Chapter 9

General discussion
9.1 INTRODUCTION

The main aims addressed in 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.

This final chapter highlights and interprets the main study findings. First, some methodological considerations are discussed. An overview of the main results is given in relation to the literature. Next, overarching themes are discussed, structured around three different perspectives: society in general, patients and relatives, and physicians. Finally, some implications for clinical practice, policy and further research are formulated.

9.2 METHODOLOGICAL CONSIDERATIONS

Different methods were used in this thesis. Chapter 2 and 3 described findings collected by an online survey, chapter 4 concerned data from a cohort study, chapter 5 was a small randomized trial, chapter 6 and 8 described data collected by a postal cross-sectional survey and chapter 7 used a mixed-methods approach, combining a postal cross-sectional survey with a qualitative interview study. All of these methods have strengths and weaknesses, which are described here.

9.2.1 Appropriate care in the last phase of life (chapter 2 and 3)

For the study on appropriateness of care in the last phase of life, a large amount of cases was gathered by an online survey. Unlike other studies, the study was not confined to a specific disease, medical specialism or care setting. Although one might argue that the results were too general, it reflected reality well. With this broad perspective, a more comprehensive overview of care in the last phase of life could be constructed, and a comparison between groups could be made.

A major limitation of a freely accessible internet questionnaire was the risk of response bias. Although 97% of the Dutch population had access to internet and 88% used it daily,(1) people who were old or ill were less likely to participate.(2) People with a strong opinion on end-of-life care were more likely to participate, illustrated by the
high number of Right to Die-NL members among the participants. Unfortunately, only a few patients participated in the study (45, compared to 547 relatives and 749 professional caregivers). Relatives and professional caregivers looked at the care from their own perspective, although the patient was central in their case descriptions. For further research, I would advise to put extra effort in reaching patients. Another potential bias is related to the retrospective data collection. Memories may become distorted over time, especially because the end of life is an emotional time.

By using open questions, participants were able to describe their experience without being influenced by the researchers. To gather a more complete picture of the cases, multiple open questions were asked. Still, the questions had to be quite general to be applicable to all cases. In some cases, it would have been informative to ask more in-depth questions about the cases, for instance about the decision-making process.

9.2.2 ADC study/LASA (chapter 4)

The participants of the study in chapter 4 were members of one of two cohort studies: LASA, representative for older people in the Netherlands, and the ADC study, which consisted of people who requested an advance euthanasia directive from Right to Die-NL. Combining these two populations made it possible to include a sufficient amount of older people both with and without an advance euthanasia directive. Although only a small minority of older adults has such a directive, 142 people with an advance euthanasia directive were included through the unique Advance Directives Cohort.

This study assessed what happened between the moment people draw up an advance euthanasia directive and the moment of their death. By using both cohort members and their relatives as source of information, data could be collected before and after death. Relatives are seen as a reliable source for data on the end of life.(3) However, the participating relatives may have forgotten some relevant information, or may not have been fully informed about the patient’s preferences on euthanasia. Next to that, the exact motives of the cohort members to request or not to request euthanasia were not known.

Finally, when interpreting the data from this study, it is important to realize that most cohort members did not suffer from cognitive decline. Advance euthanasia directives are especially relevant for people who suffer from dementia, but these people were underrepresented in the sample.
9.2.3 Evaluation of the euthanasia law (chapter 5 to 8)

In the evaluation study, 2545 physicians received a questionnaire about their attitude towards and experiences with different actions at the end of life, and 64% participated. The large random sample and high response rate made it possible to reliably estimate conceivability of performing physician-assisted dying.

Validity of results from postal questionnaires can be seriously impaired by low response rates due to response bias. Because the response rate of physician surveys can be low, extra effort was put into achieving a high response rate. Half of the medical specialists were sent a questionnaire half the length of the original questionnaire, and all non-responders received a one double-page version of the questionnaire with only the most relevant questions. Chapter 5 describes the effects of these measures. In a randomized trial, I found that the response rate to a four double-page questionnaire was not better than the response rate to an eight double-page questionnaire. Other studies suggest that more substantial reduction in length to one or two pages, does increase response rate. By sending a one double-page questionnaire to all non-responders after three months, the response rate increased from 53 to 64%. This response rate was good, especially for studies of this kind, reducing the risk of response bias. Still, it is possible that physicians with a strong opinion on performing euthanasia or physician-assisted suicide were overrepresented, which may have led to either an overestimation or an underestimation of conceivability.

The questionnaire was based on a validated questionnaire and was pilot tested. The questions seemed clear and left little room for misinterpretation. This allowed for a comparison of conceivability in different situations. Still, the cases were presented as very black-and-white, and the answer options to questions on conceivability were ‘yes’ and ‘no’. Although this is needed to quantify results and compare groups, this does not reflect reality. In reality, other factors also play a role in decision-making on euthanasia and physician-assisted suicide, such as patient-physician relationship and timing. In the interviews with paediatricians, it became clear that paediatricians often answered ‘yes, if…’ or ‘no, unless’.

End-of-life decisions in children seemed especially complicated, because of issues such as the child’s developing competence, the parents’ role in decision making and the legal situation. Because of this, there was a need to complement the quantitative data from the questionnaires with qualitative data from interviews (chapter 7). While the quantitative data allowed for valid estimations of the general attitudes of Dutch paediatricians towards physician-assisted dying in children, the interviews allowed us to better understand the nuances in decision-making in children.
Chapter 8 is one of the few studies ever performed on voluntary stopping of eating and drinking. Detailed data on 99 cases of this rare practice was collected. However, in order to gather this amount of cases, data needed to be collected from family physicians instead of directly from patients. Family physicians may not always know that patients hastened death by voluntary stopping of eating and drinking. Also, it is possible that they were not informed about all the symptoms the patient suffered from, or that they did not remember everything completely. Finally, only cases which resulted in death were included. Possibly, patients who were uncomfortable resumed eating and drinking and did not hasten death. Therefore, patients for whom VSED was relatively comfortable may have been overrepresented in this study.

9.3 MAIN FINDINGS IN RELATION TO THE LITERATURE

This thesis describes decisions people can make in the last phase of life, which can greatly affect their life and their death, as well as the people around them. It especially describes three of the most controversial decisions in the last phase of life; giving or forgoing potentially life-prolonging treatment, physician-assisted dying, and hastening death by voluntary stopping of eating and drinking (VSED).

9.3.1 Part 1: Appropriateness of care

Chapter 2 and 3 aim to gain insight into appropriateness of different aspects of care at the end of life, the first research question addressed in this thesis. In chapter 2, patients and relatives were asked to describe whether the care they had received was appropriate or inappropriate. Participants described more cases of appropriate care (n=429) than of inappropriate care (n=309), which is a positive sign. They interpreted appropriate care as a broad term, which can refer to aspects related to supportive care (62%), treatment decisions (53%), location (47%), the role of the patient’s wish (41%) and patient-physician communication (39%). Earlier studies showed that patients and relatives have multiple and diverse care needs. Chapter 2 described how appropriate care is attuned to these diverse needs, while inappropriate care is not. Appropriate care in the last phase of life is not tantamount to good palliative care. Similar to good palliative care, it concerns good symptom control, care for proxies and psychosocial care, as well as more general factors such as the right location of care, respecting patient autonomy and communication issues. However, unlike palliative care, it can also refer to decisions such as giving or forgoing potentially life-prolonging treatment and hastening of death.
Most people die after a period of illness or decline. A frequently used model to describe the last phase of life of these people is the model by Lynn and Adamson. Lynn and Adamson identified three distinct chronic illness trajectories before death; in cancer people die after a relatively short period of rapid decline, people with organ failure have a slowly declining health status interrupted by periods of sharp decline and incomplete remission, and in frailty people’s health very slowly and steadily declines until death. However, in chapter 2 of this thesis the descriptions of appropriate and inappropriate care were very similar for cancer, other physical diseases, and general decline/old age. Only appropriate care for patients with dementia was somewhat different. In dementia, medical decisions and patient-physician communication were less relevant, while factors such as location of care and supportive care were more important. In a 2013 review on prevalence of problems in the last phase of life, a similar uniformity between care needs in different disease groups was described, while dementia did not stand out in that study. They concluded that palliative care should be available to all these disease groups similarly. Chapter 2 illustrates that other aspects of appropriate care in the last phase of life, such as appropriate decision-making, location, communication and level of patient autonomy, should also be available to all patients in the last phase of life, irrespective of their diagnosis. Although there may not be a common terminal pathway because trajectories of decline differ between cancer, organ failure and frailty, it may be possible to talk about a common care pathway. In this common care pathway, care in the last phase of life is tailored to the patient’s needs instead of determined by the disease he or she is suffering from.

According to patients and relatives the most common form of inappropriate care in the last phase of life was curative overtreatment (35%). Professional caregivers put even more emphasis on overtreatment and described it in 49% of cases of inappropriate care. Undertreatment also occurred, but was much less common (6% and 3%). Chapter 3 aimed to explore the factors that determined whether giving treatment and forgoing treatment was seen as appropriate or inappropriate in hindsight. It shows that potentially life-prolonging treatment in the last phase of life can have positive and negative consequences. The same is true for forgoing treatment. These consequences are not only found in the physical domain or in life prolongation, but also in psychological, existential and social domains. For instance, giving treatment could be appropriate because it reduced disease symptoms (physical), gave a sense of control (psychological), enabled patients to gradually grow towards acceptance (existential), or prolonged life, which allowed the patient to spend more with family (social). Forgoing treatment could have similar consequences. For instance, it could allow the patient to spend the time left in the way he or she wants and to enjoy life
Chapter 9

(psy psychological), without side effects (physical), it could give opportunity to prepare for death (existential), and to spend time at home with family (social). However, both giving and forgoing treatment can also be inappropriate and have negative consequences. Therefore, it seems important that potential positive and negative consequences are discussed by the physician and patient beforehand, to allow for a well-considered decision on giving or forgoing potentially life-prolonging treatment.

9.3.2 Part 2: Patients’ preferences for hastening death and physicians’ roles in hastening death

In chapter 2, receiving aid in dying was described in 14% of cases of appropriate care, while not receiving aid in dying was described in 17% of cases of inappropriate care. This shows that in some cases, patients and relatives regard physician aid in dying as a form of appropriate care. Chapter 4 to 8 further explore situations in which patients have a wish to hasten death. These chapters describe the role physicians (can) have and the role they are willing to take on when patients express such a wish, either by euthanasia/physician-assisted suicide or by voluntary stopping of eating and drinking, which answers the second research question of this thesis.

Chapter 4 focusses on older people who had a preference for euthanasia or physician-assisted suicide. It describes the last months of life of 142 older people who were in the possession of an advance euthanasia directive. Participants rarely withdrew their advance euthanasia wish before death; 87% continued to have this wish at three months before death and 75% at three days before death. The passing of time and a decline in health status seemed to have had little effect on their ideas about euthanasia and physician-assisted dying. This finding supports the validity of ADEs as representation of someone’s advance wishes.

Still, although 78% reached the situation described in their advance euthanasia directive, only 47% of these people eventually requested euthanasia or physician-assisted suicide, and 16% died after euthanasia or physician-assisted suicide. Apparently, a stable advance euthanasia wish does not necessarily result in a request for euthanasia or physician-assisted suicide. Drafting an advance euthanasia directive may be a way of gaining a sense of control over the future; people want to be reassured that they have the possibility of euthanasia in potential future scenarios.(21) Many older people with an advance euthanasia wish did request euthanasia or physician-assisted suicide. Being worried about loss of dignity was associated with a higher chance of requesting euthanasia in people with an advance euthanasia directive. The presence of certain symptoms was not associated with a higher chance. Whether someone’s advance euthanasia wish results in a request for euthanasia or physician-
assisted suicide may depend on factors not included in this study, such as quality of palliative care, practical and social factors, and patient-physician relational factors. (22, 23)

Chapter 6 describes physicians’ experiences with and attitudes towards euthanasia and physician-assisted suicide in different cases. For this study, a national representative sample of 1456 general practitioners, elderly care physicians and medical specialists filled in a questionnaire. Most physicians had received requests for euthanasia and physician-assisted suicide (77%; especially general practitioners, 93%). A majority had performed euthanasia and physician-assisted suicide (60%; 79% of general practitioners). So although only a small minority of patients die by euthanasia, many physicians do have experience with it.

After a patient explicitly requests his or her physician for euthanasia or physician-assisted suicide, the physician’s response can depend on many factors. The role of one of these factors, the patient’s underlying disease, is described in chapter 6. Almost all participating physicians found it conceivable that they would perform euthanasia and physician-assisted suicide in patients suffering from cancer or another severe physical disease (85% and 82%). This situation was quite different for people with other causes of suffering; only 40% found it conceivable in early-stage dementia, 34% in psychiatric disease, 33% in advanced dementia and 27% in a patient who is tired of living (with medical grounds for suffering). Similar percentages were found in an earlier study on acceptability of euthanasia and physician-assisted suicide among physicians. (8) While euthanasia and physician-assisted suicide is legally permissible in these situations, most physicians would not be willing to perform it. Apparently, personal moral factors, which may be related to the legal criteria for due care, are important in decision-making. For instance, physicians may find it harder to empathize with psychosocial suffering than with physical suffering, and therefore find it harder to be convinced that a patient’s psychosocial suffering is unbearable. (24) In psychiatric disease, it may be hard to determine whether psychiatric disease is hopeless and without treatment alternatives. (25) In dementia, the lack of meaningful communication with and affirmation by a competent patient at the time of performing euthanasia can make euthanasia unacceptable to the physician. (26, 27) Especially elderly care physicians described it would be inconceivable for them to perform euthanasia in advanced dementia (14% found it conceivable, compared to 47% in early-stage dementia). More than the other physicians, they have experience with advanced dementia and can imagine the complexity of this specific scenario.
In chapter 7, the decision-making on physician-assisted dying in children is described. In this study, 172 paediatricians filled in a questionnaire and eight paediatricians were interviewed. Physician-assisted dying in children seems to be even more complicated than in adults; patients are often incompetent, predicted future suffering can play an important role, parents are important actors, and the legal situation is more complicated. Although physician-assisted dying in children is extremely rare, one quarter of Dutch paediatricians had received requests for PAD and one in eight had, at some point in her or his career, performed PAD. Similar to the other physicians, most paediatricians found it conceivable to perform PAD on request (81%). The paediatricians felt that they had a duty to relieve the patient’s suffering, and if this was not possible by palliative care, PAD was an option. The presence of parental consent and a shortened life expectancy made paediatricians less reluctant to perform euthanasia. In these cases, they felt more certain that euthanasia was the right thing to do. Interestingly, conceivability was not lower if parents requested PAD instead of the child. Most paediatricians would be willing to perform PAD in an incompetent child who suffers unbearably and without hope but is incompetent, if the parents requested it. Age did not seem to play a role in their decision. In the Dutch euthanasia act, a patient needs to request euthanasia themselves and be at least 12 years old.(28) Chapter 7 shows that most paediatricians would not restrict the option of euthanasia to cases to which the Dutch euthanasia act applies. Interviewed paediatricians felt it would be unfair to refuse to perform physician-assisted dying in patients who suffered unbearably without hope for recovery, because of their age or level of competence. These findings support the call of some paediatricians for an extension of the Dutch law.(29) The Belgian euthanasia law seems to be somewhat more in line with the paediatricians’ ideas (age is not a criterion, but competence is), but would still exclude incompetent patients in whom most Dutch paediatricians would find euthanasia conceivable at the request of the parents.(30)

Finally, chapter 8 addresses voluntary stopping of eating and drinking, another method to deliberately hasten one’s death. Almost half of Dutch general practitioners had experience with VSED. The majority found it conceivable to become involved in this practice; 81% would administer palliative sedation if needed. Patients who hastened death by VSED were mostly over 80 years old and in poor health. In line with previous studies, this study found that death arrived quickly (median 7 days) and the patients’ last days of life seemed relatively comfortable.(31-33) However, symptoms such as pain, fatigue, impaired cognitive functioning and thirst occurred in 36% of cases. Half of the general practitioners were informed in advance about the patient’s plan to stop eating and drinking. Three quarter became involved and in 28% of cases they administered palliative sedation.
Few patients who died by VSED had requested euthanasia or physician-assisted suicide (19%), and most seemed to have made a deliberate choice to hasten death in this manner. This finding stands in contrast with findings from Chabot (49% requested euthanasia before deciding on VSED), who gathered data from relatives and acquaintances in 2003. I believe the new data, derived from family physicians, gives a more valid estimation, because relatives and acquaintances often do not know what a patient did and did not discuss with his or her family physician. Reasons for the patients’ preference for VSED over euthanasia or physician-assisted suicide could be a preference for a prolonged dying phase instead of a sudden death, or a preference for a natural death. Also, it puts less burden on the physician, and the patient is less dependent on the physician to hasten death. However, in practice many patients seem to depend on their physicians to have a comfortable death bed by VSED, because symptoms frequently occurred. Many physicians became involved during VSED, sometimes they even provided palliative sedation. Other authors too, described the need for physician involvement in VSED.

9.4 UNDERLYING THEMES; THREE PERSPECTIVES

9.4.1 Death in society

Patients, relatives and physicians have different perspectives on death and dying. Although these ideas are personal, they are developed within and influenced by society. In western society, some ideas about death and dying seem to predominate. This is illustrated by some common phrases in western culture which represent value judgements; Disease can be “fought” and “conquered”, forgoing treatment means “giving up”. Death should be “embraced” and “peaceful”. A natural death (“zonder toeters en bellen”) has a positive connotation, suicide is regarded as “tragic”, euthanasia is “a brave death”. The Steering Committee for Appropriate End-of-Life Care pointed out how these generalized ideas may undermine decision-making at the end of life and could lead to inappropriate care.

Especially the idea that disease and deterioration needs to be treated, with the aim of curing or prolonging life, seems to be embedded in society. This is reflected in media reports; people with life-threatening disease are often pictured as fighters, and scientists with promising stories about new life-saving treatments are popular talk show guests. There is little media attention to the problem of overtreatment, even though this is one of the most prevalent problems in the last phase of life (chapter 2), and has a large influence on quality of life and death (chapter 3).
One of the causes for overtreatment can be found in the way society copes with disease and death. ‘Don’t give up’. ‘You can beat the disease’. ‘You are a fighter’. These are just a few phrases people with a life-threatening disease regularly hear. ‘Giving up is not an option’ and ‘Continue my battle. Join the fight against a merciless disease’ are slogans of fundraising campaigns in the Netherlands (against cancer and ALS respectively). Two-third of the participants in the study on appropriate care (patients, relatives and professional caregivers) agreed that the idea that disease needs to be fought predominates in current society, which leads to unacceptance of forgoing treatment (68%).(20) The media might play a role in this; some physicians described that the media focusses too much on new treatment options and miraculous recoveries. Also, 78% of patients and relatives and 91% of caregivers thought that the notion that life is finite needs to penetrate better in society.(20)

This thesis not only reports on people who want to postpone their death, but it also reports on people who want their death to be hastened. Predominating ideas in our society about suffering, autonomy, and hastening death influence personal opinions on euthanasia. The media influences our perception of euthanasia: people whose euthanasia requests were refused and their relatives share their heart-breaking stories on television,(42-43) while movie characters often die by euthanasia before things get messy.(44, 45) In her dissertation, Frances Norwood describes how controlling nature may be part of Dutch culture, linking the Dutch history of taking control over water to the wide acceptance of taking control over dying by euthanasia.(21) Moreover, respect for autonomy is an important principle in Dutch society,(46) and according to some groups, people should have the right to exercise control over the way they die.(47, 48)

The possibility of having to suffer in the last phase of life, or of being uncomfortable in the death bed, can be unacceptable to people. In an opinion piece in the Guardian, O’Mahony describes how society looks at physicians to provide a comfortable death. ‘There is a perception – even a consensus – that death is a problem that medicine should somehow sort out, that a “good death” is something that doctors should be able to prescribe, as we might prescribe a course of antibiotics.’(49) Some may regard euthanasia or physician-assisted suicide as a way physicians can prescribe such a “good death”.

9.4.2 The patient’s and relatives’ perspective

In chapter 2 and 3, I showed that appropriate care in the last phase of life can have different meanings. What is appropriate for one person, seems inappropriate to the other. Whether certain care is appropriate, is in the eyes of the beholder. First of all,
it depends on the individual preferences of the patient who receives the care. Their preferences may depend on their hopes, fears and worries for the end of their lives and their deaths. I will elaborate on some of these hopes, fears and worries hereafter.

**A good death or not-too-bad death**

What is a good death, and what is a good last phase of life? There is no single answer to these questions. Literally, euthanasia translates from Greek as ‘a good death’, but of course this is not the case for everyone. Many studies have been done on the concept of a good death, of which I will describe some attributes. But before proceeding, I would like to question the appropriateness of using this term. For some patients, death is never good, and they will go at great lengths to avoid it. It is unrealistic to strive for a good death in these cases. Maybe it is better to speak about, and strive for, a not-too-bad death.

The meaning of a good or not-too-bad death is different for everyone. This thesis illustrates that people make very diverse choices at the end of life. For some, all available treatments that might postpone death must be tried before they can accept death (or they may never accept death). Others regard medical interference around the death bed as unwanted and prefer a natural death. Some prefer to die suddenly and unexpectedly, others prefer to know when it is time to prepare for death. And sometimes, the quality of the last phase of life is so poor, that people long for death; death is regarded as the best option because it puts an end to one’s suffering. Quality of death does not only depend on the circumstances in which someone dies, but also on the circumstances in the last phase of life and the choices people make in this time.

**Being free from suffering**

While ideas about a good or not-too-bad death are very diverse and personal, some themes seem universal. Most people agree that being free of pain and physical suffering in the last phase of life is a main attribute to a good death. In line with this, chapter 2 describes that good symptom management and good physical care are important aspects of appropriate care. Both patients and physicians seem to realize that physical wellbeing is important, and focus on it in conversations on end of life care.

However, being free from suffering at the end of life does not only mean being free from physical suffering. A good last phase of life is a combination of physical, psychological, existential and social wellbeing. Suffering in all these dimensions can lead to a wish to hasten death. Chapter 8 describes that physical suffering was one
of the reasons why people chose to hasten death by VSED, just as it is often a reason to request euthanasia. However, other factors seem to be more important reasons to request euthanasia, such as loss of dignity and loss of autonomy.

Completion and closure
Another common hope for the end of life is the hope for completion and closure. Many people hope they will be able to prepare for death, so that they are able to say goodbye to their loved-ones and have a sense of closure. If potentially life-prolonging treatment is continued for too long, there is a risk that the patient is unable to prepare for death. The treatment may absorb all their time and energy, and by the time it is stopped the patient does not have time to prepare for death. Also, patients may focus on treatment for too long, and not realize that they are approaching death. Treatment may give the implicit message that there is still hope for recovery. When this hope is false, it may lead to denial of a patient’s terminal illness. Although ignoring the possibility of death may seem preferable at first, it is often regretted later. Therefore, it is important that physicians recognize these effects of treatment, and discuss them with their patients.

In contrast, for some patients continuing active treatment facilitates acceptance and closure. It may buy them time, which can be used to prepare for death. Even when it does not lead to prolonged survival, it may help the patient to resign to his or her situation.

Opposite to people who continue treatment in an attempt to postpone death, there are also people who want to bring their death forward. This may leave them less time to say goodbye and complete life, but may also give them more opportunity to fill in the last days of their life in accordance with their own wishes, before they deteriorate further. People who actively hasten death by euthanasia or physician-assisted suicide know when they are going to die. This is an extraordinary situation, which can make it possible to organize a personalized goodbye.

Worries about the last phase of life
Sometimes, patients do not seem to make decisions based on their hopes and preferences, but they make decisions based on their worries and fears. Having worries seems inherent with dying; In the study on advance euthanasia wishes, most patients were described to have worries in the last three months of life (according to proxies, 87%). Terminally ill patients worry about becoming dependent, losing dignity, physical suffering, losing the ability to communicate, having to leave their homes, and they can fear death itself.
The path towards death can be dreaded more than death itself. For some, the prospect of having to endure the decline or suffering that is associated with the end of life seems so unbearable, that they want to by-pass this process and die by euthanasia or voluntary stopping of eating and drinking. They may look at death as did Friedrich Nietzsche: ‘The final reward of the dead- to die no more’.

Undeniably, the last phase is not the easiest period of life. Most people who die from common diseases such as cancer, heart disease, COPD and renal disease suffer from pain, fatigue or breathlessness in the terminal phase. Other prevalent symptoms are depression, anxiety, confusion, insomnia, nausea, constipation, diarrhoea and anorexia.(60) In a small-scale study, a quarter of patients with terminal cancer described that they suffered unbearably, due to physical symptoms, loss of function, and non-physical aspects such as losing autonomy and not being able to do things that were important to them.(61) People may fear dying because they fear this. But maybe, the idea of entering a period of uncertainty is worse than these symptoms. No one knows the suffering they might have to endure at the end of life, and to what extend they might lose control over their life. Hastening death can be seen as a way out for people who find the prospect of losing control unbearable. Fear of future suffering and losing control can be a motive for people who draw up an advance euthanasia directive.

**Losing control**

A theme that came up in all of the studies included in this thesis, was the value patients attach to autonomy. Although giving potentially life-prolonging treatment, forgoing potentially life-prolonging treatment, and active hastening of death are very different, each of these actions can be aimed at maintaining or regaining control. Being able to exercise individual autonomy is identified as an important aspect of a good death in the western world.(52, 62-64) In the last phase of life most people try to exercise control over day-to-day life, treatment decisions, family issues, final days of life, and even over the time after death by making arrangements for after their death.(65) However, remaining in control often proves impossible at the end of life. People generally have to give in on their autonomy in the period before their death, because they become dependent on others or are unable to influence the course of things.(62) This loss of autonomy, or the prospect thereof, can determine a patient’s medical preferences and decision-making.

Preventing further loss of autonomy plays an important role for many people who request euthanasia. Becoming dependent, being a burden on others, and loss of dignity are prevalent reasons to request euthanasia.(56, 57, 66) Some feel that these
factors are becoming increasingly important for people who request euthanasia. (67, 68) Merely talking about the option of euthanasia can give people a sense of control. (21) Knowing that euthanasia is an option, that there is a way out, often seems to be enough; many advance euthanasia wishes never result in euthanasia requests, and many euthanasia requests are never carried out (chapter 4). (27)

Similar to people who request euthanasia, loss of autonomy, being dependent and loss of dignity were prevalent reasons for people to hasten death by voluntary stopping of eating and drinking (chapter 8). Hastening one’s death by stopping eating and drinking can be a way to regain a sense of control, without the need for a physician’s approval. (36) In euthanasia, it is mostly the physician who orchestrates the death bed. (27) In VSED, the patient is the ‘director’ of his own death bed, although they will generally lose control further in the process.

Other medical decisions at the end of life can also influence perceived level of autonomy. Starting or continuing potentially life-prolonging treatment can give a sense of personal control, because something is being done. However, potentially life-prolonging treatment can also reduce the level of perceived control. For instance, a treatment regimen or side effects of treatment can take over a patient’s life (chapter 3).

**Fear of death**

In general, people prefer life over death and will choose to undergo treatment when faced with a life-threatening disease. However, some patients go further than others for a chance to prolong life. They choose to endure burdensome treatment which makes them sick most of the time, and/or treatment which requires them to spend their time in the hospital, in exchange for a small chance of postponing death. These patients may be driven by a fear of death.

What does it mean, to fear death? If you look at death rationally, it seems as if there is nothing to fear. In his letter to Menoeceus, Epicurus wrote: ‘So death, the most terrifying of evils, is nothing to us, because as long as we exist death is not present, whereas when death is present we do not exist. It is nothing to those who live (since to them it does not exist) and it is nothing to those who have died (since they no longer exist).’ In reality however, fear of death is common. (69) Approximately one-quarter of older people in the ADC cohort feared death, according to their proxies (chapter 4). Fear of death may mean many things, such as a fear of the unknown, fear of separation or worries about loved-ones who will be left behind. (69) Moreover, in death, people are deprived of the valuable and enjoyable experiences they could have in life. (70, 71)
By choosing to undergo potentially life-prolonging treatment, it may seem to the patient that they choose life over death. However, this life may not be the one they hoped for; it may be a life full of physical, psychological, social and existential suffering and may be of very short duration. The other option, to forgo treatment, may seem like a choice for death to the patient or his loved-ones. However, it may be better described as a choice for spending the last phase of life with the best possible quality.

9.4.3 The physician perspective

Not only the patients’ personal values play a role in care at the end of life, the physicians’ values also influence treatment and care decisions. Similar to the patients, the physicians need to make decisions based on their personal values. Physicians can be confronted with ethical dilemmas when their personal values seem to conflict. In a reference work on medical ethics, Beauchamp and Childress describe four principles of medical ethics which often seem to guide physicians in their decision-making: beneficence, non-maleficence, autonomy and justice or fairness.(72) Beneficence refers to actions which aim to benefit others, while non-maleficence refers to not acting in ways that inflict harm. Autonomy concerns respecting the patient’s autonomy (although the physician’s autonomy also plays a role), and justice or fairness refers to fair distribution of treatment and care. (72) When physicians experience dilemmas, this is often caused by a tension between these four principles. I will describe some of these dilemmas and the role they play for physicians.

Considerations related to beneficence and non-maleficence

Conceivability to perform physician-assisted dying was high among general practitioners, elderly care physicians, paediatricians and other medical specialists (93%, 87%, 81%, and 74% respectively). The principle of beneficence was as an important motivation for the high conceivability among paediatricians. Beneficence also plays a role for other physicians who perform euthanasia or physician-assisted suicide.(12) The interviewed paediatricians felt they had the duty to reduce the child’s suffering to an acceptable level. If suffering could not be relieved otherwise, most would be willing to take away suffering by hastening death. Others described how performing euthanasia and physician-assisted suicide can be a somewhat satisfying action for physicians, because they feel they truly help the patient.(73, 74)

The same drive to help people can play a role for physicians who offer their patients potentially life-prolonging treatment in the last phase of life. Unfortunately, the effects of treatment at the end of life are sometimes not beneficial. Chapter 3 describes that treatment aimed at life-prolongation in the last phase of life can have
beneficial effects, but it more often seems to be harmful. Potentially life-prolonging treatment can harm patients through physical, psychological, existential and social consequences. Patients, relatives and professional caregivers often regard this treatment as inappropriate because of this.

Although physicians aim to benefit their patients, they sometimes give treatment that is most likely non-beneficial or even harmful. Both patient-related and physician-related factors can contribute to this. The patient himself may ask the physician to provide such treatment. In these cases, one might question whether the patient made this choice on the basis of complete and realistic information, and whether the patient received the support needed to come to a well-considered decision. Studies on patients with advanced cancer showed that the large majority did not realize that the chemotherapy or radiotherapy they received would not cure them. If a patient insists on treatment, the physician can be confronted with an ethical dilemma: Should he or she respect the patient’s autonomy and give the treatment of choice, or should the physician refrain from performing non-beneficial and even maleficent acts? While the physician may regard the treatment as medically futile, the treatment may still have beneficial consequences for the patient. Chapter 3 describes cases in which treatment did not improve life span and caused severe side effects, but was still seen as appropriate because it had positive psychological, existential or social consequences. This may not have been foreseen by the physician at the time of decision-making, if he or she mostly focusses on medical consequences of treatment.

There are also physician-related factors which could contribute to overtreatment in the last phase of life. In the study on appropriate care in the last phase of life, participants described some of these factors. Physicians may focus too much on treatment, and as a consequence do not (completely) discuss other options with the patient. Sometimes, physicians are too optimistic when they inform their patients about prognosis and expected treatment effects, either because they have unrealistic expectations of treatment themselves or because they do not want to take away the patient’s hope by being too honest. Also, physicians might base their advice on those rare cases in which treatment did benefit a patient. Finally, sometimes physicians may presume that the patient wants treatment, without letting the patient decide for themselves. They are driven by beneficence, even though the result may not turn out beneficial for the patient.
Autonomy
In end-of-life decision making, shared decision making is often considered ideal. (79, 80) In shared decision making, patients are empowered to make well-considered decisions together with their physician. In this way, patients can optimally exercise their personal autonomy. Patients are empowered to make decisions by being informed about the treatment options by their physicians and by being supported in their decision-making process. The patient’s preferences are leading in shared decision-making. (79, 80) However, these decisions cannot be seen as entirely autonomous, because the physician influences these decisions, explicitly or implicitly. (80) Also, the relation between the patient and the physician plays a role in decision-making, as well as the people around the patient. (81)

Often, there is a third party involved in decision-making as well; the patient’s relatives. This is especially the case when the patient is a child. In these cases, the child’s parents are important stakeholders. Chapter 7 describes how paediatricians who consider physician-assisted dying take both the patient’s developing autonomy and the parents’ autonomy in account. The paediatricians highly valued the child’s autonomy and tried to respect it, but at the same time they recognized that the child may not be able to make a well-considered decision and are used to parents as surrogate decision-makers.

According to professional norms, physicians should aim to respect patients’ autonomy (as long as this leads to medically acceptable treatment). (82) However, the physician’s own autonomy must also be respected. The physician’s autonomy is especially important in decisions on euthanasia and physician-assisted suicide. Because these actions are not normal medical practice, a physician can always refuse to perform it. Chapter 6 shows that most physicians would not perform euthanasia in all cases in which it would be legally possible. If a patient requests euthanasia and the physician has conscientious objections to performing euthanasia, the patient’s autonomy conflicts with the physician’s autonomy.

Because performing euthanasia can be emotionally burdensome, (12, 73, 74) it is important that physicians feel free to refuse requests for euthanasia. For some physicians, the emotional burden is a reason not to perform euthanasia and physician-assisted suicide. (83) I found that two-thirds of physicians dreaded the emotional burden of performing euthanasia or physician-assisted suicide, a higher percentage than any other aspect of this practice. (27) The Royal Dutch Medical Association reported that 88% of 455 physicians thought that society should be more aware of this emotional burden. (74) Physician’s autonomy can be challenged in decision making...
on physician-assisted dying. In the evaluation study of the euthanasia law, most physicians who had received requests for euthanasia or physician-assisted suicide described they sometimes felt pressure to perform it. Seventy-seven percent of them had ever experienced a feeling of pressure; they felt pressured by the patient (49%) or relatives (53%) to say yes to a request, to perform euthanasia or physician-assisted suicide as quick as possible (65%) or relatives exerted pressure to deny a request (14%). Moreover, 40% of physicians felt pressure from society to perform euthanasia. (27) This is an important issue because it interferes with the physician’s autonomy.

While patient autonomy plays a large role in discussions on legalization of euthanasia, the Dutch Euthanasia Act is based on beneficence rather than autonomy and applies to physicians instead of patients. Patients who want to hasten death by euthanasia or physician-assisted suicide are dependent on their physician for the fulfilment of this wish. Patients who wish to hasten death by voluntary stopping of eating and drinking are more autonomous in their choice to hasten death. They too, however, often lose control somewhere during the process due to reduced consciousness, delirium or reduced cognitive abilities. At that moment, patients become dependent on care and support from their physician, nurses and relatives.

**Fairness**

According to professional guidelines, physicians have the duty to provide palliative care to patients who need it. (84, 85) In contrast, physicians can always refuse a request for euthanasia or physician-assisted suicide. While patients do have the right to receive palliative care if indicated, they do not have the right to euthanasia if they suffer unbearably. (84) Euthanasia or physician-assisted suicide is never medically indicated. This means that a patient’s request for euthanasia can be refused, even though he or she suffers unbearably and without hope for recovery. This is sometimes seen as confusing and unfair.

Some physicians and authors feel that people increasingly regard euthanasia as a right, and therefore have little understanding for physicians who refuse a request for euthanasia. (12, 68) In 2010, 57% of the Dutch public thought that everybody should have a right to euthanasia, compared to 28% of physicians. (12) In reality, not everybody has equal access to euthanasia. Conceivability to perform euthanasia is higher in case of patients suffering from cancer or another severe physical disease than patients who suffer from dementia, psychiatric disease or who are tired of living. Patients who suffer physically have a higher chance that their physician would grant their request than patients who suffer psychosocially. (24)
Most physicians are more restrictive than needed according to the Euthanasia Act, but they can also be more liberal. This was especially the case among paediatricians. Seventy-two percent of paediatricians would consider hastening a child’s death in a patient under 12 if he or she suffered unbearably, and 71% would consider it at the request of the child’s parents, even though these cases would fall outside the Euthanasia Act (chapter 7). Not only paediatricians were sometimes willing to hasten death in cases which fall outside the scope of the Dutch Euthanasia Act. Eighteen percent of physicians found it conceivable to perform euthanasia in a patient who is tired of living without medical grounds for suffering, even though this is not permissible according to the regional review committees (chapter 6).

One of the explanations for the high conceivability among paediatricians to hasten death in cases which fall outside the scope of the Euthanasia Act is the principle of fairness. The paediatricians’ main aim was to relieve suffering, and this was no different for patients above or below 12, for competent or incompetent patients. They thought it would be unfair to deny the option of physician-assisted dying because of age or competence level. Legally, parents cannot request for physician-assisted dying in incompetent children over 1 year old, but they are surrogate decision-makers for all other decisions. This felt contradictory to some paediatricians; parents are expected to decide to start or forgo burdensome treatment with minor chances of survival benefit, to start or forgo potential life-saving treatment, but they cannot decide to end the child’s suffering if it cannot be relieved otherwise.

9.5 IMPLICATIONS FOR CLINICAL PRACTICE, POLICY AND FURTHER RESEARCH

9.5.1 Implications for clinical practice

Being involved in end-of-life care is one of the most rewarding aspects of medicine, because it is such a crucial period in both the patient’s life and the life of their loved-ones. However, it is not easy, and can burden physicians with moral dilemmas. Good end-of-life care requires of physicians to have an open attitude, a holistic view, and a lack of fear to think and talk about death and dying. To respond to the challenges in end-of-life care, physicians need to be open to the preferences and values of the patient, as well as recognize the role of their own values. Both play a role in decision-making.
Have a broad perspective on care
Appropriate care in the last phase of life is not only about making appropriate treatment decisions, it also includes providing sufficient supportive care, making sure the patient is in an appropriate location, good patient-physician communication and taking the patient’s wish into account (chapter 2). In patient care in the last phase of life, all these dimensions of appropriate care should be kept in mind. If a physician regularly checks patient’s needs in each of these dimensions, appropriateness of care will improve. Box 1 gives an overview of the questions a physician may ask to systematically assess all dimensions of appropriate care.
Box 1: List of questions for physicians

“Am I providing appropriate care in the last phase of life?”

1 Supportive care

- Do I regularly check whether new care needs emerge?
- Can the patient (or relatives) reach me when needed and will the patient receive good quality care in out-of-office hours?
- Does the patient need more physical care, or do I expect he/she will do so in the near future?
- Are the patient’s relatives appropriately involved, do they feel supported and not overburdened?
- Is the patient in need of psychological support?
- What wishes does the patient have outside the medical scope for which he/she may need my help?

2 Treatment decisions

- Are there curative/life-prolonging treatment options available and does the patient want these?
- If yes: are both I and the patient convinced that the benefits of treatment outweigh the harms?
- Does the patient have burdensome physical symptoms now or do I expect them in the near future?
- If the patient has requested assisted dying: have I been clear in my standpoint and do we regularly discuss this wish?

3 Location

- Where does the patient want to be in the last phase of life and what is the preferred place of death?
- Can the patient’s needs be met in the current location, now and in the future?

4 Role of the patient’s wish

- How much autonomy does the patient seek in decision making and in self-care?
- Do I know the patient’s care preferences and do I act in accordance with them?

5 Communication

- Do I regularly discuss current and future care with the patient?
- Have I provided the patient with intelligible, complete and realistic information on prognosis, treatment options and risks?
- Do I give the patient enough opportunity to talk and do I know the patient’s argumentation behind certain choices?
- Have I ever asked the patient for feedback?

Note: Based on the findings in chapter 2
**Be aware of non-physical consequences of treatment**

Treatment is not an aim in itself, it is a way of achieving aims. Giving and forgoing treatment may not only have physical consequences or influence lifespan, it can also have psychological, existential and social consequences. These are generally not discussed at the time of decision-making.\(^{(54, 55, 86, 87)}\) I, like other authors, call for a more holistic approach to medical decision-making in the last phase of life.\(^{(86, 88, 89)}\) Not only physical consequences of treatment and potential life prolongation should be discussed, but also psychosocial and existential consequences, because these consequences can have a major influence on quality of life and death.

**Get to know your patient**

While the five dimensions of appropriate care seem universal and apply to different diseases, each patient is different. What is appropriate for one patient, might be inappropriate for another patient. Therefore, caregivers should not presume to know a patient’s needs and aims, but check regularly with the patient. Physicians and patients should discuss what aims the patient has, and what values are important to the patient. Subsequently, the physician can help the patient in relating their aims and values to the treatment options. In this way, a patient can make a well-informed and well-considered decision on treatment in the last phase of life, according to the principles of shared decision making.\(^{(80)}\) This does not only improve appropriateness of care, it also makes a physician’s work more interesting.

**Explore a patient’s advance euthanasia wish**

Quite a different issue in end-of-life care is how to respond to patients who want to hasten death. The patient may bring up the subject in the form of an early notification, by drawing up an advance euthanasia directive. It seems that physicians should interpret this as a need for reassurance; a way for the patient to cope with worries about their last phase of life. Therefore, if a patient visits the doctor’s office to present an advance euthanasia directive, physicians could inquire about the patient’s hopes, worries and fears, and address these. Also, this moment could serve as starting point for advance care planning, focusing on other aspects of end-of-life care as well.

**Allow for careful deliberation before responding to a euthanasia request**

Physicians can be asked to perform euthanasia or physician-assisted suicide in cases in which they feel reluctant to do so. In many cases, this reluctance is not associated with worries about breaking the law, but with conscientious objections. I would advise physicians to recognize this reluctance and be open about it, also when the physician cannot give a definite answer yet. Saying yes to a request for euthanasia or physician-assisted suicide is a big commitment. Just as important
as the question ‘does this case fall within the criteria of the euthanasia law?’ is the question ‘can I personally support euthanasia or physician-assisted suicide and cope with the performance thereof, in this patient, and at this moment?’ To answer this question, physicians need some time to explore the patient’s motivation and nature of suffering. Physicians often feel pressured to grant requests for euthanasia and physician-assisted suicide,(27) but it seems unwise to take hurried decisions. Even in cases in which a decision needs to be made in a short time, it seems important to take adequate time for deliberation, to prevent that the decision to grant or refuse a request leads to feelings of doubt, guilt or regret. If a physician decides not to grant a patient’s request, he or she still has a lot to offer the patient in the field of palliative care. In case the patient persists in his or her wish for euthanasia or physician-assisted suicide, the physician can refer the patient to another physician who may grant this request, for instance at the end of life clinic.

**Become involved if a patient plans VSED**
When a patient informs their physician about their intention to hasten death by stopping eating and drinking, a physician has the moral duty to act upon this.(38, 90, 91) The KNMG (Royal Dutch Medical Association) published a guidance paper on the role of the physician in VSED, which can be a useful tool for physicians.(90) Physicians can inform the patient about what they can expect, and if the patient persists and wants their physician’s support, start to arrange the necessary care. Symptoms such as delirium, decubitus, and oral problems may be prevented with the right preventive measures, such as instructions to family, pressure relief mattresses and mouth care. The patient and physician can together make a plan what to do if certain problems arise. Because symptoms often occur during the process of VSED, it is preferable for the physician to frequently visit the patient in order to detect and respond to problems early. Also, because the patients’ relatives are often involved, the physician can play a role in supporting them.

**Physicians cannot solve everything**
Finally, as physicians we may sometimes need to be more humble and recognize the boundaries of medicine. Not all problems in the last phase of life can be solved by medicine. There is no pill against loneliness, no medical treatment for missing a purpose in life. ‘We have thrust on to doctors and hospitals the messy, intractable and insoluble aspects of life, principally old age and death.’(92) Physicians try to solve all these problems by what we have: medication, surgery and other therapies. If physicians more often realize that medicine cannot take away all suffering, this may prevent overtreatment and other forms of inappropriate care.


9.5.2 Implications for policy

On a societal level, there is much to improve in people’s attitude towards the end of life. (40, 93) Despite common belief, the end of life is not necessarily a period of severe suffering. The end of life is a time of uncertainty. Instead of being afraid of this, it would be better if people approach this time well-prepared and with some confidence. Many physical and psychological problems can be treated well by palliative care. Euthanasia can be a way to stop suffering, but it is often not preferred by the patient or needed to take away suffering. Also, it sometimes seems that some people do not realize that dying is an inseparable part of life, and medicine cannot solve all issues that are associated with it. If this notion becomes more accepted in our society, people may be better able to prepare for their end of life.

Stimulate the public to think and talk about the end of life

The KNMG Steering Committee for Appropriate End-of-Life Care, as well as IKNL, call for a campaign aimed to stimulate the public to think about and discuss their end-of-life care preferences, and to increase awareness on the boundaries of medical care. (40, 93) This may stimulate more people to form and discuss their preferences for the end of life, which can lead to more appropriate and personalized care in the future. Until now, there has not been a national campaign, but there are local initiatives on the level of primary care practices and care institutions. Also, a coalition of medical, patient, and elderly organizations published a brochure aimed to stimulate patients to think about their last phase of life. (94)

No arguments for a law change for adults

Does everything that seems morally right, need to be regulated by law? (72) Before the Euthanasia Act came into force, physicians already performed euthanasia. If they abided by the criteria of due care, they were not punished for it. One might wonder whether a Euthanasia Act is needed to regulate practice.

However, one should not underestimate the importance of the Dutch Euthanasia Act. It serves as a safeguard for careful practice, because it brings the practice out in the open and makes monitoring possible. It serves as guidance for physicians. Physicians appreciate the existence of the act because it gives a feeling of security. It is seen as guidance beforehand, and gives a sense of objective approval afterwards. (8, 95)

This thesis describes that most physicians were more restrictive than the Dutch Euthanasia Act prescribes them to be. However, I do not feel this should be reason to restrict the law. The act does not describe a duty, but it describes a possibility. Physicians can decide for themselves whether they want to use the space the act
gives them. At the same time, lobby groups call for extension of the scope of the Euthanasia Act. It seems like the scope of the Act will remain topic of discussion, and there will always be people who fall outside of it.

**Need for regulations for physician-assisted dying in children between 1 and 12**

In children between 1 and 12, there are no clear guidelines on when physician-assisted dying can be acceptable. However, most paediatricians agree that there are cases in which it is ethically acceptable, and would be willing to perform it. The Dutch minister of Health describes that physicians may successfully defend themselves at court by the principle of force majeure (a conflict of duties between relieving suffering and obeying the law). However, paediatricians feel the need for more security and guidance. It seems that a national regulation similar to the regulation for neonates and/or an extension of the euthanasia law towards competent children under 12 could offer them this security and guidance. Also, it would facilitate monitoring of this practice. At present, research is being initiated on the paediatricians’ needs and on possible solutions.

**9.5.3 Implications for research**

With this thesis, I hope to add valuable information to the existing evidence on end-of-life care. At the same time, some new questions emerged during my studies which still need to be answered.

First of all, both giving and forgoing potentially life-prolonging treatment can have very diverse consequences. At this moment, little is known about the aims patients have at the moment of decision-making. If physicians have more understanding about the patients’ aims, they can better inform the patients about the pros and cons of different treatment options.

Secondly, I found that maintaining control plays an important role for patients at the end of life and it seems an important factor in decision-making. It would be interesting to learn how different treatments and decisions contribute a feeling of control, and how we can best provide patients with a feeling of control.

Thirdly, this thesis describes patients who voluntarily stop eating and drinking. Similar to the other studies on this practice, this concerned a retrospective study and did not directly involve patients. Research should focus on learning more from the patient’s perspective. Physicians need this information to better inform patients who consider hastening death by VSED and to be able to provide appropriate care to them.
Fourthly, I would advise researchers to design questionnaires that are very short (for instance, one double-page) to improve response rate. However, if a longer questionnaire is necessary, length of the questionnaire does not seem to matter anymore. Finally, I would like to reshift focus somewhat. Euthanasia and other ways of hastening death are very interesting topics, because of the ethical dilemmas they are associated with. However, researchers should realize that only a small minority of people request physician-assisted dying (8.4%).(97) Therefore, I would like to call for more research on more prevalent subjects at the end of life. One of the most important problems in end-of-life care at this moment, is overtreatment. Approximately one-third of patients receive some form of overtreatment at the end of life. (98) Research is needed on ways to prevent overtreatment, such as ways of improving patient-physician communication, and developing decision aides. Moreover, research should focus on improving appropriateness of care in the last phase of life in general, for instance by studying how to support people in advance care planning, how care can be better tailored to the patient’s wishes, how to make the patient feel supported and in control in the last phase of life, or increase the chance of patients being able to live and die at the place and under the circumstances they prefer.
REFERENCES

30. Proposition to change the law of 28 May 2002 concerning euthanasia with the aim of making euthanasia for minors possible [In Dutch and French], Belgian Senate, Session of 2013-2014(2013).
37. KNMG Royal Dutch Medical Association and V&VN Dutch Nurses’ Association. Caring for people who consciously choose not to eat and drink so as to hasten the end of life. Utrecht, 2014.
40. Steering Committee for Appropriate End-of-Life Care. Just because we can, doesn’t mean we should- Appropriate end-of-life care. KNMG Royal Dutch Medical Association. Utrecht, 2015.
44. Oerlemans R. Komt een vrouw bij de dokter. Benelux Film Distributors; 2009.
49. O’Mahony S. We doctors can’t prescribe a ‘good death’. The Guardian. 5/22/2016.
64. Mak JM, Clinton M. Promoting a good death: an agenda for outcomes research—a review of the literature. Nurs Ethics. 1999;6(2):97-106.
General discussion


92. O’Mahony S. The way we die now. Head of Zeus, 2016.

93. IKNL integraal kankercentrum Nederland. Palliatieve zorg in beeld. 2014.


