



Chapter 1

General introduction

There are many ways in which our lives can end. Just as no life is the same, no death is the same. Death can come sudden or be preceded by a prolonged sickbed, it can present itself without warning or be expected, it can be embraced or fought, dignified or degrading, and anything in between. Although we might avoid thinking about dying, most people have preferences about the last phase of their lives and their deaths.⁽⁵⁾ Some people prefer the idea of a sudden death, others hope for time to prepare.^(6, 7) Some hope for a natural death and others want personal control over the last moments of their life.

Is there really something to choose about the way we die? Death often announces itself too early, when we are not quite finished with life. It can also come too late, when people suffer unbearably due to disease or other causes. In the first case, people can desire to postpone death, and may want their physician to give extensive treatments to achieve this. In the second case, people can develop a desire to be relieved of suffering by hastening their deaths, and ask their physician to help them. In both cases, physicians need to decide how to respond, and may be faced with moral and ethical dilemmas. This thesis will give some insight into patients' preferences in the last phase of life, and the way physicians deal with these preferences.

The main aims of this thesis are:

- To gain insight into the appropriateness of care in the last phase of life, especially regarding the decisions to give or forgo potentially life-prolonging treatment.
- To study the role physicians (can) have and the role they are willing to take on when patients express a wish to hasten death, either by physician-assisted dying or by voluntary stopping of eating and drinking.

To introduce the topics addressed in this thesis, this chapter gives some background information on care in the last phase of life, especially care that aims to postpone or hasten death. It gives some epidemiological and legal background information on giving and forgoing potential-life prolonging treatment and on hastening death. Next to that, some ethical considerations regarding the decision-making process are given. Finally, knowledge gaps and the research questions addressed in this thesis are described.

1.1 CARE IN THE LAST PHASE OF LIFE

The last phase of life is a period of hopes and fears. People may simultaneously hope for a good quality of life until the end, hope for the opportunity and ability to prepare for death (7) and hope for prolongation of life. At the same time, fears are prominent; people may fear death or dying, fear being in pain, fear losing their dignity and fear losing control.(7-9) People can be affected by physical and mental decline, by debilitating symptoms of disease and by side effects of treatment. Loved ones and professional caregivers play important roles, yet they have their own ideas about what constitutes a good death as well. Next to that, they are themselves greatly affected by this period. Physicians have a lot to offer, but their treatment can also do harm. All these factors combined create a great challenge to provide appropriate care in the last phase of life. Whether the care provided in this period is appropriate, depends on how caregivers address and respond to the patient's preferences, hopes and fears.

Aims of care

Care in the last phase of life can have different aims, roughly categorized into three (partly overlapping) groups; improving or maintaining quality of life, prolonging life and hastening death. This thesis will focus on the second and third groups; care that influences the timing of death.

Improving or maintaining quality of life

Firstly, important aims of care in the last phase of life are to improve or maintain quality of life or to relieve suffering without aiming to hasten death. Examples are pain medication, psychosocial care and palliative sedation. This care is referred to as palliative care. The WHO defined palliative care as 'an approach that improves the quality of life of patients and their families facing problems 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'.(1) This thesis does not focus on palliative care, although it is frequently described in relation to other care.

Prolonging life

Another frequent care aim in the last phase of life is to prolong life. Examples are prescribing antibiotics for pneumonia, chemotherapy for cancer, cardiopulmonary resuscitation in case of a cardiac arrest or artificial hydration in dementia. Potentially life-prolonging treatment is not always beneficial; many of these treatments are burdensome and potentially harmful. Therefore, the decision whether to give or forgo

potentially life-prolonging treatment can be experienced as a trade-off between having a chance of prolonging life and maintaining a good quality of life. These decisions can be very difficult, and are ideally made by the patient and physician together. To make a well-considered treatment decision, both the physician's medical knowledge and the patient's preferences should play a role.(10) In some cases, a patient is unable to be involved in decision-making, and the relatives and physician need to decide on their behalf.

Sometimes, potentially life-prolonging treatment has more negative effects than positive effects. In the literature, terms such as overtreatment, inappropriate treatment, non-beneficial treatment, disproportionate treatment or futile care are used. (11-14) Clear definitions of these terms are lacking, but they could be described as treatment that is ineffective in achieving the desired goals, and/or is likely to cause more harm than benefit.(11) In this thesis, the term overtreatment is used.

Hastening death

The third possible aim of care at the end of life is to hasten death, because living becomes unbearable. Actions that aim to hasten death are euthanasia, physician-assisted suicide and voluntary stopping of eating and drinking. In euthanasia, a physician administers lethal drugs to the patient on his or her explicit request, with the intention of and resulting in the patient's death. In physician-assisted suicide the physician provides the patient with lethal drugs on his or her explicit request, and the patient ingests the drugs him- or herself. In voluntary stopping of eating and drinking, the patient deliberately stops ingesting food and fluids, with the intention to hasten death. These three acts are controversial and are frequently debated in society.(15, 16) End-of-life decisions that aim to hasten death can especially pose moral dilemmas on physicians, who need to decide whether they want to be involved in these actions.

1.2 PREVALENCE OF AND TRENDS IN END-OF-LIFE DECISIONS IN THE NETHERLANDS

Palliative care

An estimated 54% of deaths in the Netherlands are non-acute; these people die of chronic diseases, such as cancer, cardiac failure and dementia. These deaths are typically preceded by a sickbed, in which time people often have a need for palliative care.(17) Most of these patients probably receive some treatment to alleviate pain

and other symptoms. In 2010, intensified alleviation of symptoms with the possible unintended consequence of hastening death was given in 45% of cases (18). Continuous deep sedation until death (palliative sedation) was given in 18% of cases in 2015. (19)

Applying or forgoing potentially life-prolonging treatment

Besides palliative care, people usually receive one or more potentially life-prolonging treatments in their last phase of life. Modern medicine continually develops new treatments which can be applied in advanced disease, which can prolong life. This development, however, does not only have positive consequences. These treatments are often burdensome and come with a considerable risk of side effects, while they may have little benefit. In the western world, there is an increasing trend in the use of aggressive treatment in patients with terminal cancer.(20, 21) Awareness that potentially life-prolonging treatments are not appropriate in all cases is growing. The Choosing Wisely Campaign in (amongst others) the USA and Canada, as well as The Royal Dutch Medical Association (KNMG) in the Netherlands, has drawn attention to the harms of treatment at the end of life.(22, 23) In a survey among 1589 Dutch physicians, 62% believed that patients in the last phase of life are being overtreated.(24)

In a recent review on overtreatment at the end of life in patients around the world, the magnitude of the problem was explored. Approximately 36% of patients received some form of overtreatment at the end of life. This frequently concerned unwarranted blood tests (37%-49%), chemotherapy in the last six weeks of life (33%), resuscitation attempts (28%), unnecessary imaging studies in the last three months of life (25%), non-beneficial ICU admission (7%-10%), administering different kinds of medication (11%-75%) and other interventions such as haemodialysis (10%-41%). (11) In the Netherlands, 77% of cancer patients are admitted to an acute care hospital in the last six months of life, and 18% receive chemotherapy in that time.(25)

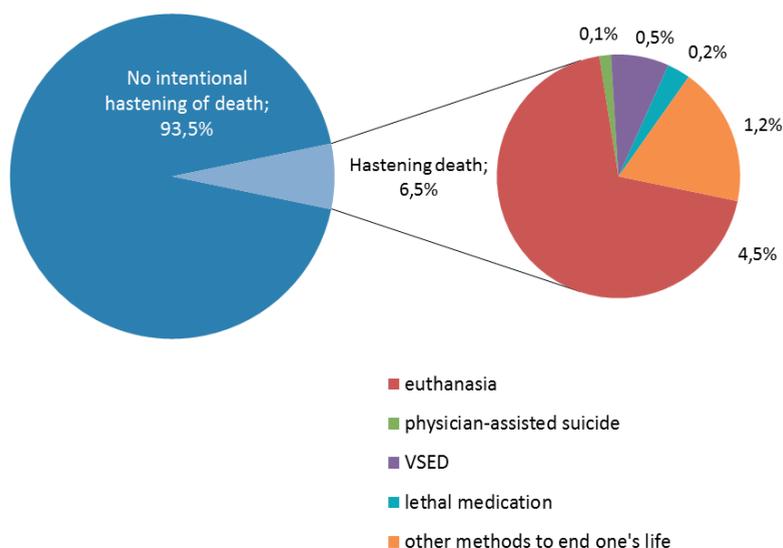
Eventually, 37% of deaths in the Netherlands are preceded by a decision to forgo treatment, with the possibility of hastening death. (26) Treatment can be withheld (not started; 14%), withdrawn (stopped; 13%) or one aspect of treatment can be withdrawn while another aspect can be withheld (13%). Treatments most often forgone are artificial nutrition or hydration, antibiotics and other medication.(26)

Active hastening of death

While decisions on applying and forgoing curative treatment are common at the end of life, decisions that aim to actively hasten death are made in a minority of cases (figure 1). In 2015, euthanasia or physician-assisted suicide was performed in 4.6% of deaths (euthanasia 4.5% and physician-assisted suicide 0.1%). In another 3.8%

of deaths, the deceased had requested euthanasia or physician-assisted suicide, but this was not performed.(19) Other ways to hasten death were voluntary stopping of eating and drinking (0.5%), ingestion of lethal drugs (0.2%) or other, mostly violent, methods to end one's life (1.2%).(19) In children aged 1 to 17, physicians hastened the patients' death in approximately 2.6-3.0% of deaths in 2010. This mostly concerned patients under the age of 12, at the request of the parents.(27, 28)

Figure 1: Prevalence of intentionally hastening one's death in the Netherlands, 2015.(19)



Not included (because the patient was not actively involved): Intentional hastening of death by a physician, without a patient request. Prevalence was 0.3%.

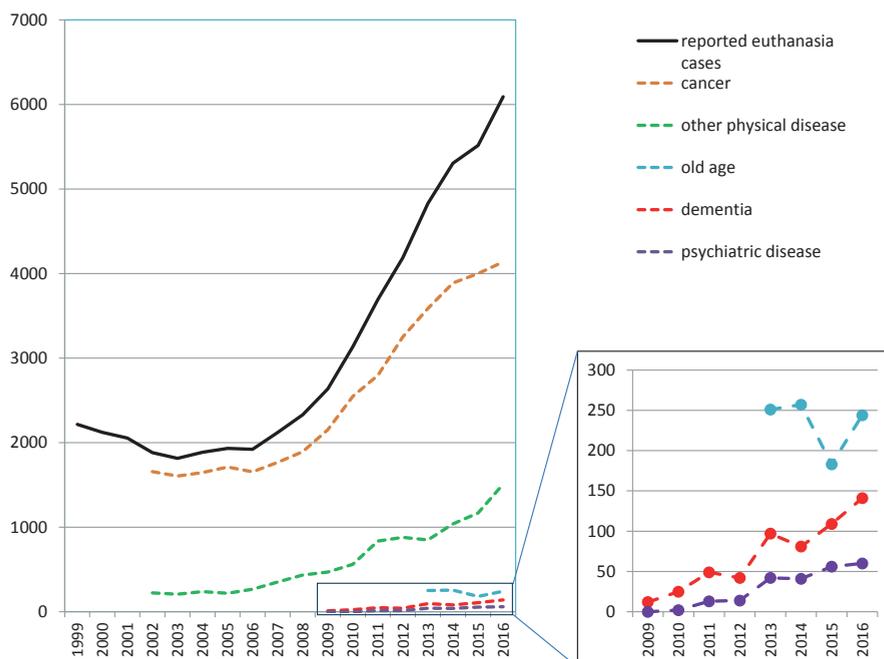
VSED: Voluntary stopping of eating and drinking

Other methods to end life: Suicide, mostly by violent methods

In the Netherlands, the prevalence of euthanasia and physician-assisted suicide is increasing since 2005 (although the slope levels off since 2013; figure 2). Most reported cases of euthanasia and physician-assisted suicide concern patients with cancer (68%) or other severe physical diseases (25%), such as neurological disease, heart disease or pulmonary disease.(29) Despite the fact that the media reports mainly on cases of euthanasia in old age (referred to as people who are tired of living), dementia and psychiatric disorders,(15) in reality a minority of cases of euthanasia and physician-assisted suicide concerns this population: in 2016, only 4% of reported cases involved people suffering from an accumulation of factors or conditions in

old age, 2% of cases involved people suffering from dementia (almost all in an early stage of disease) and only 1% suffered from psychiatric disease.(29) Approximately 6% of all adults has an advance euthanasia directive, describing the wish for euthanasia in certain future scenarios, such as dementia. This is the most common advance directive in the Netherlands.(30, 31)

Figure 2: Prevalence of different causes of suffering in reported cases of euthanasia and physician-assisted suicide in the Netherlands, 1999-2016.(32)



1.3 LEGAL SITUATION

To understand how decisions are made that aim to postpone or hasten death, some background information on Dutch law is required. Relevant laws and regulations are described here, as well as the professional standards concerned.

Giving or forgoing life-prolonging treatment

According to the Patient's Rights (Care Sector) Act, patients have the right to participate in medical decision-making. They must be informed about their situation, the different treatment options and their consequences and risks.(33) If the patient is

unable to make informed decisions, their representative can decide on their behalf (this is often the partner, parent or child). If a patient makes a well-informed decision to forgo treatment, physicians have to respect this wish.⁽³⁴⁾ Patients have the right to refuse all treatments, but not to receive all treatments. A physician can refuse to provide the treatment of the patient's choice, if the harm clearly outweighs the benefit, because he is responsible for providing 'good care'.⁽³³⁾

Euthanasia and physician-assisted suicide

The Dutch Euthanasia Act

The Netherlands is one of the few countries with regulation in place aimed to facilitate euthanasia and physician-assisted suicide. Other countries with comparable laws on euthanasia or physician-assisted suicide are Belgium, Luxembourg, Colombia, Switzerland and the U.S. States Oregon, Vermont, Washington and California). Contrary to popular belief, performing euthanasia or assisting in suicide is still a crime in the Netherlands, and has been included in the Dutch Criminal Code since 1881. However, an exception for physicians was described in Dutch law in 2002. If physicians adhere to the criteria described in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (also known as the euthanasia act), they are exempted from prosecution.⁽³⁵⁾

Before it was laid down in the Euthanasia Act, euthanasia was already legally accepted through case law. The rationale behind this is the conflict of duties physicians might have when a patient requests euthanasia or physician-assisted suicide. The physician has the duty to obey the law and preserve a patient's life, but at the same time he has the duty to relieve the patient's suffering.⁽³⁶⁾ Section 40 of the Criminal code describes that a person is not criminally liable if he commits a crime as a result of a force majeure.⁽³⁷⁾ The sense of duty to relieve suffering in line with the patient's wishes can be such a force majeure. When the Euthanasia Act came into effect in 2002, euthanasia was already widely accepted in the Netherlands, a reporting system was already in place and over 2000 cases of euthanasia and assisted suicide had been reported every year.⁽³⁶⁾ The Euthanasia Act merely formalized the practice of euthanasia.

Physicians can only be exempted from prosecution if they adhere to the criteria for due care. These are:

- 1) The physician is convinced that the patient made a voluntary and well-considered request for euthanasia or physician-assisted suicide;

- 2) The physician is convinced that the patient suffers unbearably and there is no prospect of recovery;
- 3) The physician has informed the patient about his or her situation and prognosis;
- 4) The physician and the patient decide together that there is no reasonable treatment alternative;
- 5) At least one other, independent physician has been consulted, and has assessed whether the criteria for due care are met (although agreement is not mandatory);
- 6) Euthanasia or physician-assisted dying is performed with due medical care. (35)

The act does not distinguish between euthanasia and physician-assisted suicide. Physicians are obliged to report every case of euthanasia or physician-assisted suicide to the municipal forensic pathologist afterwards, who reports to a regional review committee. These committees, consisting of a physician, an ethicist and a legal expert, assess whether the criteria for due care are met. If necessary, they can forward the case to the Board of Procurators-General.(35) Between 2007 and 2011 the review committees judged that the physician did not act in accordance with the due care criteria in 36 out of almost 14,000 reported cases.(16) This mostly concerned the consultation of an independent physician (criteria 5) or the performance of euthanasia or physician-assisted suicide itself (criteria 6). In only 7 cases, the committees judged that the physician had not acted in accordance with one of the other criteria for due care.(2) Since 2002 no physician has been prosecuted for a reported case of euthanasia or physician-assisted suicide.(19)

Interpreting the Dutch Euthanasia Act

The Dutch Euthanasia Act is a physician's act, aimed to guide physicians and to protect physicians from prosecution. Its existence does not imply that patients have the right to euthanasia or physician-assisted suicide. A physician is always free to refuse a request for euthanasia or physician-assisted suicide.

Not all the criteria for due care can be objectively measured. It can be especially difficult to assess whether the patient suffers unbearably.(38) Because only the patient can decide whether his or her suffering is unbearable, the physician needs to assess the situation from the patient's perspective.(39)

Not all legally relevant aspects are described in the Euthanasia Act. The Act should be seen as the legal framework, which is specified further by case law and medical professional guidelines. The regional review committees have published a code of practice which can assist physicians in judging legitimacy of euthanasia in different cases.(40) I will describe four situations in which assessing the criteria for due care is

complicated, or which are controversial in the Netherlands; Euthanasia or physician-assisted suicide in case of psychiatric disease, dementia, being tired of living, and physician-assisted dying in children.

Psychiatric disease

The Dutch Euthanasia Act does not distinguish between patients who suffer from physical disease and patients who suffer from psychiatric or psychological disease. However, the regional review committees require physicians to be especially prudent in case of non-physical suffering, especially in assessing whether the patient made a well-considered decision to hasten death, because psychiatric disease can affect the patient's judgement of his or her situation. Also, extra care needs to be taken in assessing whether there is no hope for recovery and whether there are no reasonable treatment alternatives. Despite the fact that a patient can decline treatment if it is too burdensome, promising treatment options need to be considered. For these reasons, the review committees advise to consult an independent psychiatrist.(40)

Dementia

In early stage dementia, patients are still capable of understanding their situation and prognosis, and of expressing their wishes. They may suffer unbearably from the prospect of progressive dementia, and request euthanasia on this ground. In these cases, the regional review committees judge that the due care criteria can be met.(40) The situation is more complicated in case of advanced dementia, when patients can no longer judge their situation and express their wishes. Central to the Euthanasia Act is the requirement that the patient requests euthanasia himself, a proxy cannot request for euthanasia on the patient's behalf. However, if a patient is no longer capable of expressing his or her wishes, a previously written advance euthanasia directive can replace an oral request for euthanasia.(35) The physician still needs to comply with the other criteria for due care. The Royal Dutch Medical Association urges physicians to be very reticent, because it is hard to comply with the criteria of unbearable and hopeless suffering in these cases. If a patient is no longer able to communicate meaningfully, it is hard to determine whether the patient suffers unbearably.(41)

Tired of living

Being tired of living is defined as suffering caused by the prospect of having to continue living with a very poor quality of life (not predominantly caused by a physical or psychiatric disease) leading to a persistent death wish.(42) In 2002, the Dutch Supreme Court judged that the Euthanasia Act does not apply to people who are tired of living, because the main cause of suffering is not a medically classifiable ill-

ness or condition.(43) In people who are tired of living, suffering is mainly existential and psychosocial, such as loss of function and autonomy, loneliness, the pain of not mattering and the inability to express identity. (41, 44) Since 2002, the situation has changed somewhat and both the KNMG and the regional review committees state that unbearable suffering can be caused by an accumulation of minor problems, both medical and non-medical. However, they argue that only suffering that has some medical basis (one or more conditions or ailments) falls into the domain of medicine. (40, 41) Currently, euthanasia or physician-assisted dying on the basis of being tired of living can fall under the Euthanasia Act, but only if there is some medical ground for suffering. Recently, Dutch politicians have started a debate about this prerequisite and some political parties are arguing for an expansion of the scope of the Euthanasia Act. A conceptual legislative proposal has been put forward, with the intention to broaden the scope of the Euthanasia Act to older people who are tired of living in the absence of medical ground of suffering.(45)

Children

The Euthanasia Act does not apply to children under the age of 12, because these children are not regarded competent by Dutch law.(46) Competent children over the age of 12 can request for euthanasia or physician-assisted suicide. In children aged 12 to 15, parents need to consent to their child's request for physician-assisted dying. In children aged 16 to 17 years, parents need to be involved in decision-making but do not need to consent.(35) The regional review committees ask physicians to carefully examine whether the patient is competent to request for euthanasia or physician-assisted suicide. Between 2002 and 2014, only 5 cases of euthanasia or physician-assisted dying have been reported to the review committees.(40)

There is no law that exempts physicians from prosecution if they deliberately hasten death in children under 12. However, there is a separate legal provision for hastening death in neonates. In two court cases in 1996, it was judged that hastening death of neonates can be justified in some cases, on the basis of the argument of force majeure: the duty to relieve suffering outweighed the duty to retain life.(47) In 2005, 'the Groningen Protocol for Neonatal Euthanasia' was published by a group of paediatricians and endorsed by the Dutch Paediatric Association, describing criteria for physician-assisted dying in neonates.(47) In 2007, the Dutch government regulated physician-assisted dying in neonates in the 'Establishment of a central committee of experts for late term abortion in a category 2-case and termination of life of neonates', based on the Groningen Protocol. In this legal provision, the criteria for due care are described, which need to be adhered to in order for physicians to be exempted from prosecution.

The criteria for due care are:

- 1) The patient suffers unbearably and without hope of recovery, medical treatment is futile and there is certainty about the patient's diagnosis and prognosis;
- 2) Both parents consent with physician-assisted dying;
- 3) The parents have been fully informed about the patient's diagnosis and prognosis, and the parents and physician(s) are convinced that there are no reasonable treatment alternatives;
- 4) A second independent physician has confirmed the above;
- 5) Physician-assisted dying is performed with due medical care.(48)

The regulation only applies to children below 1 year old. Since 2007, there is a multidisciplinary review committee where physicians have to report physician-assisted dying in new-borns.(49)

While the regulation for neonates applies to children under the age of one, and the Euthanasia Act applies to children over the age of 12, there is no specific regulation for children aged one to 11. The Dutch Paediatric Association calls for regulation for children in this age group who suffer unbearably and without hope of recovery. (50) They plead for an extension of the regulation for neonates to older incompetent children, while making euthanasia available for competent children below 12 in the Euthanasia Act. The Dutch minister of Health, Welfare and Sport answered this call by requesting for more research. Furthermore, she described that paediatricians who perform physician-assisted dying in children between 1 and 12 may be exempted from prosecution if the Public Prosecution Service accepts the defence of force majeure.(51)

Voluntary stopping eating and drinking

There is much discussion about the concept of voluntary stopping of eating and drinking. Some authors argue that voluntary stopping of eating and drinking can in some cases be regarded as suicide.(52, 53) In discussions about this, it becomes clear that the concept of suicide is not very well defined. The WHO defines it as 'the act of deliberately killing oneself',(3) and one could argue that voluntary stopping of eating and drinking is not an act but rather the forgoing of an act. In the scientific literature, there is disagreement about whether death by omitting to eat and drink should be seen as suicide.(54, 55) This discussion is especially relevant because of the legal implications. Aiding a person in committing suicide is a crime in the Netherlands, with the exception of formal physician-assisted suicide (Criminal Code, section 294-2). In the Netherlands, deliberately hastening death by voluntary stopping of eating and drinking is not regarded suicide. The KNMG argues that voluntary stopping of eating and drinking should be differentiated from suicide because it concerns an

omission instead of an act. The KNMG compares it with decisions such as refusal of antibiotics for pneumonia, or chemotherapy for cancer.(56) Because people have the right of self-determination they have the right to refuse treatment. Similarly, they have the right to forgo food and fluids.(55-58)

If patients have the right to forgo food and fluids, physicians have the moral duty to respect a patient's decision to stop eating and drinking, if it is well-considered. The next question is whether the physician and other caregivers have to become involved if needed. People have the basic human right to relief of distress, so this may imply that physicians and nurses have the duty to provide care for these patients.(41, 57, 58) In line with this, the KNMG describes physicians have the duty to provide this care. However, in their standpoint on this issue, they also leave room for conscientious objections of the caregivers. Physicians may transfer their duty to provide care to a colleague (while staying responsible for good care until the colleague takes over).(56)

1.4 ETHICAL DILEMMAS IN DECISION-MAKING

Patients and physicians make decisions on the basis of their personal norms and values. In turn, their personal norms are influenced by societal norms and professional norms. These different norms and values on end-of-life decisions such as euthanasia and forgoing potentially-life prolonging treatment are frequently debated in the media and in Dutch society.

In the Netherlands, the medical career of physicians starts with taking a modern version of the Hippocratic oath. At the heart of this oath are key ethical principles of beneficence and non-maleficence; physicians should help patients and do no harm. (59) However, at the end of life, patients may ask physicians to provide treatment that is likely to cause serious harm by side effects, or assist in actions that will lead to the patient's death. Not surprisingly, these decisions are not easily made and confront the physician with ethical dilemmas. These dilemmas can be traced back to key ethical values. In a reference work on medical ethics, 'Principles of biomedical ethics' by Beauchamp and Childress, four principles of medical ethics are identified; respect for autonomy, beneficence (acting in the benefit of the patient), non-maleficence (do no harm) and justice (or fairness).(60) When ethical dilemmas exist, there is often a conflict between these principles. In this thesis, I will refer to these ethical principles.

Physicians play a large role in decision-making at the end of life. Ideally, the patient and physician share the responsibility of decision-making at the end of life, and make these decisions in a dialogue (shared decision-making).(61) In practice, physicians greatly influence decisions that are made. The information they provide and the preferences they have, direct the patient's treatment choices.(62-65) The physician's role is even more prominent in euthanasia and physician-assisted suicide: this is only an option if the physician consents. Also, support of a physician may determine whether a patient is successful in hastening death by voluntary stopping of eating and drinking.(53)

Giving or forgoing treatment

Decisions on giving or forgoing treatment often represent ethical dilemmas. For physicians, these decisions can feel like a trade-off between beneficence and non-maleficence: While the physician feels the moral duty to help a patient by giving treatment that might prolong his or her life, treatment has a high risk of serious side effects. Physicians may be forced to choose between respecting the patient's autonomy and non-maleficence if a patient wants to continue treatment that causes more harm than benefit. The physician may want to respect the patient's choice, but does not want to expose the patient to futile and harmful treatment. The opposite can also occur: A patient might refuse treatment of which the physician expects it will improve quality of life. The physician needs to decide whether he can respect this decision or will continue to try to persuade the patient to agree with treatment. In other cases, the physician might question whether the patient's decision is well-considered, or whether the patient's family is allowed to play a role in decision-making. There are no easy answers to these questions.

Hastening a patient's death

In the Netherlands the acceptance of euthanasia and physician-assisted suicide is high; only 5% of the general public and 7% of physicians is against euthanasia and physician-assisted suicide.(66) However, euthanasia and physician-assisted suicide are not normal medical practice, contrary to giving or forgoing treatment. When a patient asks their physician to assist them in hastening death, a physician can have conscientious objections to this. This is especially complicated if the patient has already made up his mind about what they want. Sometimes, the physician has little time for contemplation on his or her role in the patient's hastening of death. Patients might already have stopped eating and drinking with the intention to hasten death. Other patients may quickly deteriorate and request for euthanasia to be performed as soon as possible. In other cases, physicians have a lot of time to contemplate on the

patient's preference, for instance when they receive an advance euthanasia directive to be carried out in possible future scenarios.

When a physician is confronted with a request for euthanasia or physician-assisted suicide, he or she needs to decide whether this would be in line with the Euthanasia Act and how this relates to his or her own moral framework. Conflicts between some key ethical principles may arise, such as a conflict between the patient's autonomy and the physician's autonomy.

Although the Euthanasia Act is developed from the basis of beneficence (taking away suffering), the principle of autonomy currently dominates the Dutch debate about euthanasia and other ways of hastening death.(67, 68) In the last years, two citizen groups took the lead in this debate: the 'Own Free Will' (Uit Vrije Wil) citizens' lobby group (now disestablished) and the Right to Die-NL (NVVE) citizens' society. Both groups lobby for self-determination and free choice in ending of life. They argue that people should have the right to decide about their own death, and have the right to die without suffering. In their opinion, a physician should not stand in the way of a patient with a well-considered death wish.

Another ethical principle commonly referred to in the debate, is justice or fairness. Many people do not know that euthanasia or physician-assisted suicide is not a patient right, and that physicians are free to refuse requests for personal reasons. In popular literature, denial of euthanasia is shown as personal tragedies, resulting in more suffering and violent suicides.(68-70) In these reports, it is sometimes described as unfair that these people's death wishes are not carried out. Especially patients who suffer from psychiatric disease, dementia or who are tired of living are often described in media. It is not known whether physicians indeed more often find it inconceivable to perform euthanasia or physician-assisted suicide in these cases.

For physicians, principles such as beneficence and non-maleficence might be more important in their decision-making.(67) Out of a desire to help people, they might be willing to assist patients in hastening their deaths. However, assisting in hastening death can be seen as a maleficent act at the same time. In many religious traditions, taking a human life is considered wrong.(71) Finally, physicians may also think about their own wellbeing. Performing euthanasia is one of the most emotionally burdensome actions a physician might perform.(72) Therefore, a physician needs to be able to fully support this decision.

1.5 THIS THESIS

Gaps in knowledge

This thesis aims to contribute to our knowledge on appropriateness of care in the last phase of life and physician's attitude towards patient preferences that can hasten death.

A good last phase of life depends on many factors.^(73, 74) Care can play a large role in this, but care in the last phase of life is not always appropriate. Despite the fact that this term is often used, few studies have been done on appropriateness of care and treatment in the last phase of life. It is not known what people mean when they talk about appropriate and inappropriate care in the last phase of life. Also, it is not clear why treatment is seen as appropriate in some cases, and as inappropriate in other cases.

Having control over dying may be seen as appropriate by some. This is illustrated by the fact that some people prefer active hastening of death in certain future scenarios. Patients with a preference or a wish for euthanasia or physician-assisted suicide can approach their physician early, when their preference is not yet applicable to their situation, or later, when they explicitly request for euthanasia. It is not known whether people with an advance euthanasia directive are consistent in their preference. This information is important, because it helps physicians in interpreting an advance directive for euthanasia.

If a patient suffers unbearably, he or she can request their physician to perform euthanasia or physician-assisted suicide. The chance that their physician would grant their request probably depends on many factors. It is not known whether cause of suffering is a decisive factor for physicians deciding on euthanasia or physician-assisted suicide. Physician-assisted dying in children seems even more complicated than in adults. However, little is known about decision-making on physician-assisted dying among paediatricians.

Finally, voluntary refusing of hastening death may be the most autonomous way of controlling dying. Still, patients may need help from their physicians, and it is not known whether these physicians become involved. While physicians are expected to inform and provide care to patients who voluntarily stop eating and drinking, little information is available to physicians on this practice.⁽⁴¹⁾

Research aims

The main aims of this thesis are:

- To gain insight into appropriateness of different aspects of care at the end of life, especially decisions to apply or forgo potentially life-prolonging treatment.
- To study the role physicians (can) have and the role they are willing to take on when patients express a wish to hasten death, either by physician-assisted dying or by voluntary stopping of eating and drinking.

Part 1: Appropriateness of care at the end of life

The first part of this thesis revolves around appropriateness of care in the last phase of life. Chapter 2 aims to give an overview of the aspects that are important in end of life care. It puts the results of this thesis into perspective; while this thesis focusses on end-of-life decisions that can prolong life or hasten death, appropriate end of life care seems much broader than that. Chapter 2 describes what care patients and relatives perceive as appropriate care and as inappropriate care in the last phase of life.

Chapter 3 further explores an important element of appropriate care in the last phase of life; decisions to apply or forgo potentially life-prolonging treatment. This chapter shows that these decisions were sometimes described as appropriate, and sometimes as inappropriate. Potential positive and negative consequences of both decisions are described. This information can be used by physicians to better inform their patients at the time of decision-making.

Part 2: Decisions that aim to hasten death

Some people develop a preference for or a desire to hasten death. The most prevalent methods to hasten death are euthanasia (and physician-assisted suicide) and voluntary stopping of eating and drinking. The second part of this thesis focusses on these decisions.

Patients can present with an advance wish for euthanasia before they are at the end of life. Chapter 4 describes older people with an advance euthanasia directive, and assesses whether these people are stable in their advance euthanasia wish and eventually request euthanasia.

Next, I turn to the physician's perspective. Chapters 6 to 8 describe the results from a cross-sectional study among physicians on end-of-life decisions. In chapter 5 a small side study on the relation between questionnaire length and response rate is described. Chapter 6 and 7 describe conceivability among physicians to perform physician-assisted dying in different scenarios. The focus is on the scenarios which

especially pose ethical dilemmas. Chapter 6 concerns scenarios applicable to general practitioners, elderly care physicians and medical specialists. In chapter 7 the attitude of paediatricians towards physician-assisted dying in minors is explored. Finally, chapter 8 describes the attitude of general practitioners on voluntary stopping of eating and drinking, and the role they play in this practice.

1.6 METHODS

This thesis is based upon three studies:

Appropriate care in the last phase of life

The first study was embedded in a KNMG project on appropriate care in the last phase of life, which aimed to identify the main problems in care in the last phase of life, and to improve this care.(22) In 2013, a national online questionnaire study on appropriateness of care in the last phase of life was done. The questionnaire was openly accessible online. Potential participants were invited through social media by different organizations for patients, citizens, older people and medical professionals. Participants could be patients, relatives of patients, physicians, nurses and other professional caregivers who had experience with care in the last phase of life. In total, 1648 people participated in this study; 91 patients, 593 relatives, 349 physicians, 389 nurses and nurses' aides and 251 other caregivers. In the first part of the questionnaire participants were asked, by open questions, to describe their experiences with care in the last phase of life, which they would describe as either appropriate or inappropriate. They were also asked what the consequence of this care was. Results of these questions are described in chapter 2 and 3. The rest of the questionnaire contained questions on appropriate care in the last phase of life in general. The results of these questions are published elsewhere.(75) According to Dutch law, no review by a medical ethics committee was needed for this study.(76) The open answers were coded and categorized by the method of thematic analysis.(77)

ADC study/LASA

To study advance euthanasia wishes over time existing data was used, collected from 2005 to 2011 in two cohort studies: the Advance Directives Cohort Study (ADC study) and LASA (Longitudinal Aging Study Amsterdam). The ADC Study was set up in 2005 and consisted of 5561 people with an advance directive issued by Right to Die-NL (NVVE).(78) LASA was set up in 1992 and is a nationally representative cohort of older people (n=2165).(79) In these studies, people over the age of 55 were

followed until their death, and if they had given consent to do so, their proxies were asked to participate after their death (n=548). In 2005 (and LASA members also in 2002), all participants received questions about their health status, advance care preferences and possession of different advance directives. If they died before 2009, their proxies received a questionnaire on the last three months of the cohort member's life. Response rate was 72% in the ADC study and 59% in LASA. From this information, data on advance euthanasia wishes and the possession of advance euthanasia directives was extracted. Also, the cohort members' preferences at three months before death and three days before death, and information about whether the cohort members acted in accordance with their wish was collected. In chapter 4, the results of the study on evolution of advance euthanasia wishes are presented. The study was approved by the medical ethics committee of the VU University Medical Center.

Evaluation of the euthanasia law

In 2011-2012, the Dutch Euthanasia Act was evaluated for the second time. This is a five-yearly study on the efficacy and side-effects of the Act and chapters 5 to 8 were part of this project. For this study, 2800 physicians (general practitioners, elderly care physicians, paediatricians and other hospital-based specialists) received a questionnaire by post, of whom 2545 were eligible. Of these, 1628 physicians participated (64.0%). Different questionnaires were sent to the different physicians groups. The hospital-based specialists were randomly assigned to receiving the complete eight-page questionnaire or a reduced four-page questionnaire to improve response rate. In chapter 5 a small substudy comparing the response rate on the regular and the shortened questionnaire is described. The questionnaires contained questions on experience with (requests for) euthanasia and physician-assisted suicide and questions on attitude regarding this subject. These results are described in chapter 6 and 7. The results from the paediatrician questionnaires were further explored in face-to-face semi structured interviews. A subsample of 440 general practitioners received extra questions on their experience with voluntary stopping of eating and drinking. Chapter 8 describes these results.

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