CHAPTER 1

General introduction
GENERAL INTRODUCTION

This thesis reports on research into the way people with early-stage Alzheimer’s disease experience their disease and their perspectives on future care and treatment. It also addresses how advance directives for euthanasia (ADEs) affect patient care in Dutch nursing homes from the perspective of elderly care physicians (ECPs) and relatives of patients with dementia.

This introductory chapter outlines the background of the study, followed by a description of the aims and the definition of the research boundaries. Subsequently the research questions, the methods used and an outline of the thesis are presented.

BACKGROUND

With the worldwide process of ageing, the number of people with Alzheimer’s disease and related dementias is increasing and this increase is expected to continue in the future. According to a recent estimate there are some 35.6 million people who are living with dementia worldwide in 2010 and this number is estimated to almost double every 20 years to 65.7 million in 2030 and 115.4 million in 2050 [Alzheimer’s Disease International, 2009]. In the Netherlands the number of people with dementia, which added up to approximately 175,000 people in 2001, is expected to increase to 412,000 in 2050 [Gezondheidsraad, 2002]. The most common form of dementia is Alzheimer’s disease (AD): approximately 70% of all new cases in the Netherlands are diagnosed with AD, 15% involves vascular dementia, and 15% are other types of dementia (e.g. Lewy Body dementia, frontotemporal dementia, Parkinson dementia) [de Lange, 2007]. Although the large majority of people with dementia live and are cared for in the community, in the advanced stages of the disease many people are admitted into a nursing home or care home and they eventually die there. In the Netherlands this applies to approximately 90% of all people with dementia aged 65 years or older [Houtekier et al., 2010]. Dementia is characterized by a gradual loss of mental and physical capacities and is associated with increasing dependence on others and a progressive loss of autonomy, selfhood and personality [Cohen and Eisdorfer, 1986; Davis, 2004]. In view of the progressive nature of the disease and the ageing world population, many elderly people are afraid they might develop Alzheimer’s disease (AD) or a similar dementing illness [Laforce and McLean, 2005], all the more since no cure is available (yet).

Although there are increasing possibilities for early diagnosis in dementia, the therapeutic possibilities cannot keep pace and remain limited. As a result a growing number of elderly ‘at risk’ are looking for means to avoid a life with dementia. One of the possibilities to influence a possible future with dementia is to prepare a written advance directive. Such directives are composed by often healthy individuals, well before decisional incapacity becomes an issue, and are intended to give directions for future care and how medical decisions are to be made in the event of incompetence.

Different types of written advance directives can be distinguished. A first distinction can be made between proxy directives and treatment directives. Proxy directives are directives in
which another person is empowered to make decisions on behalf of the author. In treatment directives the author him- or herself specifies the types of medical treatment and specific conditions under which they are desired or refused. Treatment directives can be either negative (non-treatment directives in which specified medical interventions are refused) or positive (specified interventions are requested). In the Netherlands a special type of positive directives is recognized, namely the ‘advance directive for euthanasia’ (ADE) in which the authors request the responsible doctor to perform euthanasia in specified situations of incompetence. Often standard documents are used which involve the combination of an ADE, a proxy directive, and a non-treatment directive. The non-treatment directive automatically replaces the ADE, should the latter not be complied with. Non-treatment directives have a strong legal status in the Netherlands. Under the Medical Treatment Contracts Act [Wet op de Geneeskundige Behandelingsovereenkomst (WGBO), 1995] they are legally binding for physicians, whereas positive advance directives are not. In case of a positive directive physicians will make their decisions based on their professional assessment of the situation, but they are not obliged to follow such a directive. Advance directives for euthanasia (ADEs) have been given a special legal status in the Netherlands with the introduction of the euthanasia law in 2002 [Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002]. The euthanasia law was not accepted without dispute and was preceded by many years of discussion and an intensive public debate. Unlike many other end-of-life decisions, euthanasia was not considered ‘normal medical practice’ in the Netherlands; rather it was characterized as ‘a form of medical treatment of an exceptional nature’ [KNMG, 2003]. Initially, euthanasia practice was limited primarily to people with severe physical conditions and a short life expectancy, but from the mid 1980s onward attention was generally drawn towards the possibilities of life-terminating actions in case of incompetent patients, including patients with dementia. The Royal Dutch Medical Society (KNMG) set up a committee [Commissie Aanvaardbaarheid Levensbeëindigend handelen (CAL)] which examined and published several reports on the admissibility of life-terminating actions in case of incompetent patients, including patients with dementia [KNMG, 2003]. In addition, the Dutch Association of Elderly Care Physicians (then NVVA, currently named VERENSO) formulated a position on euthanasia and assisted suicide in cases of incompetent patients with an advance directive for euthanasia [NVVA, 1997]. From 1994 the then Minister of Public Health, Els Borst, intervened in the debate in a private capacity, favouring legislation that would allow euthanasia in cases of dementia based on a written advance directive. With the enactment of the euthanasia law this possibility was realized in article 2, paragraph 2, which holds that an oral request for euthanasia may be replaced by a written advance directive (first requirement of due care – see table1) as long as the remaining requirements of due care (2-6 – see table1) are met in a ‘corresponding way’. In addition, the physician is obliged to report the cause of death to the municipal coroner and report the case to the regional review committee; the latter will determine whether the physician has practiced due care. In case the review committee is of the opinion that the physician has not acted in accordance with the requirements of due care the case will be reported to the Board of Prosecutors-General (Public Prosecution Service) and the Health Care Inspectorate.
Table 1 Requirements of ‘due care’ in the Dutch Euthanasia Act

| 1. The physician is convinced that the patient has made a voluntary and well-considered request |
| 2. The physician is convinced that the patient’s suffering is unbearable, and that there is no prospect of improvement |
| 3. The physician has informed the patient about his or her situation and prospects |
| 4. The physician has come to the conclusion, together with the patient, that there is no reasonable alternative in light of the patient’s situation |
| 5. The physician has consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above, and |
| 6. The physician has terminated the patient’s life or provided assistance with suicide with due medical care and attention. |

In principle this euthanasia law of 2002 opened the door for incompetent people, like people with dementia, to have their ADE complied with. However, the use of advance directives, especially ADEs, by patients with dementia remains a much-debated topic and raises a number of key problems which formed the background of our study. They include:

1. The experienced suffering of people with dementia and the applicability of the requirement of unbearable suffering in the euthanasia law;
2. The dilemma of discrepancies between earlier wishes and current interests of the patient with dementia;
3. The application of the requirements of due care in case of advance directives for euthanasia of patients with advanced dementia;
4. The changing opinion on the role of advance directives as instruments for advance care planning.

### 1. Suffering

It seems obvious that people with advanced dementia may experience consequences from dementia such as feelings of sorrow, anxiety or pain. Just like other, mentally healthy elderly people they may also develop additional physical disabilities and illnesses. However, whether this constitutes ‘unbearable suffering’, as formulated in the second requirement of due care in the euthanasia act, is questionable, as this requires the ability not only to experience but also to evaluate and judge one’s situation. An important argument against the applicability of the criterion of ‘unbearable suffering’ is that dementia involves an increasing loss of ‘awareness’. As a result a person in the advanced stages of dementia is no longer able to relate his situation to the disease and to link this to its irreversibility [Gezondheidsraad, 2002]. Based on this argument the Dutch Association of Elderly Care Physicians [NVVA, 1997], the Royal Dutch Medical Association [KNMG, 2003] and the Health Council of the Netherlands [Gezondheidsraad, 2002] conclude that dementia as such cannot be a valid reason for life-terminating actions. Euthanasia or assisted suicide is considered justified only in exceptional cases in which the suffering is caused by other, additional illnesses or untreatable complications of the dementia [KNMG, 1993].

These arguments caused a shift in the discussion on euthanasia in dementia to the earlier phases of the disease at the start of the 21st century. This shift is based on the assumption that in the early stages of dementia people are (still) aware of their situation and they are
(still) competent to express their wishes for euthanasia. It is suggested that people in the early stages of dementia can suffer as a result of the prospect of future decline [Gezondheidsraad, 2002]. Attention is regularly drawn to this kind of suffering by the media, for example following the physician-assisted death of the Belgian author Hugo Claus in 2008. Based on this presupposition, and taking into account the increased possibilities of early diagnosis of dementia, one would expect an increase of euthanasia among people in the early stages of dementia after the introduction of the Dutch euthanasia law in 2002. However, according to the available data the number of reported cases of euthanasia because of dementia is limited. The most recent report of the regional review committees [2009] reports 12 cases of requested euthanasia or assisted suicide of people in the early stages of dementia. Although there is a slight increase in the number of requests for euthanasia by people with dementia since the establishment of the review committees in 2003, it is very low compared to the total number of patients with dementia. There are several possible explanations for these relatively low numbers. The first is found in the reluctance amongst physicians to perform euthanasia, although this applies mostly to cases of people with advanced dementia who have an advance euthanasia directive [Hertogh et al., 2007; Hertogh, 2009; van Delden, 2004]. Secondly, the knowledge among physicians about the legal possibilities of euthanasia in cases of dementia is found to be limited [Onwuteaka et al., 2007], despite education and media attention. Yet another reason for the limited number of cases of euthanasia in dementia that cannot be ruled out is that requests by people with dementia are not picked up or are misunderstood by physicians or – even worse – interpreted or treated as requests that will fade away with time as the disease progresses. A fourth reason might be that the number of requests for euthanasia is perhaps lower than the prevalence of dementia and the fear of the disease that exists in society would suggest. Apart from the few cases of euthanasia in dementia that received ample media coverage, little attention has been given to the perspective of patients with dementia themselves in this matter. The debate on (unbearable) suffering in dementia mainly involves healthy elderly people who are fearful of developing dementia but do not (yet) have it. However, the way in which people with dementia themselves experience their disease and their situation has been largely ignored in the Netherlands. Attention for the patient perspective is growing – especially in studies abroad [i.e. Clare, 2002; Clare, 2003; Gilmour and Huntington 2005; Macquarrie, 2005; see chapter 2] – but these studies focus mainly on awareness, insight and coping in dementia patients and much less on the anticipated suffering from the patient’s perspective and their future prospects [Steeman et al., 2007].

2. Earlier wishes and current interests
As long as a patient is considered competent his current wishes and preferences are central in the choices regarding medical care and treatment. Only in the event of decisional incapacity will an advance directive replace a person’s wishes. A diagnosis of dementia is a complicating factor when it comes to compliance with advance directives. First of all, patients with dementia differ from incompetent patients, e.g. comatose patients, in the sense that dementia involves an often slow but progressive process that results in gradually diminishing competence over the course of the disease. Secondly, even though people with
dementia may (rightly) be labelled as incompetent, they remain alert, involved in their situation and able to interact with their environment. Thus, they can still have subjective experiences and they continue to have wishes and preferences. Consequently, a situation may arise in which the current wishes of the person with dementia (expressed in words or behaviour) conflict with their former preferences as formulated in the advance directive. This results in the dilemma of how to respect the wishes or interests of the person with dementia and still do justice to the wishes expressed in the advance directive. This dilemma has been discussed extensively, both in the international ethical literature [e.g. Dresser, 1995; Dworkin, 1986; Jaworska, 1999; Parfit, 1984] and in more recent Dutch literature on advance directives and euthanasia [e.g. Widdershoven and Berghmans, 2001; van Delden, 2004; Hertogh et al., 2007; Schermer, 2009]. However, it remains unclear how these issues are handled in actual care practice.

3. Requirements of due care in case of an advance directive for euthanasia

The requirements of due care which must be met by physicians under the euthanasia law were developed through jurisprudence, prosecutorial policy and opinions of the medical profession in the years prior to the introduction of the law. This implies they are developed in a practice of euthanasia and assisted suicide of competent patients only. Article 2, paragraph 2 of the euthanasia law, which is of highly relevant to physician assisted death in the case of incompetent patients such as patients with dementia, was not based on prior jurisprudence. This article holds that an oral request can be replaced by an advance directive as long as the remaining requirements of due care are met in a ‘corresponding way’. The term ‘in a corresponding way’ was added in an amendment to the law to clarify that the requirements should be met as much as possible given the situation at hand [Tweede Kamer, 2000-2001, 26 691, nr. 35]. However, it is not clearly documented how this is to be interpreted in practice. If these requirements are taken literally, it is obviously impossible to meet all of them in the case of an incompetent patient who is no longer able to express his current wishes [van Delden, 2004; Hertogh, 2009]. For example, if meaningful communication is not possible the physicians simply will not be able to ‘come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient’s situation’ (4th requirement; italics added). This presumes dialogue and communication between patient and physician and emphasizes the importance of shared decision making, which was also underlined in the explanatory memorandum to article 2. Nowhere in the explanatory memorandum does it become clear whether meeting the requirements of due care in ‘a corresponding’ way implies a different interpretation of the requirements than for euthanasia in the case of a competent patient. After questions about this matter were asked in the Dutch parliament, the written reply of the then responsible ministers of Justice and of Health, Welfare and Sports said that, in the case of an incompetent patient with an advance directive for euthanasia, the physician indeed cannot build on consultation with the patient as such communication is no longer possible. In cases like this his own assessment of the situation, consultation with other health care professionals who treat or have treated the patient, and consultation with the patient’s family and other proxies must convince the elderly care physician (ECP) that there is, indeed,
unbearable suffering and no reasonable alternative [Tweede Kamer, 2000-2001, 26 691, nr. 24]. It is unclear whether this suggestion with regard to meeting the requirements of due care in a ‘corresponding way’ is adopted in current practice, and whether this is a feasible procedure for physicians.

4. Changing opinion on advance directives
The moral power of advance directives is derived from the principle of respect for the patient’s (precedent) autonomy. They were developed as a way of allowing people to state their preferences for future care and how medical decisions are to be made should they become incompetent. However, the concept of advance directives has been increasingly criticized over the years, and there is growing consensus about its limitations [Hertogh, 2011; Gillick, 2010; Sudore and Fried, 2010; Messinger-Rapport et al., 2009; Perkins, 2007; Kirschner, 2005; Seymour, 2004]. Points of criticism include the fact that patient’s preferences do not appear to be stable over time, and that family members of patient have difficulty assessing the patient’s wishes adequately. These kinds of limitations generated an increased emphasis on the importance of the patient’s wishes being discussed by patient, physician and the patient’s family on a regular and continuous basis. This process is referred to as advance care planning (ACP), which clearly involves more than the mere signing of an advance directive. In the case of patients with dementia starting early with ACP is essential because of the diminishing possibilities for their active involvement and meaningful communication as a result of the cognitive deterioration. In this sense they differ from people with other progressive diseases, like cancer. The time for ACP to take place is limited and should be used efficiently. To further develop the concept of ACP in dementia care it is essential to gain insight into the perspective of patients with dementia, their views with regard to future care and treatment, and their receptiveness to ACP.

AIMS

Summarizing the background of this study: in the current debate on life-terminating actions in case of dementia the perspective of the patients with dementia themselves has been mostly absent, especially with regard to themes like experienced suffering and their thoughts on the future, including future care and treatment. In addition there are many questions about how advance directives for euthanasia affect patient care in Dutch nursing homes and about the experiences of physicians and relatives of patients with dementia. To clarify these points the research, as reported on in this thesis, aimed to:

I. Describe how people with early-stage Alzheimer’s experience their disease, and their perspectives on future care and treatment.

II. Obtain insight into the way advance directives for euthanasia (ADEs) affect patient care in Dutch nursing homes, and the experiences of elderly care physicians (ECPs) and relatives of patients with dementia who had an advance directive for euthanasia.

III. Specify the implications for clinical practice and make recommendations for health care policy and future research based on the results of aims I and II.
DEFINITIONS OF RESEARCH BOUNDARIES

Although dementia comes in many forms, this research, with the exception of the review in chapter 1, focuses on Alzheimer’s disease in an elderly population. First of all, Alzheimer’s disease is the most common form of dementia; it accounts for approximately 70% of all cases of dementia [Alzheimer’s Association (USA), 2011, Alzheimer Nederland, 2011]. A second reason is that the clinical manifestation of Alzheimer’s disease, especially in elderly people, is the paradigm of dementia for many people. It is this ‘picture’ of dementia that is feared by many elderly people and that people frequently have in mind when drafting an advance directive. A third reason is the fact that little casuistry is available about euthanasia in especially this most prevalent type of dementia [Hertogh et al., 2007]. The decision to research advance directives (including advance directives for euthanasia) in a nursing home setting is based on the fact that most (elderly) people with dementia are admitted to a nursing home in the advanced stages of the disease and die there. A nursing home in the Netherlands is an institution that provides temporary or long-term multidisciplinary treatment, based on each patient’s personal needs and wishes, and on an integration of relevant cure and care for mainly elderly patients who need plural, more complex continuing care and monitoring [Schols et al., 2004]. There are approximately 65,000 nursing home beds in the Netherlands in 345 nursing homes. More than half (58%) of these beds are organized in dementia special care units. The other 42% are meant for somatic patients and geriatric rehabilitation [Actiz, 2006]. Elderly care physicians (ECPs) have their principal site of practice in these nursing homes. Their specialty, formerly called nursing home medicine, involves a 3-year specialist training programme [Koopmans et al., 2010]. One full-time ECP is responsible for approximately 100 nursing home patients [Hoek et al., 2003].

RESEARCH QUESTIONS AND OUTLINE OF THE THESIS

In order to reach the aims listed above, we used a combination of quantitative and qualitative research methods to answer the questions presented below. A qualitative exploratory survey was conducted in which 24 community-dwelling people with early-stage dementia of the Alzheimer’s type (AD) were interviewed about their experiences with their illness and their perspectives on future care and treatment (Part I, questions 1 & 2). To obtain insight into the experiences of elderly care physicians (ECPs) and relatives of patients with dementia with ADEs, we conducted a survey among elderly care physicians, followed by additional interviews with physicians and relatives of deceased patients with dementia who had an advance directive for euthanasia (Part II, questions 3, 4 & 5). The study was approved by the Medical Ethics Committee of the VU University Medical Center.
**Part I  Dementia: the patient’s perspective**

1. **How do people with dementia experience and value their situation?**
   How do these experiences relate to the suffering that is associated with dementia and feared by the general public?
   Chapter 2 describes the results of a literature review investigating what is known about living through dementia from the patient’s perspective. The international clinical and scientific literature was explored to provide this overview.
   Chapter 3 deals with the issue of ‘suffering’ in dementia, and is based on the results of a qualitative exploratory survey aimed at investigating the personal experiences of people with early-stage Alzheimer’s disease with regard to their illness and the extent to which they experience their situation as ‘suffering’. ‘Unbearable’ suffering is one of the requirements of due care that must be met according to the Dutch euthanasia law. In light of this direct link to the euthanasia legislation and euthanasia debate in the Netherlands, this article was originally published in Dutch and it was translated for this thesis.

2. **What are the thoughts of people with early-stage Alzheimer’s disease with regard to future care and treatment?**
   What does this imply for advance care planning (ACP)?
   Chapter 4 describes the results of a qualitative survey in which semi-structured interviews were conducted with individuals diagnosed with early-stage Alzheimer’s. The interviews covered their thoughts on the future and advance care planning.

**Part II  Advance directives in dementia care**

3. **What are the relevant problems addressed in the ethical debate on advance directives in cases of dementia?**
   What is known from empirical research on the validity and effectiveness of advance directives in the clinical practice of dementia care?
   How do the problems of the ethical debate relate to what is known from empirical research?
   In chapter 5 the ethical debate on advance directives in cases of dementia is summarized. This chapter also discusses how the issues of this debate relate to what is known from empirical research concerning the practice of advance directives in dementia care.

4. **What is the current practice regarding compliance with advance directives for euthanasia (ADEs) in Dutch nursing homes?**
   Do law-based opportunities lead to more euthanasia?
   Chapter 6 covers part of the results of the survey completed by elderly care physicians (ECPs) who work in Dutch nursing homes. Insight is provided into the current practice
regarding compliance with ADEs in light of the legal possibility offered by the new euthanasia law to perform euthanasia in cases of patients with dementia.

5. What are the experiences of elderly care physicians (ECPs) and relatives of patients with dementia in the decision-making process around compliance with the advance directive for euthanasia (ADE) in nursing homes?

Chapter 7 discusses the way ADEs of people with dementia are dealt with in nursing home practice, but the main focus is on the personal experiences of ECPs in practice. The results are based on the survey completed by ECPs, in which casuistry was provided. Furthermore, the experiences of a selection of ECPs and relatives, are described which were explored through additional interviews.

The thesis is concluded with chapter 8, which provides a summary of the conclusions and a general discussion on the contribution of this study to the knowledge about, and insight into, the use of advance (euthanasia) directives in dementia care. Furthermore, the implications of the results with regard to the role of advance directives in advance care planning in dementia are elaborated.
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