS) from 0 mm (definitely agree) to 100 mm (definitely disagree)

**Table 4** Different background factors, life values and attitudes explaining physicians' decision to increase the morphine dose ( $n = 323$ ) versus not ( $n = 767$ ) in forward logistic regression analysis

	<i>n</i>	<i>OR</i>	<i>(95% CI)</i>	<i>P-value</i>
Year of the survey				
1999	578	ref.		
2015	512	1.40	(1.05, 1.88)	0.024
Sex				
Female	534	ref.		
Male	556	1.51	(1.11, 2.05)	0.009
Age	1090	1.02	(1.01, 1.04)	0.007
Own advance directive				
No	1026	ref.		
Yes	64	1.74	(1.00, 3.03)	0.051
Faith in God				
Important	489	ref.		
Not important	601	1.64	(1.23, 2.19)	0.001
Assisted suicide is reprehensible (VAS)	1090	1.13	(1.08, 1.19)	< 0.001
Physicians can't estimate cancer pain (VAS)	1090	0.94	(0.89, 0.99)	0.021
Physician groups				0.014
Oncologists	120	ref.		
Surgeons	252	2.50	(1.40, 4.46)	0.002
Internists	268	2.37	(1.34, 4.20)	0.003
GPs	450	2.30	(1.33, 3.97)	0.003

ref, reference

VAS, visual analogue scale

GP, general practitioner

Knowledge about the benefits of palliative care has grown in recent decades, and it is considered a part of everyday care in life-threatening illnesses [10, 28, 29]. Therefore, it is not surprising that almost all of the respondents in 2015 considered palliative care as a way of enabling a good death. However, in another study only 51–70% of physicians believed that palliative care was able to prevent the need for euthanasia and PAS [22].

Although advanced care planning has shown a positive impact on the quality of end-of-life care [30, 31], the prevalence of advance directives varies largely. In the United States, the prevalence of advance directives seems to have increased from approximately 10% up to 21–55% among the elderly in the last 10 years [32, 33], while a Finnish study from 2004 showed that only 12% of the home-dwelling elderly had a living will [34]. In our study, physicians found the advance directives of the patients now more helpful than they were in 1999, but having an advance directive of their own was still uncommon among doctors in 2015 even though they were older and more experienced than in 1999. This finding might reflect a division between personal life values and experiences in clinical work.

In general, physicians accepted potentially lethal morphine dosing more frequently now than in 1999, although approximately two-thirds of the doctors were still unwilling to provide this. This result might be due to actual acceptance of hastening death at the end-of-life, better knowledge regarding the use of opioids or both. It is now known that clinically relevant respiratory failure is not a problem when opioids are titrated against cancer pain [35]. Since 1999, there has been growing evidence that the use of opioids for symptom control in advanced diseases has no effect on survival and even high doses of opioids do not seem to shorten life during end-of-life care [20, 21]. In a study conducted in the Netherlands, physicians administered similar dosages of opioids in 1995, 2001 and 2005; however, compared with previous years, in 2005, they thought that life was shortened by opioids or their intension was to hasten death by administering opioids less frequently [16]. On the other hand, high doses of opioids do cause respiratory depression [17–19], and the potential of opioid to hasten death during end-of-life care is almost impossible to study with prospective randomized trials. Although we did not ask the intention behind physicians' willingness to increase the morphine dose, it was clearly stated in the patient

scenario that increasing the dose might lead to the patient's death. Oncologists were most reluctant to provide the dose increase, and their opinion did not change between 1999 and 2015. However, they were probably the most familiar with the influences of opioids in clinical practice as well as the studies on this issue. Our results reflect that surgeons, internists and GPs have become increasingly willing to hasten death according to a patient's wishes today than they were 16 years ago, although improved knowledge on the low risk of using opioids during end-of-life care probably influenced our results.

Our results are in line with the study by Miccinesi et al. in which oncologists were the least in favour of using lethal drugs [22]. In our study, the difference between oncologists and other physician groups remained in the results of the logistic regression analysis. These findings might be observed because oncologists take care of these patients on a more regular basis and are perhaps aware that a patient's wish to hasten death does not always imply a genuine wish to die, but might be the result of overwhelming emotional suffering [36], which could be relieved by therapy.

Religion has been confirmed to have a tremendous effect on end-of-life decisions and attitudes towards euthanasia and PAS [1, 22, 27]. In the present study, faith in God was also found to decrease physicians' willingness to administer potentially lethal morphine dose. The number of physicians who had faith in God is lower in the present survey than in 1999, which might be one reason for the increasing support for euthanasia and hastened death. In a previously mentioned study, Löfmark et al. concluded that a non-religious philosophy of life increased physicians' willingness to perform euthanasia and PAS, possibly by emphasizing patient autonomy [27]. Advance directives were relatively uncommon among physicians, but having one seemed to increase the willingness to double the morphine dose; however, the influence of advance directives did not quite reach statistical significance in our logistic regression analysis. To our knowledge, the influence of doctors' own advance directives on end-of-life decisions has not been previously reported.

We suggest that completing an advance directive for oneself may lead to greater acceptance of death, even if this is hastened in a situation without hope for a cure.

Male sex and older age were independently associated with physicians' willingness to double the morphine dose. Previous studies on these factors are somewhat controversial. Females have been shown to be less supportive towards ending life without explicit request from the patient, but also to be more supportive of alleviating pain and other symptoms regardless of the possible life-shortening effects [22, 26]. In general, younger physicians accept PAS more often but are less willing to withdraw life-prolonging treatments than older physicians [2, 22, 26]. The exact reasons

why age and sex are related to the tendency to administer potentially lethal morphine dose in our study remains unknown, but perhaps more experienced physicians do not believe that such a morphine dose would actually kill the patient. Furthermore, men are reported to approve of assisted death more often than women in the general population [1].

Developments in medicine have allowed many interventions for patients with very advanced diseases, but the low survival rates for cardiopulmonary resuscitation (CPR) in the cancer population have not changed [37]. Furthermore, advanced care planning, which increases the prevalence of do-not-resuscitate orders, is probably a more common practice today than in the 1990's [31, 38]. In our study, physicians' willingness to start CPR in a patient with very advanced cancer was relatively low and did not change over the study years, in a contrast to the more ethically difficult and complex attitude regarding hastening death. Of interest, the decision about CPR did not influence physicians' willingness to hasten death through the dual effect of a high morphine dose. We suggest that physicians' willingness to hasten death is mainly related to their personal attitudes and values rather than medical facts, which probably guide the decision to withhold CPR.

Finally, we should state that changes in the surrounding society, general attitudes and clinical decision-making in Finland and Europe since the 1990s might have had a substantial influence on our results. In a large international study, the use of lethal doses of drugs after the explicit request of a patient with a terminal illness and uncontrolled symptoms was accepted by 35–78% of physicians, depending on the country [22]. This large range describes the cultural influence on the difficult decision to hasten death, but the numbers are quite similar to those found in our study. Public attitudes towards assisted death have changed since the 1990s to become more permissible, which has led to legalization of assisted death in some countries and increased political support for it in Finland [1, 2]. At the same time, knowledge and awareness of palliative care have grown in Finland through national and international recommendations [39–41]. However, this has happened later than in some other European countries such as the UK [3, 4]. In addition, patient autonomy and shared decision-making in treatment-choices are increasingly emphasized as important ethical principles throughout Western countries [5, 6, 42]. Patients' rights regarding treatment decisions were incorporated into Finnish law in 1992, and respecting the patient's wishes is currently one of the main principles in the ethical guidelines of the Finnish Medical Association [8, 9]. This social and cultural context together with the shift from paternalism towards a more patient-centred approach in clinical decision-making probably influenced the responding physicians' considerations on the reprehensibility of hastened death and their willingness

to comply with patients' requests in the ethically complex situation in our study [6, 43].

### Strengths and limitations of the study

Limitations of this study need to be acknowledged. Our response rate (56%) is a limitation even though our study population is large and the response rate is higher than that in many recent studies [44–46]. The study population is also a representative sample, as it reflects the overall distribution of specialties and gender among Finnish physicians [47]. The follow-up period is long enough to detect relevant changes in attitudes and decision-making. Answers to the hypothetical scenarios might differ from the decisions made in clinical practice, but these questions are difficult to study in real life situations.

### Conclusions

Considering a hypothetical case scenario, Finnish physicians accepted the risk of hastening death more often in 2015 than in 1999. The specialty of the physician, gender, and faith in God strongly influenced their acceptance to this practice. Oncologists were the most reluctant of all the specialists studied to hasten death. Euthanasia, but not assisted suicide, was considered slightly less reprehensible in 2015. Relieving suffering, while considering the justification to hasten death, is a complex ethical question. Therefore, both training in medical ethics and medicine are needed for high quality end-of-life care.

### Abbreviations

CPR: Cardiopulmonary resuscitation; GP: General practitioner; ICU: Intensive care unit; IQR: Interquartile range; PAS: Physician-assisted suicide; UK: the United Kingdom; VAS: Visual analogue scale

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### Availability of data and materials

The datasets used and analysed during the study are available from the corresponding author on reasonable request.

### Authors' contributions

RP, JL, HH and PLKL designed the study outline and the questionnaire. RP, JL and PLKL collected the data. RP, JL, PLKL and RM analysed the data. RP and RM performed the final statistical analysis. All the authors contributed to the writing and reviewing of the manuscript and approved the final manuscript.

### Ethics approval and consent to participate

The study was approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101) and participation was voluntary and anonymous.

### Competing interests

The authors declare that they have no competing interests.

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### Author details

<sup>1</sup>Faculty of Medicine and Life Sciences, University of Tampere, Tampere, Finland. <sup>2</sup>Department of Oncology, Palliative Care Unit, Tampere University Hospital, Teiskontie 35, R-building, 33520 Tampere, Finland. <sup>3</sup>Faculty of Social Sciences, University of Tampere, Tampere, Finland. <sup>4</sup>Rehabilitation Center Apila, Kangasala, Finland.

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# **PUBLICATION**

## **III**

**Has there been a change in the end-of-life decision-making over the past 16 years?**

Piili Reetta P, Lehto Juho T, Metsänoja Riina, Hinkka Heikki, Kellokumpu-Lehtinen Pirkko-Liisa I

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# Has there been a change in the end-of-life decision-making over the past 16 years?

Reetta P Piili,<sup>1,2</sup> Juho T Lehto,<sup>1,2</sup> Riina Metsänoja,<sup>3</sup> Heikki Hinkka,<sup>4</sup> Pirkko-Liisa I Kellokumpu-Lehtinen<sup>1,5</sup>

<sup>1</sup>Faculty of Medicine and Health Technology, Tampere University, Tampere, Finland

<sup>2</sup>Department of Oncology, Palliative Unit, Tampere University Hospital, Tampere, Finland

<sup>3</sup>Faculty of Social Sciences, Tampere University, Tampere, Finland

<sup>4</sup>Rehabilitation Center Apila, ret, Kangasala, Finland

<sup>5</sup>Department of Oncology, Tampere University Hospital, Tampere, Finland

## Correspondence to

Dr Reetta P Piili, Faculty of Medicine and Health Technology, Tampere University, Tampere 33520, Finland; reetta.piili@tuni.fi

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## ABSTRACT

**Objectives** Physicians' decision-making in end-of-life (EOL) care includes many medical, ethical and juridical aspects. We studied the changes of these decisions over time and factors influencing them.

**Methods** A postal survey including two hypothetical patient scenarios was sent to 1258 Finnish physicians in 2015 and to 1182 in 1999. The attitudes, values and background factors of the physicians were also enquired.

**Results** The response rate was 56%. The physicians' decisions to choose palliative approaches over active or intensive care increased from 1999 to 2015 when a terminally ill prostate cancer patient had probable iatrogenic gastrointestinal bleeding (53% vs 59%,  $p=0.014$ ) and waited to meet his son (46% vs 60%,  $p<0.001$ ) or a minister (53% vs 71%,  $p<0.001$ ). Training in EOL care independently increased palliative approaches. Patient's benefit (96% vs 99%,  $p=0.001$ ), ethical values (83% vs 93%,  $p<0.001$ ) and patient's (68% vs 86%,  $p<0.001$ ) or physician's (44% vs 63%,  $p<0.001$ ) legal protection were considered more influential to the decisions in 2015, while the family's benefit was regarded as less influential to the decisions than it was in 1999 (37% vs 25%,  $p<0.001$ ). Physicians were more willing to give a hospice voucher for an advanced breast cancer patient in 2015 (34% vs 58%,  $p<0.001$ ).

**Conclusions** Our findings may reflect the transition to a stronger emphasis on patient-centred care and a stronger tendency to avoid futile therapies that have only short-term goals. The results highlight that education in all aspects of EOL care should be incorporated into the post-graduate training of medical specialties that take care of dying patients.

## INTRODUCTION

Individualism has been rising in western countries.<sup>1 2</sup> This can also be seen in

medicine, where shared decision-making and patient-centred care are now preferred by most physicians and patients.<sup>3–5</sup>

However, concerns have been raised about the excessive autonomy of patients, which can result in costly, ineffective and even futile treatments.<sup>6</sup> The right of the patient to be involved in treatment decisions was included in Finnish law in 1992.<sup>7</sup> However, the Finnish National Supervisory Authority for Welfare and Health has stated that ineffective or futile therapies should not be used even though the patient requests them.<sup>8</sup> Physicians have to strike a balance between the wishes of the patient and family, legal and ethical aspects and evaluate the benefit, harm and cost of the care. This makes decision-making very challenging.

Decision-making in end-of-life (EOL) care involves many ethical, legal, medical and psychological aspects, and physicians' background characteristics, specialties, attitudes and values play a part in this complex process.<sup>9–15</sup> The specialty of a physician impacts their decision-making, as oncologists have been shown to be more opposed to accepting the risk of hastening death by using high doses of drugs for symptom control compared with other specialties, but they are more willing to withhold or withdraw futile treatments in EOL care.<sup>12 16 17</sup> Religion is shown to be associated with the unwillingness to withdraw life-supportive care,<sup>16 18 19</sup> whereas age and gender of the physician are inconsistent factors in the decision-making.<sup>11 17 19–21</sup>

Decision-making should be consistent in the same types of clinical situations regardless of the physician who is responsible for the care of the patient. The surrounding society and atmosphere do change over time, which might also influence medical decisions. As the values

and attitudes of the physician have a great impact on the decision-making, it is important to know whether these have changed over the years and how the possible changes affect the decisions that physicians make regarding EOL care. A better understanding of the background factors and changes in decision-making will help to define important educational aspects of decision-making in EOL care and will help to produce practical guidelines to provide high-quality and equal care to all patients.

The aim of this study was to identify whether physicians' decision-making has changed over the past 16 years and to explore the factors influencing and explaining these decisions.

## METHODS

### Participants

A postal survey with a similar questionnaire was conducted in 1999 and 2015 with Finnish physicians. In both years, the sample included 500 general practitioners (GPs), 300 surgeons and 300 internists who were randomly selected from the register of the Finnish Medical Association, together with all Finnish oncologists ( $n=82$  in 1999 and  $n=158$  in 2015). Non-responders were reminded twice. A cover letter including an introduction to the study, an assurance of anonymity and a statement of voluntariness was mailed together with the questionnaire.

### Questionnaire

Seven hypothetical patient scenarios were presented in the questionnaire. Following the patient scenarios, attitudes regarding several moral and ethical aspects were assessed with a 100 mm visual analogue scale from 'definitely agree' (0 mm) to 'definitely disagree' (100 mm). These included, for example, statements concerning euthanasia, palliative care, the role of religion in ethical decisions, advanced directives and healthcare economics, together with physicians' satisfaction with their own health, work and salary. There were also questions concerning the responders' background and personal features.

Changes in these attitudes have been reported earlier.<sup>22</sup> The questionnaire has been previously used and validated with Finnish physicians.<sup>10 11</sup>

### Patient scenarios

We included two patient scenarios in this study:

Scenario 1 presented an 82-year-old retired forest worker, who had received a diagnosis of prostatic cancer 3 years ago. During the past year, he received treatments for bone metastases. He has now been in hospital for 1 month, almost bedridden, and needs help with all functions. His mental condition has been normal. His general condition has weakened over the past week, he is now bedridden, and has received large doses of pain medication. Today, he has become comatose. His haemoglobin count has decreased to 68 g/L,

while the week before it was 118 g/L. His blood pressure is 80/40 mm Hg. There is no verbal or written advance directive. The patient's wife has previously said that she expects the doctor to make all treatment decisions according to his/her best understanding. After the scenario, the doctors were asked to choose one of the given treatment options. The concepts used in the treatment options were explained as follows: (a) palliative care: good nursing, sufficient medications for pain and other symptoms, and intravenous hydration only when it is considered to relieve the patient's symptoms; (b) active care: use of antibiotics, intravenous hydration or blood transfusions aimed at saving the patient's life in a life-threatening condition and (c) intensive care: moving the patient to an intensive care unit. After the initial question for scenario 1, four additional alternatives were presented, each ending with the same treatment options: (a) It has been discovered that the patient's faeces are black. You remember having prescribed ketoprofen for pain a week ago; (b) The patient's son is coming from America the day after tomorrow to see his father while he is still alive; (c) The patient has had spiritual anxiety and there is a planned appointment with a minister and the Lord's Supper tomorrow and (d) The patient's written advance directive has been found, in which the patient has expressed that all active interventions should be withheld if there is no hope for recovery. After asking for the treatment decisions, a Likert-type scale was presented to evaluate the influence of different factors (patient's benefit, family's benefit, patient's legal protection, physician's legal protection, ethical values, patient's age, cost of care and patient's social status) on the decisions (from 1—very little influence to 5—very much influence).

In scenario 2, a 68-year-old patient suffers from breast cancer with bone metastases. She is bedridden and her general condition has rapidly collapsed. She is in a community hospital ward and is receiving adequate pain treatment with which she is pleased. She is depressed and wants to transfer to a hospice for her last days. She feels that the atmosphere on the ward is very restless and 'institutional'. You have the right to issue a voucher for the costs of hospice care (€290 per day) to be paid by the community hospital. The costs would be approximately double compared with those in a community hospital, and the chief doctor has advised you to use great discretion in issuing vouchers. Your solution: (a) to accept the transfer, (b) to accept the transfer, provided that the patient pays the extra costs herself, (c) not to accept, because according to normal practice, the patient's care belongs to the community hospital ward, and there are no special problems in her care, (d) I don't know and (e) other solution.

Responders were instructed at the outset to answer the questions in sequence from beginning to the end and not to change their answers later.

### Statistical analysis

In the patient scenarios, the answers were converted into two options. In patient scenario 1: choosing palliative care (response a) or choosing active and intensive care (responses b and c). In patient scenario 2: willing to give a voucher for hospice (response a) or not willing to give a voucher (other responses). The answers on the 4-point Likert scale concerning values were converted to the following 2-point scale: 1–2 for ‘not important’ and 3–4 for ‘important’, and the answers on the 5-point Likert scale concerning the influence of different factors were converted to the following 2-point scale: 1–3 for ‘not much influence’ and 4–5 for ‘much influence’.

The two-scale patient scenarios, background factors and values were tested using the Pearson  $\chi^2$  test. Two-sided p values that were less than 0.05 were considered to be statistically significant.

The models explaining the decision to choose palliative care in patient scenario 1 and willingness to give a voucher for hospice in patient scenario 2 were created using forward stepwise logistic regression. Models were created from the scenarios that had a statistically significant difference between the study years.

Background factors, life values and attitudes were all included in the model.<sup>22</sup> The p value for significance was set at 0.10 to enter and 0.15 to remove from the model.

The data analysis was performed using IBM SPSS Statistics for Windows, V.23.0

## RESULTS

### Responders

The characteristics of the responders are presented in table 1. Altogether 1373 valid responses were obtained. In 1999, the responders were younger ( $p<0.001$ ), had shorter working experience ( $p<0.001$ ) and were more often men ( $p<0.001$ ) compared with the responders in 2015. Oncologists reported having participated in post-graduate EOL training significantly more often ( $p<0.001$ ) than other physicians (58% vs 22%).

### Change in decision-making

The overall changes in decision-making in the different patient scenarios according to physician group are presented in table 2. Statistically significant changes towards the palliative care approach were found when the terminally ill prostate cancer patient had probable iatrogenic gastrointestinal (GI) bleeding (scenario 1a), his son was coming to see him in 2 days (scenario 1b) and he had a Lord's Supper with a minister planned for the next day (scenario 1c). The oncologists' approach remained unchanged during the years studied. When an advance directive was found, most physicians (86%–94%) consistently chose a palliative care approach in both of the years studied. All of the physicians' groups were more willing to give a voucher

**Table 1** Characteristics of the participants

	Surgeons			Internists			GPs			Oncologists			Total	
	1999	2015		1999	2015		1999	2015		1999	2015		1999	2015
Number (% of total)	175 (24)	142 (22)		184 (25)	153 (47)		316 (43)	245 (49)		54 (7)	104 (66)		729 (100)	644 (100)
Response rate, %	58	47		61	47		63	49		51	66		62	51
Female, n (%)	33 (19)	47 (33)		60 (33)	81 (53)		170 (55)	173 (71)		30 (56)	85 (82)		293 (41)	386 (60)
Mean age (range), years	48 (33–66)	51 (33–64)		48 (32–70)	52 (33–65)		42 (25–63)	47 (25–63)		46 (25–65)	48 (35–61)		45 (32–67)	50 (25–67)
Working place*														
Outpatient unit	1	2		15 (9)	15		242 (78)	208 (86)		2	4		260 (37)	229 (36)
Hospital	146 (85)	124 (88)		123 (71)	122		33 (11)	24 (10)		44 (83)	61 (88)		346 (49)	361 (57)
Other	24 (14)	15 (11)		35 (20)	12		35 (11)	10 (4)		7 (13)	8		101 (14)	45 (7)
Years from graduation, median (range)†	22 (2–42)	26 (7–42)		21 (7–41)	26 (8–42)		16 (1–35)	21 (0–40)		18 (9–34)	22 (7–40)		19 (1–42)	23 (0–42)
Married, n (%)	140 (81)	119 (84)		142 (79)	124 (81)		228 (73)	198 (81)		45 (83)	71 (71)		555 (77)	512 (80)

\* For 32 participants, working place was not available.

† For 19 participants, year of graduation was not available.

GPs, general practitioners.

**Table 2** Numbers and proportions of physicians choosing a palliative care approach over active/intensive care for the terminally ill patient with a prostate cancer (scenario 1) and willing to give a voucher for hospice for the advanced breast cancer patient (scenario 2)

Number (%)	Surgeons				Internists				GPs				Oncologists				Total			
	1999	2015	P	value*	1999	2015	P	value*	1999	2015	P	value*	1999	2015	P	value*	1999	2015	P	value*
	1999	2015	value*		1999	2015			1999	2015			1999	2015			1999	2015		
Scenario 1	145 (84)	118 (84)	0.381		145 (80)	124 (82)	0.642		263 (84)	198 (82)	0.712		48 (89)	87 (84)	0.376		601 (83)	527 (83)	0.712	
Scenario 1a	97 (56)	76 (55)	0.860		86 (47)	86 (57)	0.067		160 (51)	145 (51)	0.024		38 (70)	67 (64)	0.453		381 (53)	374 (59)	0.014	
Scenario 1b	81 (47)	84 (47)	0.015		78 (43)	87 (57)	0.010		139 (44)	145 (44)	<0.001		31 (57)	64 (62)	0.565		330 (46)	380 (60)	<0.001	
Scenario 1c	91 (52)	95 (52)	0.007		97 (53)	105 (69)	0.003		161 (51)	171 (71)	<0.001		34 (64)	79 (76)	0.119		384 (53)	450 (71)	<0.001	
Scenario 1d	149 (86)	127 (90)	0.234		156 (86)	134 (89)	0.486		291 (92)	227 (93)	0.674		48 (89)	98 (94)	0.229		644 (89)	586 (92)	0.078	
Scenario 2	89 (63)	89 (63)	<0.001		61 (33)	102 (67)	<0.001		99 (31)	121 (50)	<0.001		23 (43)	59 (57)	0.092		244 (34)	371 (58)	<0.001	

Scenario 1: Prostate cancer patient (original scenario).  
Scenario 2: Prostate cancer patient with black faeces after ketoprofen prescription.  
Scenario 1a: Prostate cancer patient waiting to meet his son the day after tomorrow.  
Scenario 1b: Prostate cancer patient waiting to meet his son the day after tomorrow.  
Scenario 1c: Prostate cancer patient waiting to meet a minister tomorrow.  
Scenario 1d: Prostate cancer patient with the advance directive.  
Scenario 2: Breast cancer patient.  
\*Pearson  $\chi^2$  test.  
GPs: general practitioners.

**Table 3** Factors reported by the physicians to have influenced their decisions concerning the care of the terminally ill prostate cancer patient

Having much influence	1999	2015	P value*
Patient's benefit	700 (96%)	628 (99%)	0.001
Family's benefit	265 (37%)	166 (25%)	<0.001
Patient's legal protection	493 (68%)	545 (86%)	<0.001
Physician's legal protection	319 (44%)	401 (63%)	<0.001
Ethical values	599 (83%)	638 (93%)	<0.001
Patient's age	335 (46%)	255 (40%)	0.023
Costs of care	68 (9%)	61 (10%)	0.861
Patient's social status	13 (2%)	5 (1%)	0.106

\*Pearson  $\chi^2$  test.

for hospice to the patient with advanced breast cancer in 2015 than in 1999.

#### Physicians' opinions on the factors influencing their decisions

Physicians' opinions on the factors influencing their decisions concerning the terminally ill prostate cancer patient are summarised in table 3. Patient's benefit, ethical values and patient's or physician's legal protection were more influential on the physicians' decision-making in 2015, while the influence of family's benefit and patient's age decreased.

#### Factors associated with physicians' decisions

The results from the logistic regression analysis of the decisions concerning the terminally ill prostate cancer patient with probable iatrogenic GI bleeding and who was waiting to meet his son or a minister (scenarios 1a–c) are presented in table 4. The year of the survey remained a significant independent factor explaining the physicians' decision in every scenario. In general, the physicians answering in 2015 were less eager to choose active or intensive care. The willingness to withdraw life-sustaining treatments and having post-graduate EOL training were also significantly associated with a decreased likelihood of choosing active and intensive care in these scenarios. In addition, men more often chose a palliative care approach for the terminally ill prostate cancer patient when GI bleeding was detected and when his son was coming.

Table 5 presents the results from the logistic regression analysis for the factors associated with the willingness to give a hospice voucher to the breast cancer patient with advanced disease (scenario 2). In the analysis, the responders in 2015 were more willing to give a voucher than the responders in 1999.

#### DISCUSSION

Physicians in 2015 chose a palliative care approach more often than those in 1999 for the terminally ill prostate cancer patient when he had probable iatrogenic GI bleeding and when he was waiting to meet his son or a minister in the next few days. The physicians

thought that their decision-making was more influenced by patient's benefit, ethical values and patient's or physician's legal protection and less by family's benefit and patient's age than did the physicians in 1999. They were also more willing to give a voucher for hospice when the patient with advanced breast cancer wished for it during her EOL care.

Palliative care as defined by the WHO aims to improve the quality of life of patients and their families when facing life-threatening illness, it neither hastens nor postpones death.<sup>23</sup>

In our study, most of the physicians chose a palliative care approach for the prostate cancer patient in the EOL care situation when no additional ethical complexities were present. This basic decision-making did not change between the years studied, showing the general medical acceptability of palliative care in this hypothetical case scenario. Further, after finding the patient's advance directive stating that active treatments should be withheld if there is no hope for recovery, almost all physicians chose a palliative care approach, without difference between the years examined. This is well in line with earlier studies showing that advance directives help decision-making in EOL care, although physicians are concerned whether advance directives genuinely express a patient's own will.<sup>24 25</sup>

When two short-term goals (meeting the son or a minister in the next few days) and a suspicion of iatrogenic bleeding were presented, the proportion of the physicians choosing a palliative care approach decreased, but significantly less in 2015 than in 1999. These scenarios forced responding physicians to make ethically demanding decisions. One can argue that life-sustaining interventions might be ethically justified as a part of the palliative care to achieve these patient-centred short-term goals. On the other hand, more aggressive life-prolonging interventions in this case scenario might lead to overwhelming and prolonged suffering, together with the substantial costs of futile treatments.

In 2015, physicians were less influenced by family's benefit, which probably reflects their unwillingness to choose active and intensive care when the son of the terminally ill prostate cancer patient was coming. The lower influence of the family's benefit may be due to rising individualism in western countries.<sup>1 2</sup>

Religion has earlier been shown to have tremendous effect on EOL decisions.<sup>16 18 19 21 26</sup> We have previously shown that physicians had less faith in God and considered religion to be less influential in ethical decisions in 2015 than they did previously.<sup>22</sup> Thus, it is not surprising that an appointment with a minister shifted the treatment decisions to life-prolonging modalities less often in 2015 than in 1999. Guilt has been shown to be one of the reasons why futile treatments are carried on in EOL care.<sup>27</sup> This could explain, at least to some extent, why approximately half of the physicians chose

**Table 4** Different background factors and attitudes explaining the decision to choose active/intensive care (n=482) over a palliative care approach (n=610) concerning the prostate cancer patient with probably iatrogenic GI bleeding and when he is waiting to meet his son or a minister (scenarios 1a–c) in forward logistic regression analysis

	Scenario 1a				Scenario 1b				Scenario 1c			
	n	OR	(95% CI)	P value	n	OR	(95% CI)	P value	n	OR	(95% CI)	P value
Year of the survey				0.006				<0.001				<0.001
1999	578	ref.			579	ref.			580	ref.		
2015	514	0.65	(0.48 to 0.88)		515	0.41	(0.30 to 0.56)		515	0.47	(0.36 to 0.63)	
Withdrawal of life-sustaining treatments is reprehensible (VAS*)	1092	0.92	(0.87 to 0.97)	0.001	1094	0.94	(0.90 to 0.99)	0.028	1095	0.91	(0.86 to 0.96)	0.001
People should pay costs of factitious diseases by themselves (VAS*)	1092	0.96	(0.91 to 1.00)	0.071								
Advance directives have been helpful in my decisions (VAS*)					1094	0.95	(0.90 to 0.99)	0.028	1095	0.95	(0.90 to 0.99)	0.029
I'm pleased with my salary (VAS*)					1094	0.96	(0.92 to 1.00)	0.049				
Religion has influence when I make ethical decisions (VAS*)									1095	0.93	(0.89 to 0.97)	<0.001
It is waste of resources to treat patients over 80 years of age in intensive care units (VAS*)	1092	1.07	(1.02 to 1.13)	0.009				0.001	1095	1.05	(1.00 to 1.11)	0.065
Gender				0.005								
Female	537	ref.			539	ref.						
Male	555	0.67	(0.51 to 0.88)		555	0.65	(0.50 to 0.84)					
Marital status												
Single									68	ref.		0.055
Common-law marriage												
Married									98	0.82	(0.43 to 1.57)	0.554
Divorced									841	0.63	(0.37 to 1.06)	0.080
Widowed									76	1.16	(0.58 to 2.32)	0.667
Time from graduation (years)	1092	0.99	(0.97 to 1.00)	0.058					12	0.92	(0.26 to 3.31)	0.899
Amount of administrative work (hours)	1092	0.98	(0.97 to 1.00)	0.055	1094	0.98	(0.97 to 1.00)	0.024	1095	0.99	(0.97 to 1.00)	0.047
Taking care of a family member in end-of-life				0.006								
No	422	ref.										
Yes	670	0.69	(0.52 to 0.90)									
Post-graduate end-of-life training				<0.001				<0.001				0.011
No	808	ref.			809	ref.			810	ref.		
Yes	284	0.54	(0.39 to 0.73)		285	0.60	(0.45 to 0.80)		285	0.68	(0.51 to 0.92)	
Length of life				0.089								
Important	762	ref.										
Not important	293	0.77	(0.57 to 1.04)									
Physician groups				0.093								
Oncologists	121	ref.										
Surgeons	251	1.44	(0.85 to 2.42)									
Internists	270	1.84	(1.1 to 3.04)									
GPs	450	1.35	(0.85 to 2.13)									

\*VAS, Visual analogue scale (0 definitely agree and 10 definitely disagree). One unit is equivalent to 10 mm on a 100 mm VAS.

GPs, general practitioners; ref., reference.



**Table 5** Different background factors and attitudes explaining the willingness to give a voucher for hospice (n=488) versus not (n=610) for the patient with advanced breast cancer (scenario 2) in forward logistic regression analysis

	n	OR	(95% CI)	P value
Year of the survey				<0.001
1999	582	ref.		
2015	516	2.62	(1.96 to 3.50)	
Withdrawal of life-sustaining treatments is reprehensible (VAS*)	1098	1.06	(1.00 to 1.12)	0.051
People should pay costs of factitious diseases by themselves (VAS*)	1098	1.07	(1.02 to 1.13)	0.004
Physicians can't estimate cancer pain (VAS*)	1098	0.93	(0.89 to 0.98)	0.006
My health is excellent (VAS*)	1098	1.10	(1.04 to 1.18)	0.003
It is waste of resources to treat patients over 80 years of age in intensive care units (VAS*)	1098	1.07	(1.01 to 1.12)	0.017
Gender				0.084
Female	541	ref.		
Male	557	0.78	(0.59 to 1.03)	
Age (years)	1098	0.98	(0.96 to 0.99)	0.003
Post-graduate end-of-life training				0.089
No	811	ref.		
Yes	287	0.76	(0.56 to 1.04)	
Physician groups				0.007
Oncologists	121	ref.		
Surgeons	254	0.92	(0.55 to 1.54)	0.760
Internists	271	0.93	(0.57 to 1.52)	0.761
GPs	452	0.58	(0.37 to 0.91)	0.018

\*VAS, visual analogue scale (0 definitely agree and 10 definitely disagree). One unit is equivalent to 10 mm on a 100 mm VAS.

GPs, general practitioners; ref., reference.

an active approach on discovery of GI bleeding that was likely caused by the previously prescribed keto-profen, although this shift to life-sustaining treatment was slightly less common in 2015. Nevertheless, the principal justification for every treatment should be the patient's benefit, not the physician's attitudes and feelings in everyday decision-making. One of the reasons for the increased tendency to choose a palliative care approach in 2015 might be a better understanding of palliative care, which leads to the avoidance of futile therapies in EOL care even in ethically complex situations. This assumption was further supported by the analysis of background factors for decision-making, which revealed an association between training in EOL care and choosing a palliative care approach.

Using logistic regression analysis, we also investigated whether the changes between the years were genuine. It appeared that the significant differences in decision-making still remained after taking into account confounding factors. In addition, some other important factors that influenced the decisions were discovered, including the constant effect of post-graduate EOL training. As a whole, physicians who considered the withdrawal of life-sustaining treatments to be less reprehensible chose a palliative care approach more often in all scenarios. This is understandable when taking into account the nature of palliative care, in which considering the withdrawal of life-sustaining treatments to be reprehensible could be problematic.

The age of the physician seems to be a conflicting factor in EOL decision-making.<sup>19</sup> In our previous study, younger age was associated with an unwillingness to withhold or withdraw therapies,<sup>17</sup> but in this study, age did not explain the decisions to choose a palliative care approach. Male gender was associated with the palliative decision when the prostate cancer patient had probable GI bleeding and when his son was coming the next day. The influence of gender is also unclear in EOL decision-making, as some studies have shown that female physicians are more in favour of active treatments and in some studies, there is no gender-dependent difference in withholding or withdrawing life-sustaining treatments.<sup>11 17 19 20 28</sup>

Only approximately 10% of the respondents in both years considered costs of care to influence their decisions, and the patient's social status was even less influential. Some studies do report that a patient's financial resources influence physicians' decision-making,<sup>29</sup> while our results probably reflect the Finnish healthcare system, where the cost of care is covered by the society with tax money. The influence of a patient's age decreased during the years studied. This finding is likely due to the advances in medicine in recent years. In contrast to older studies where age significantly influenced patient survival in critical illnesses,<sup>30 31</sup> the survival of cancer patients was not associated with age in a recent study by Martos-Benítez *et al.*<sup>32</sup>

The influence of patient's benefit to physicians' decision-making rose to 99% from an already high percentage of 96%, while family's benefit decreased from 37% to 25% between the years studied. The rise of individualism in western parts of the world might reflect this change, as well as the fact that today respecting the patient's wishes is one of the main principles in the ethical guidelines of the Finnish Medical Association.<sup>1 2 33</sup> Both patient's and physician's legal protection was considered more influential now than 16 years ago. In Finland, patient's rights regarding treatment decisions were incorporated into Finnish law in 1992,<sup>7</sup> which has obviously impacted the high level of influence of the patient's legal protection. Thus, our results also raise a question as to whether physicians are more concerned about malpractice claims now than they were 16 years ago. The data from malpractice claims are conflicting, as some studies show an increasing amount of malpractice claims, while in others, there is a clear decrease.<sup>34 35</sup> In contrast to our results, the law appeared to play a limited role in EOL medical decision-making with doctors prioritising patient-related clinical and ethical considerations in a recent study from Australia.<sup>36</sup> On the other hand, that study is partly in line with our study, as ethical values were also considered to be highly influential by our responders. Our findings emphasise the complexity of EOL decision-making and the different factors that affect it, as physicians consider both legal and ethical aspects to be important, and one does not exclude the other.

Physicians in 2015 were more willing to give a voucher for hospice when the breast cancer patient in EOL care wished for it. The increase in a palliative care approach for the terminally ill prostate cancer patient might reflect the tendency to avoid futile therapies even when contrasting with the patient's wishes. This increasing willingness to give a hospice voucher may, in turn, be a reflection of the rise in patient-centred care where there is a focus on shared decision-making complying with patient's preferences.<sup>4 5 37</sup> The difference between the study years remained in the logistic regression analysis concerning the patient with advanced breast cancer. However, GPs were more unwilling to give a voucher compared with oncologists. In Finland, most of the dying patients are taken care of in community hospitals by GPs. Thus, our finding may reflect the better knowledge of GPs about the facilities in the community hospitals or the financial realities in the communities. On the other hand, oncologists may face the most difficult cases in EOL care, leading to a willingness to offer specialised palliative care in a hospice. Our results call for ongoing communication between the specialties to build-up palliative care pathways with optimally arranged EOL care based on the needs of every individual patient.

The limitations of this study need to be acknowledged. Our response rate (56%) is a limitation due to

possible non-response bias even though our study population was a large and representable sample of Finnish physicians. Because the follow-up period is long, it was possible to detect relevant changes in attitudes, values and decision-making. Physicians responding questions regarding hypothetical scenarios might give different answers compared with their actual decisions in clinical practice, but we suggest that the answers do sufficiently reflect real-life decision-making. However, future research should try to evaluate the basis of decision-making in the clinical practice of EOL care and whether education in palliative care influences these decisions.

## CONCLUSION

Compared to 1999, physicians in 2015 were more reluctant to choose active life-prolonging treatments over palliative care approaches for short-term goals in EOL care. However, they were more willing to give a voucher for hospice when a patient requested it. Patient's benefit, ethical values and patient's or physician's legal protection were more influential on the physicians' decision-making in 2015, while the influence of family's benefit and patient's age decreased. Our findings may reflect changes in general attitudes and the medical atmosphere towards patient-centred care and the decreased importance of family and religion in Finnish society, together with a better knowledge of the principles of palliative care.

The results highlight the importance of education of EOL care, including not only the medical facts but also the ethics related to decision-making. All of these aspects should be incorporated into post-graduate training in specialties that take care of dying patients.

**Contributors** RPP, JTL, HH and P-LIK-L designed the study outline and the questionnaire. RPP, JTL and P-LIK-L collected the data. RPP, JTL, P-LIK-L and RM analysed the data. RPP and RM performed the final statistical analysis. All the authors contributed to the writing and reviewing of the manuscript and approved the final manuscript.

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## PUBLICATION IV

**Does decision-making in end-of-life care differ between graduating medical students and experienced physicians?**

Alminojä Aleksii\*, Piili Reetta P\*, Hinkka Heikki, Metsänoja Riina, Hirvonen Outi,  
Tyynelä-Korhonen Kristiina, Kaleva-Kerola Jaana, Saarto Tiina, Kellokumpu-  
Lehtinen Pirkko-Liisa I, Lehto Juho T

\*These Authors share the first authorship of this article.

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## Does Decision-making in End-of-life Care Differ Between Graduating Medical Students and Experienced Physicians?

ALEKSI ALMINOJA<sup>1\*</sup>, REETTA P. PIILI<sup>1,2\*</sup>, HEIKKI HINKKA<sup>3</sup>, RIINA METSÄNOJA<sup>4</sup>,  
OUTI HIRVONEN<sup>5</sup>, KRISTIINA TYYNELÄ-KORHONEN<sup>6</sup>, JAANA KALEVA-KEROLA<sup>7</sup>,  
TIINA SAARTO<sup>8</sup>, PIRKKO-LIISA I. KELLOKUMPU-LEHTINEN<sup>1,2</sup> and JUHO T. LEHTO<sup>1,2</sup>

<sup>1</sup>Faculty of Medicine and Health Technology, Tampere University, Tampere, Finland;

<sup>2</sup>Department of Oncology, Tampere University Hospital, Tampere, Finland;

<sup>3</sup>Rehabilitation Center Apila (ret.), Kangasala, Finland;

<sup>4</sup>Faculty of Social Sciences, Tampere University, Tampere, Finland;

<sup>5</sup>Department of Oncology and Radiotherapy, Turku University Hospital,  
and Department of Clinical Oncology, University of Turku, Turku, Finland;

<sup>6</sup>Centre of Oncology, Kuopio University Hospital, Kuopio, Finland;

<sup>7</sup>Department of Oncology, Mehiläinen Länsi-Pohja Ltd, Kemi, Finland;

<sup>8</sup>Helsinki University Hospital, Comprehensive Cancer Center,  
Department of Palliative Care and Faculty of Medicine, University of Helsinki, Helsinki, Finland

**Abstract.** *Background/Aim:* Appropriate decision-making in end-of-life (EOL) care is essential for both junior and senior physicians. The aim of this study was to compare the decision-making and attitudes of medical students with those of experienced general practitioners (GP) regarding EOL-care. *Materials and Methods:* A questionnaire presenting three cancer patient scenarios concerning decisions and ethical aspects of EOL-care was offered to 500 Finnish GPs and 639 graduating medical students in 2015-2016. *Results:* Responses were received from 222 (47%) GPs and 402 (63%) students. The GPs withdrew antibiotics ( $p<0.001$ ) and nasogastric tubes ( $p=0.007$ ) and withheld resuscitation ( $p<0.001$ ), blood transfusions ( $p=0.002$ ) and pleural drainage ( $p<0.001$ ) more often than did the students. The students considered euthanasia and assisted suicide less reprehensible ( $p<0.001$  in both) than did the GPs. *Conclusion:* Medical students were more unwilling to withhold and withdraw therapies in EOL-care than were the GPs, but the students considered

euthanasia less reprehensible. Medical education should include aspects of decision-making in EOL-care.

There is a growing demand for palliative care in Europe due to the increase in noncommunicable diseases (1). Therefore, physicians should have basic skills needed to change the goal of the treatment from life-prolonging therapies to end-of-life (EOL)-care.

Appropriate decisions needed for high-quality EOL-care involve, for example, statements regarding cardiopulmonary resuscitation (CPR), hydration, and diagnostic tests. Many physician-related factors (e.g., age, experience and personal attitudes) have been shown to influence these decisions (2-4). In addition, the changing public attitudes towards EOL-care and euthanasia influence the complexity of these issues (5).

The physicians' decisions regarding life-sustaining treatments vary between different treatment modalities (6-8). In a survey of American internists, blood products and haemodialysis were among the most likely withdrawn therapies, while mechanical ventilation and intravenous fluids were more commonly continued (6). Withdrawing treatment is generally experienced as more difficult than withholding them (9).

The education and experience of a physician have been shown to influence decision-making in EOL-care (8, 10). Although newly-graduated physicians often feel unprepared for providing EOL-care, they face the complexity of the decision-making process just as the senior physicians (11, 12). However, the difference between graduating medical students and physicians in making these decisions remains to be studied.

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\*These Authors share the first authorship of this article.

*Correspondence to:* Reetta P. Piili, Department of Oncology, Tampere University Hospital, Teiskontie 35, R-building, 33520 Tampere, Finland. Tel: +358 331163161, e-mail: reetta.piili@tuni.fi

**Key Words:** Decision-making, end-of-life care, education, medical students, palliative care.

The aim of this study was to evaluate and compare the decision-making and attitudes of medical students and experienced GPs regarding several aspects of EOL-care of cancer patients. The results could be useful for the planning of medical education concerning decision-making in EOL-care.

## Materials and Methods

**Participants.** In autumn 2015, a postal survey with a questionnaire was sent to 500 GPs who were randomly selected from the registry of the Finnish Medical Association [details published earlier by Piili *et al.* (8, 13)]. The survey was sent twice to non-respondents. A questionnaire with the same hypothetical patient scenarios was offered to all Finnish medical students during their last year of medical school (Table I). All five universities with a faculty of medicine (Tampere, Helsinki, Turku, Kuopio and Oulu) participated in the study during the autumn of 2015 and the spring of 2016 depending on the graduation date at each university. The questionnaire was given to 639 students during a teaching session and returned to the teacher either personally or by post. Valid responses to the questionnaire were obtained from 402 (63%) and 245 (49%) of the students and GPs, respectively. After excluding GPs who had graduated less than five years ago, 222 (47%) GPs were included in this study. This study was approved by the Regional Ethics Committee of Tampere University Hospital, Finland (R15101).

**Questionnaire.** The questionnaire included seven patient scenarios, of which three were used in this study. In addition, there were several questions concerning the attitudes and background factors of the respondents. Attitudes towards several ethical and personal aspects were assessed with a 100-mm visual analogue scale (VAS) from “definitely agree” (0 mm) to “definitely disagree” (100 mm). These included, for example, statements concerning euthanasia, palliative care, the role of religion and advance directives in the decision-making process. The respondents were instructed to answer the questions in the given order and to not change their answers once given. This questionnaire has been previously used and validated among Finnish physicians (2-4).

**Patient scenarios.** *Scenario 1:* An 82-year-old forest worker was diagnosed with prostate cancer 3 years ago. During the past year, he has received treatments for bone metastases. He has now been hospitalized for a month, is almost totally bedridden, and needs help with all activities. His mental condition has been normal. His general condition has weakened during the past week to the point where he is now totally bedridden and is receiving large doses of pain medication. Today, he became comatose. His haemoglobin count is 68 g/l, while a week ago it was 118 g/l. His blood pressure is 80/40 mmHg. There is no verbal or written advance directive. The patient's wife has previously said that she expects the doctor to make all treatment decisions according to his/her best understanding. After the scenario, the doctors were asked to choose one of the given treatment options. The concepts used in the treatment options were explained as follows: a) palliative care: good nursing, sufficient medication for pain and other symptoms, and intravenous hydration only when suggested to provide relief of the patient's symptoms; b) active care: use of antibiotics and intravenous hydration or blood transfusions aimed at saving the patient's life in a life-threatening condition; c) intensive care: transfer of the patient to an intensive care unit (ICU).

*Scenario 2:* A 32-year-old female patient is brought by ambulance to the emergency unit. She is accompanied by her husband who says his wife has inoperable brain cancer. She has been receiving maximum radiotherapy, but this was discontinued three weeks ago. She has deteriorated considerably during the past week. The patient has now had an epileptic seizure and has been unconscious since the attack. After 20 min at the hospital, the patient stops breathing, and there is no pulse. Your treatment decision as a doctor on call is one of the following: a) to start cardiopulmonary resuscitation (CPR) or b) to withhold CPR.

*Scenario 3:* A 62-year-old male patient with lung cancer and metastases was admitted to the hospital ward and received high-dose morphine medication. Due to respiratory weakening, he had become comatose the night before. He also suffered from severe anaemia and had abundant pleural effusion and fever. After the presentation of the patient scenario, there was a question about the treatment decision: Which of the following treatments already started (\*) or planned would you withhold or withdraw? The decision responses were expressed on a scale from 1 (I definitely would not) to 5 (I definitely would). The treatments were a) antibiotics (\*); b) mechanical ventilation (\*); c) blood transfusion; d) pleural drainage; e) chest X-ray examination; f) laboratory tests; g) intravenous hydration (\*); h) nasogastric tube (\*); i) thrombosis prophylaxis (\*); and j) supplementary oxygen (\*).

**Statistical analysis.** The answers were re-categorized dichotomously for the statistical analysis for the Scenarios 1 and 3. The conversion was conducted as follows (responses shown in brackets): In the Scenario 1, “choosing palliative care” (a) and “not choosing palliative care” (b and c) and in the Scenario 3, “withhold or withdraw” (4 and 5) and “to not withhold or withdraw” (1, 2 and 3). The comparison of the students and the GPs was performed using the Pearson Chi-Square test for the dichotomous variables (Figure 1 and Table II) and Mann-Whitney U test for the continuous variables (Table III). P-values less than 0.05 were accepted as statistically significant. The data analysis was performed using IBM SPSS Statistics for Windows, version 24.0.

## Results

Characteristics of the participants are presented in Table I. All the students were under 50 years old, while over half of the GPs had reached this age. The GPs' median time from graduation was 23 years (range=5-40 years).

**Treatment decisions in end-of-life care.** The decisions of the students and GPs in patient scenarios 1 and 2 are shown in Figure 1. The GPs were more likely not to resuscitate the patient with an inoperable brain tumour (scenario 2), while the majority of both the students and the GPs chose the palliative care in the comatose patient with prostate cancer (scenario 1).

**Willingness to withhold or withdraw therapies.** The GPs were more likely to withdraw or withhold therapies than the students in a patient with an end-stage lung cancer (Table II). This difference was significant in withdrawing antibiotics and the nasogastric tube, and withholding blood transfusion, pleural drainage and taking a chest X-ray.



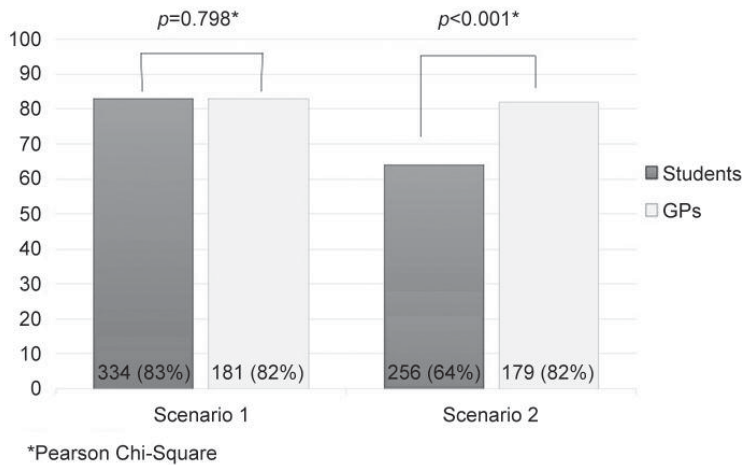


Figure 1. Proportions of students and general practitioners (GPs) choosing palliative-care approach for the comatose prostate cancer patient (scenario 1) and deciding not to resuscitate the patient with inoperable malignant brain tumour (scenario 2).

**Attitudes.** The students considered euthanasia and assisted suicide significantly less reprehensible than did the GPs ( $p<0.001$  in both) as shown in Table III. Religion had a stronger influence on ethical decisions among the GPs than it did among the students. Most of the GPs and the students did not feel burn out, assessed their own health as excellent and achieved satisfaction from being a doctor.

## Discussion

The graduating medical students were less willing to withdraw or withhold therapies such as resuscitation in EOL-care compared to experienced GPs. On the other hand, they considered euthanasia and assisted suicide less reprehensible than did the GPs.

In our study, the GPs were generally more willing to withdraw or withhold possible life-prolonging treatments than the medical students. Our results are in line with the study by Rivera and co-workers in which internal medicine faculty members accepted withholding or withdrawing life-sustaining therapy more often than the students (14). However, to our knowledge, there are no previous detailed surveys on medical students' opinions regarding life-prolonging therapies during EOL-care.

According to our results, the GPs were more willing than the students to withhold blood transfusions, pleural drainage and chest X-rays in a patient scenario representing EOL-care. The benefit of blood transfusions in EOL-care is often brief and adverse effects may occur (15). Dyspnoea can sometimes be alleviated by pleural drainage, but the

Table I. Characteristics of the participants.

	Students		General practitioners	
Number	402		222	
Response rate	63%		47%	
Female, n (%)	248	(62%)	157	(71%)
Age, median years (range)	26	(23-46)	51	(30-65)
Age distribution, n (%)				
<25	40	(10%)	0	(0%)
25-34	347	(86%)	26	(12%)
35-49	15	(4%)	80	(36%)
≥50	0	(0%)	116	(52%)

procedure is invasive (16). We suggest that the main reason that GPs are more willing to withhold these procedures is because they have experience on the risks and inconveniences of these interventions among frail patients. The GPs also withdrew antibiotics more frequently than the medical students. Antibiotics might occasionally be beneficial in EOL-care, but it is unclear whether students were aware of this or whether their decision was due to the difficulty in withdrawing therapies (17). Interestingly, the nasogastric tube was withdrawn more frequently by the GPs than the students, whereas there was no difference between the groups in withdrawing intravenous hydration. Neither intravenous hydration nor artificial feeding have been shown to improve survival or symptom control in EOL-care (18-22). Almost half of the students and one third of GPs would

Table II. Numbers and proportions of the students and the general practitioners (GPs) deciding to withdraw or withhold therapies in the scenario representing a patient with an end-stage lung cancer (scenario 3).

	Students		GPs		p-Values*
Decision to withdraw					
Antibiotics	150	(37%)	120	(55%)	<0.001
Mechanical ventilation	300	(75%)	176	(81%)	0.095
Intravenous hydration	128	(32%)	75	(34%)	0.543
Naso-gastric tube	225	(56%)	147	(67%)	0.007
Thrombosis prophylaxis	219	(55%)	137	(63%)	0.056
Supplementary oxygen	18	(5%)	13	(6%)	0.440
Decision to withhold					
Blood transfusion	265	(67%)	172	(79%)	0.002
Pleural drainage	84	(21%)	92	(42%)	<0.001
Chest X-ray	162	(41%)	114	(52%)	0.006
Laboratory tests	178	(45%)	114	(53%)	0.060

\*Pearson Chi-Square test.

Table III. Attitudes of students and general practitioners (GPs).

	Students		GPs		p-Values**
Attitudes, median VAS* (IQR)					
Active euthanasia is reprehensible	58	(20-77)	24	(3-66)	<0.001
Withdrawal of life-sustaining treatments is reprehensible	93	(80-98)	93	(77-98)	0.588
Assisted suicide is reprehensible	38	(10-69)	10	(2-51)	<0.001
End-of-life care is satisfying	26	(12-49)	17	(3-36)	<0.001
People should pay costs of factitious diseases by themselves	66	(40-84)	76	(47-95)	<0.001
Advance directives have been helpful in my decisions	14	(3-30)	5	(2-22)	<0.001
Good palliative care enables good death	4	(1-11)	4	(1-10)	0.372
Physicians can't estimate cancer pain	46	(28-65)	50	(28-72)	0.053
Religion influences me when I make ethical decisions	88	(50-98)	74	(43-96)	0.001
Being a doctor gives me satisfaction	15	(4-28)	8	(2-19)	<0.001
My health is excellent	13	(6-25)	14	(6-24)	0.708
I feel burn out, tired of work	85	(59-94)	85	(66-95)	0.250
I'm pleased with my salary	13	(3-29)	18	(7-45)	<0.001
It is a waste of resources to treat patients >80 years in ICU	70	(50-85)	78	(59-93)	0.001

\*Attitudes expressed on a visual analogue scale (VAS) from 0 mm (definitely agree) to 100 mm (definitely disagree). \*\*Mann-Whitney U-test. VAS: Visual analogue scale; IQR: interquartile range; ICU: intensive care unit.

not withdraw antithrombotic medication in EOL-care, although they are likely to be unbeneficial. Thus, these issues should be included in both undergraduate and postgraduate education in palliative medicine.

In a Brazilian study, 46% of medical students did not object to withdrawing artificial life support (23), while 75% of the medical students were willing to withdraw mechanical ventilation in our study. The variability among countries regarding the withdrawal of mechanical ventilation probably explains this difference (24). However, the students seem to comply with the practices of experienced physicians in Finland as 81% of the GPs also withdrew mechanical ventilation.

In our study, twice as many students (36%) as GPs (18%) were ready to attempt CPR on the patient with advanced brain tumour. Although advances in medicine may also benefit patients with very advanced diseases, the rate of hospital discharge after CPR for cancer patients is still only approximately 10% (25). Using this same patient scenario, we have previously demonstrated a correlation between younger age and attempted CPR among Finnish physicians (2). The growing clinical experience of a physician probably offers more insight into whether CPR may or may not be futile. On the other hand, over 80% of both the students and the GPs chose palliative care in a patient clearly approaching

death (comatose patient with prostate cancer in scenario 1). Although the palliative care approach in this scenario could be regarded as obvious, our result shows that medical schools in Finland seem to offer a basic understanding of EOL-care.

In Western Europe, attitudes towards euthanasia and PAS have become more accepting among the public and, to a lesser extent, among physicians and medical students (5, 13, 23, 26). In our study, the students considered euthanasia and assisted suicide less reprehensible than the GPs. In a study from Puerto Rico, 40% of the medical students and 20% of members of the medical faculty accepted euthanasia (14), while only 26% of students and 17% of the physicians accepted euthanasia in a Polish study (27). Our results are not only in line with those of previous studies, but also highlight this difference in the changing atmosphere towards hastened death. We suggest, that the students' lack of clinical experience, younger age, as well as being less influenced by the impact of religion on their decisions may explain their greater acceptance of euthanasia as these factors have been associated with increased acceptance among the public and physicians (5, 13, 28).

Our aim was not to affirm right or wrong answers to the questions presented, although some basic skills in decision-making during EOL-care were evaluated. Nevertheless, the majority of dying patients are taken care by GPs in Finland, and just graduated junior doctors are expected to work as a GP. Our results offer some insight into the educational needs, because the decision-making in EOL-care should include the same clinical principles for every patient regardless of the experience of a physician. Medical students have been found to feel underprepared to have discussions about EOL-care with a patient (11, 12, 29). Furthermore, their knowledge about assisted dying, DNR orders, advance directives and many aspects of palliative medicine is still known to be inadequate (30-33). On the other hand, undergraduate curricula in palliative medicine increases students' knowledge on palliative care (34, 35) and their attitudes towards EOL-care change after an observational experience in hospice (36). This calls for well-planned educational programmes in palliative medicine in every medical school and continuous postgraduate education. The medical and ethical principles of the complex decision-making in the EOL-care are the cornerstones of this education.

Some limitations of our study must be acknowledged. The response rates (63% for the students and 47% for the GPs) limits the generalizability of our results, though they are higher than in many previous surveys of physicians (37). Our survey presenting hypothetical patient scenarios may also elicit different answers compared to the decisions made in clinical practice. However, it would be difficult to study these questions in a real-life setting and we suggest that the answers do reflect the general tendencies that contribute to

decision-making. Finally, the GPs are a heterogenous group of physicians, which might lessen the comparability between the GPs and the students. To improve the validity of this comparison, we included only experienced GPs.

## Conclusion

GPs are more willing to withhold or withdraw therapies suspected of being futile in EOL-care than graduating students, although this difference varies between the treatments. In contrast, students consider euthanasia less reprehensible than do the GPs. Our results call for systematic undergraduate and postgraduate education in palliative medicine, including the medical and ethical aspects of decision-making in EOL-care.

## Conflicts of Interest

The Authors declare no conflicts of interest regarding this study.

## Authors' Contributions

RP, PLKL, HH and JL designed the study outline and the questionnaire. RP, OH, KTK, JKK, TS, PLKL and JL collected the data. AA, RP, PLKL, JL and RM analysed the data. AA, RP and RM did the final statistical analysis. All the Authors contributed to the writing and reviewing of the manuscript and approved the final manuscript.

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