

Summary

INTRODUCTION

In their last phase of life people hope for a good quality of life and a good quality of death. Medical care can have a big impact on this. The meaning of a good quality of life and death is very personal, but it involves physical wellbeing as well as psychological, existential and social wellbeing. A patient's personal hopes, fears and expectations about the last phase of life lead to diverse care preferences. Patients may prefer to start or continue potentially life-prolonging treatment, or they may prefer to forgo such treatment. Some patients may even prefer to hasten their death, by euthanasia, physician-assisted suicide or voluntary stopping of eating and drinking. Because of all these different preferences, providing care to patients in the last phase of life can be a challenging task for caregivers. Moreover, the physicians' own ideas and values also play a role in the care they provide to patients at the end of life, and they can be confronted with moral dilemmas when a patient has a certain preference. Therefore, in decisions on giving or forgoing potentially life-prolonging treatment and decisions on hastening death, both the patient's preferences and the physician's values play a role.

Decisions to give or forgo potentially life-prolonging treatment are frequently made in the last phase of life. An estimated 36% of patients in the western world receive some form of overtreatment at the end of life,⁽¹⁾ and 37% of Dutch deaths are preceded by the decision to forgo treatment.^(2, 3) Active hastening of death is well-known in the Netherlands, but much less common: approximately 4.6% of people die by euthanasia or physician-assisted suicide and 0.5% die by voluntary stopping of eating and drinking.^(4, 5)

In this thesis, patient preferences for the last phase of life are explored, especially those preferences which aim to postpone or hasten death. Subsequently, this thesis explores how physicians would respond to patients who wish to hasten their deaths.

RESEARCH AIMS

The main aims of this thesis are:

- To gain insight into appropriateness of care in the last phase of life, especially 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.

PART 1: APPROPRIATE CARE IN THE LAST PHASE OF LIFE

Chapter 2 and 3 present the findings of a study on appropriateness of care. For this study, an internet questionnaire was designed for people who had experience with care in the last phase of life, as patient, relative, physician or nurse. In the questionnaire, people described the care and indicated whether they regarded the care as appropriate or as inappropriate.

Forty-five patients and 547 relatives of patients described 738 cases. The care was described as appropriate in 429 cases and inappropriate in 309 cases. Five dimensions of appropriate care were identified in these cases, described in **chapter 2**. These dimensions were:

- 1) Supportive care (62% of cases): appropriate supportive care included continuous support, good physical care, care for proxies, psychosocial care, good continuity and coordination, and social support.
- 2) Treatment decisions (53% of cases): In some cases, giving potentially life-prolonging treatment was seen as appropriate, while in other cases forgoing of this treatment was appropriate. Other appropriate treatment decisions were adequate symptom control and physician-assistance in hastening death.
- 3) Location (47% of cases): the appropriate location was mostly home, but could also be a long-term care facility, hospice or hospital.
- 4) Role of the patient's wish (41% of cases): appropriate care often followed the patient's wish or gave the patient a feeling of control.
- 5) Communication (39% of cases): appropriate patient-physician communication included the presence of (regular) dialogue, a physician with a right attitude, who listens and informs well.

In the cases which the participants described as inappropriate, the care was mostly inappropriate because of inappropriate treatment decisions (69%; especially giving

potentially life-prolonging treatment; 35%), inappropriate supportive care (54%), or inappropriate communication (50%).

Chapter 2 shows that appropriate care is a very broad term, which can refer to different aspects of care. Although the meaning of appropriate care varied greatly between individuals, few differences were found between patients with cancer, other physical diseases, general decline and dementia. Apparently, the care needs of these patients are quite similar.

The most common type of inappropriate care was overtreatment. However, some participants described potentially life-prolonging treatment as appropriate. Similarly, forgoing potentially life-prolonging treatment was mostly described as appropriate, but could also be inappropriate. **Chapter 3** aims to give some insight in this problem. It describes the consequences of giving potentially life-prolonging treatment, as well as the consequences of forgoing such treatment. Fifty-three cases of appropriate giving of treatment were analysed, 310 cases of overtreatment, 271 cases of appropriate forgoing of treatment and 32 cases of undertreatment. Participants were 222 relatives of patients, 164 nurses, 147 physicians, and 23 patients. The consequences could be categorized in five groups: physical consequences, psychological consequences, social consequences, existential consequences and a shortened or prolonged life span. Both giving and forgoing treatment could have positive and negative consequences in these five dimensions.

For instance, giving treatment could reduce symptoms (physical), give a sense of control (psychological), enable patients to grow towards acceptance (existential), or prolong life, allowing for more time with family (social). However, giving treatment was more often seen as inappropriate, for instance because it demanded too much energy (physical), caused anxiety (psychological), unawareness or unacceptance of approaching death (existential), and treatment could prevent the patient from spending time at home with family (social). Forgoing treatment could have similar consequences. It could allow the patient to enjoy life without interference (psychological) and without side-effects (physical), to prepare for death (existential), or spend time at home with family (social consequence).

Physical, psychological, existential and social wellbeing are all important factors in the last phase of life. (6-8) Therefore, potential consequences in each of these dimensions should be taken into account at the time of decision-making. However, physicians and patients mostly focus on physical consequences and potential life-prolongation in conversations about giving or forgoing treatment.(9-11) If potential

consequences in the other dimensions are not discussed, the risk is high that inappropriate treatment decisions are made.

PART 2: PATIENT'S PREFERENCES FOR HASTENING DEATH AND PHYSICIAN'S ROLES IN HASTENING DEATH

The second part of this thesis describes patients who have a preference or a wish to hasten death, and physicians' ideas about aiding these patients. **Chapter 4** describes older people who do and do not have an advance euthanasia directive, in which they declared to have a preference for euthanasia in certain future scenarios. Subjects were deceased members of one of two cohorts; the Longitudinal Aging Study Amsterdam (LASA) or the Advance Directive Cohort Study (ADC). Data on possession of advance euthanasia directives was collected during life. After death, the subjects' relatives were asked to describe their last three months before death. Of the 142 older people with an advance euthanasia directive, 87% still had an advance euthanasia wish three months before death and 75% persisted in this wish at three days before death. Eventually, 47% requested euthanasia or physician-assisted suicide and 16% died by euthanasia or physician-assisted suicide. Of the people without an advance euthanasia directive (n=180), 21% had an advance euthanasia wish at three months before death and 6% requested euthanasia or physician-assisted suicide.

Chapter 4 shows that advance euthanasia wishes are quite stable over time, and that having an advance euthanasia directive makes a future euthanasia request more likely. However, it also shows that an advance wish does not necessarily result in requests for euthanasia or physician-assisted suicide, even if the scenario as described in the advance euthanasia directive occurs. Possibly, advance directives for euthanasia may best be interpreted as a way to express worries and an attempt to gain a sense of control over the future. Physicians can best respond to these directives by discussing the patient's worries and start a conversation about end-of-life care.

Chapter 5 to 8 describe findings from the evaluation study of the euthanasia law. In this study, 1628 physicians participated. They filled out a questionnaire on attitude towards and experiences with, among others, physician-assisted dying and voluntary stopping of eating and drinking.

Chapter 5 is a methodological study, which found that response rate to a four double-page questionnaire was not higher than response rate to an eight double-

page questionnaire. Sending a very short version of the questionnaire, counting only one double-page, to non-responders after three months improved the response rate from 53% to 64%.

Chapter 6 describes the attitude of a random national representative sample of general practitioners (n=708), elderly care physicians (n=287), and medical specialists (n=461) towards performing euthanasia and physician-assisted suicide. Most had received requests for euthanasia or physician-assisted suicide (77%) and had performed this (60%). Conceivability to perform euthanasia or physician-assisted suicide was high (86%). Especially in case of cancer or other severe physical diseases performing euthanasia or physician-assisted suicide was conceivable for most physicians (85% and 82%). A minority of physicians found performing euthanasia or physician-assisted suicide conceivable in case of psychiatric disease (34%), early-stage dementia (40%), advanced dementia (33%) and in patients who were tired of living in the absence of a severe disease (27%). In all of these cases, euthanasia and physician-assisted suicide can be legally allowed. Apparently, most physicians were more restrictive than the euthanasia act prescribed them to be. However, 18% of physicians found it conceivable to perform euthanasia or physician-assisted suicide in patients who are tired of living without medical grounds for suffering, although this falls outside the euthanasia act.

The chance that a request for euthanasia by a patient with a psychiatric disease, dementia or who is tired of living will be granted by their own physician seems low. Multiple factors could contribute to this. In case of psychiatric disease, dementia and tiredness of living, suffering is predominantly psychosocial instead of physical. This makes it harder for physicians to empathize with the suffering and label it as unbearable.⁽¹²⁾ In psychiatric disease, physicians may doubt whether there is hope for recovery, treatment alternatives and whether the request is well-considered.⁽¹³⁾ In advanced dementia, the patient can no longer describe their suffering and the physician can no longer share the responsibility of euthanasia with the patient, which may make it inconceivable to perform euthanasia. Finally, because euthanasia in these cases is rare, physicians may have cold feet.

Chapter 7 shows that conceivability to perform physician-assisted dying is high among paediatricians. In a national sample of 172 paediatricians (response rate 62%), 81% found it conceivable to hasten death in children between 1 and 17. Physician-assisted dying in children is rare, but still 26% of paediatricians had received a request (mostly from a patient's parents) and 16% had performed it. Conceivability was similarly high in patients below and above 12 years. Moreover, most paediatrici-

cians would be willing to perform physician-assisted dying at the request of the parents of a child (71%). The Dutch euthanasia act does not apply to children under 12, nor does it apply to children whose parents request physician-assisted dying on their behalf.

The quantitative data was complemented by qualitative interviews with eight paediatricians. The paediatricians described that their decision on physician-assisted dying would not depend on whether or not the case would fall within the euthanasia law. They would always be reluctant to hasten a child's death, but would do so if it was needed. The medical ethical principles of beneficence and fairness played a large role for them. Physician-assisted dying was seen as a beneficent act if unbearable suffering could not be relieved otherwise. The paediatricians argued that it would be unfair not to perform this beneficent act in children below 12 or in children who were not competent to request euthanasia themselves. An important restrictive factor in decision-making was the medical-ethical principle of autonomy, both of the patient and the parents. The paediatricians needed to be sure that the child had a wish to die, and that the parents consented with it. If the parents of an incompetent child requested physician-assisted dying, the paediatricians would involve the child as much as possible in decision-making.

The last study in this thesis describes patients who voluntarily stop eating and drinking with the intention to hasten death. In contrary to euthanasia, this is a little-known way to hasten death. Although this practice is uncommon, 46% of general practitioners in the national sample had had a patient under their care who died by voluntary stopping of eating and drinking (n=708, response rate 72%). **Chapter 8** describes 99 patients who hastened their death in this way, as described by their general practitioners. The patients were mostly above 80 years old (70%), had a severe disease (76%; 27% with cancer), a short life expectancy (74% less than a year) and were dependent on others for everyday care (77%). Few had requested their physician for euthanasia or physician-assisted suicide (19%). It seems that most patients who choose to hasten death by voluntary stopping of eating and drinking deliberately choose this method over euthanasia or physician-assisted suicide. They were generally younger than patients who request euthanasia or physician-assisted suicide and had cancer less often.

In most cases, the general practitioner became involved in the care for the patient who stopped eating and drinking (62%), sometimes to administer palliative sedation (28%). A minority of general practitioners described symptoms in the last three days of life. Most thought that it went in accordance with the patient's wish. Other studies

too, described voluntary stopping of eating and drinking as a relatively comfortable way to hasten death.(14, 15) However, in many cases palliative care is needed to ensure the patient is comfortable.(16)

DISCUSSION

Because care in the last phase of life can both positively and negatively influence quality of life and death, it is very important that this care is appropriate. Appropriate care in the last phase of life is both individualized and holistic, in line with the diverse needs and preferences of patients. Appropriate care can concern treatment decisions as well as aspects related to supportive care, location, autonomy and communication. For physicians, it can be hard to timely recognize inappropriate care. For some patients, hastening death seems appropriate and they ask their physician to aid them. This can be a difficult request for their physician.

In the studies described in this thesis, three different perspectives on appropriate care in the last phase of life emerged. The perspective of patients and their relatives and the physicians' perspective are influenced by the way disease and death are looked upon in society. The prevailing view is that disease needs to be treated and hopefully cured. If you decide against treatment, you give up. Moreover, having control over your life is highly valued in modern society, as well as being free from suffering. The end of life is often accompanied by a loss of independence and control, and by suffering. Sometimes euthanasia is seen as an acceptable way to regain a sense of control and to take away suffering.

Patients and relatives describe the need to relieve physical suffering as well as a need to relieve suffering of a psychological, social or existential nature. Many people have fears and worries about their end of life, such as worries about losing autonomy, physical suffering and fear of death. These fears and worries can influence decision-making.

Physicians can be confronted with difficult dilemmas when providing care to a patient in the last phase of life. These dilemmas are often related to four key principles in medical ethics, namely beneficence, non-maleficence, autonomy and justice or fairness. Beneficence is reflected in the aim to relieve suffering. When palliative care is not successful in taking away suffering, physicians may regard euthanasia as the only remaining option. In other cases, physicians show beneficence by offering

potentially life-prolonging treatment to patients in the last phase of life, although this treatment sometimes does more harm than good. Sometimes, a patient wants to undergo a burdensome treatment with little chance of success, and the physician needs to decide between respecting the patient's autonomy and abiding by the principle of non-maleficence. The patient's autonomy plays a large role in requests for euthanasia. However, the physician's autonomy also needs to be respected. Because performing euthanasia poses a heavy emotional burden on physicians, they need to feel free to refuse a patient's request. If a physician declines a request, this may feel unfair. Especially patients who suffer psychologically instead of physically have limited access to euthanasia.

RECOMMENDATIONS

On the basis of this thesis, some recommendations can be made. Firstly, physicians can improve appropriateness of care by having a broad perspective. This includes recognizing the diverse care needs of patients, and realizing that treatment has both physical and psychosocial consequences. Shared decision-making is preferable in most situations, which includes openly discussing treatment options and possible consequences of these options.

Physicians are free to refuse requests for euthanasia. However, many physicians feel pressure to grant a request. This is unacceptable, because it interferes with the physician's decision-making and can lead to crossing of personal boundaries. Patients sometimes decide to hasten death by voluntary stopping of eating and drinking. In this case, physician involvement is preferable to make sure the patient is comfortable.

Finally, some general advice can be given. All of our lives will end. For most of us, death will be preceded by a period of declining health, and we will be in need of care. Therefore, it seems good to realize this in time, to think about our preferences at the end of life, and discuss these with our relatives and physician. This preparation can improve appropriateness of care in the last phase of our lives, and thereby improve our quality of life and death. At the same time, it is good to realize that we cannot turn to medicine to solve all problems that arise in the last phase of life. There is a role for physicians, patient organizations, medical organizations, policy makers and researchers in finding ways to provide people with realistic information and to motivate and support people in advance care planning.

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