CHAPTER 8

General discussion
GENERAL DISCUSSION

The aims of this study were the following: I) to describe the experiences of people with early-stage Alzheimer’s disease with their disease and their perspectives on future care and treatment; II) to 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) to specify implications for clinical practice and make recommendations for health care policy and future research based on the results of parts I and II. In this final chapter an overview of the main research findings with regard to part I and part II is presented and discussed, followed by the discussion of some methodological issues. Subsequently, a few key issues on the euthanasia law, advance care planning and advance directives are reflected upon. In the final part of the discussion the third aim of the study is addressed by focussing on the implications for clinical practice and recommendations for health care policy and future research.

MAIN FINDINGS

The main findings of the study are presented and discussed following the two parts of this thesis ‘Dementia: the patient’s perspective’ and ‘Advance directives in dementia’ and the research questions as outlined in the general introduction.

Part I Dementia: the patient’s perspective

Research question 1 (Chapters 2 and 3)

How do people with dementia experience and value their situation?

What is the meaning of these experiences in relation to the suffering that is associated with dementia and feared by the general public?

Chapter 2 reviews the international literature on the experiences of living through dementia from the patient’s perspective [de Boer et al, 2007]. The literature retrieved shows that people with dementia are often aware of their situation and also very capable of sharing their experiences. At the same time this literature study yields a more nuanced picture than the state of dreadful suffering that the negative prejudices of the general public believe dementia must be. For example, in a study on quality of life as experienced by people with dementia, 67% of the participants with mild to moderate dementia claimed to enjoy a good to very good quality of life [Cahill et al. 2004]. Nonetheless, the impact of dementia and the experiences of loss resulting in multiple negative emotions should also be underscored. In this context memory loss is mentioned, but also problems with communication and orientation, loss of control, autonomy, independence and self-esteem, and multiple losses in skills and abilities.
Chapter 3 of this thesis presents the results of a qualitative exploratory survey, which investigated the experiences of 24 community-dwelling people with early-stage dementia of the Alzheimer’s type (AD) with regard to their illness and the extent to which they experience their situation as ‘suffering’. The focus was on AD as this is the most common and paradigmatic type of dementia. The participants in these interviews were very capable of discussing their experiences, as long as they were given enough time and space. As the interview progressed participants gained trust, and initial denial often changed into more openness about their personal problems and experiences with dementia. This supports the findings of other research that states that the (un)awareness of people with dementia of their situation is not only dependent on neurobiological factors (cognitive deterioration) but also on psychological (i.e. coping strategies, personality) and social factors (i.e. social network, interaction with others) [Clare 2002, Clare 2004, Steeman et al, 2007]. The interviewees in this study indicated they did not experience their situation ‘as a whole’ as one of dreadful suffering.

Both the studies identified in the literature review and the results of the qualitative interviews with people with early-stage AD indicate that despite the great impact of dementia on the lives of those affected, people with dementia do not undergo their disease passively but try to deal with its effects and challenges by using different coping strategies. Dementia (especially Alzheimer’s disease) allows people to adapt and adjust to their changing situation, as it is not a disease that appears overnight, but often involves a process of insidious onset and gradual progression. As a result of such adaptive processes actual experiences of the disease can deviate from the ideas of the general public and people’s own anticipatory beliefs about life with dementia. Such differences should be carefully considered in discussions on advance directives, because there is a reasonable chance that people with dementia ultimately will not act in accordance with their earlier values and anticipatory beliefs regarding a life with dementia. With this in mind, it becomes essential to communicate with people with dementia about future care and treatment on a continuous basis, especially if the aim is to adjust advance care planning (ACP) to their actual wishes and needs.

Research question 2 (Chapter 4)

What are the thoughts of people with early-stage Alzheimer’s disease (AD) with regard to future care and treatment?

What does this imply for advance care planning (ACP)?

The interviews with people with early-stage AD also focussed on their thoughts about the future. This is important because being able to plan for the future and actually planning future care and treatment are often mentioned as relevant motives for early diagnosis of dementia [e.g. Alzheimer Europe 2011]. The interviews showed how, for people with dementia, thinking about the future is an ongoing process of balancing hopes and fears that is influenced by several internal (e.g. feelings of being a burden to others, attribution of the experience) and external factors (e.g. information and treatment received). This balancing seemed to result mainly in ‘living life one day at a time’ and relying on others, rather than initiating actions with regard to looking ahead and planning for the future. It was argued that
this observed lack of openness towards thinking about the future can be described as a self-protective mechanism, used by people to keep the threat they consider dementia to be outside their consciousness [Dröes 2007, Harman et al. 2006, McQuarrie 2005, van Dijkhuizen 2006]. However, trust was established during the course of the interviews, which resulted in more openness of participants. By bringing up the subject of ACP in this setting, participants were stimulated to express their thoughts on the future and ACP. The knowledge about advance directives among participants was found to be limited and those who had an advance directive showed no awareness of it during the interview or they postponed the applicability of its content. These findings show that thinking about the future and engagement in ACP of people with early-stage AD on their own initiative is limited. In this respect they do not differ from people with other life-threatening diseases such as cancer. However, they do differ in the sense that as the disease progresses the possibilities for their active involvement in ACP will diminish as a result of cognitive deterioration. Waiting (too) long may lead to a situation in which planning ahead with the person with dementia him/herself is no longer possible. Therefore, the initiative for planning care in advance should come from others than the people with dementia themselves. However, taking into account the fact that people in the early stages of AD are primarily trying to cope with their condition, it is essential that interventions aimed at stimulating ACP are in tune with the needs and wishes of the patient. Whether it is ethically justified, under all circumstances, to stimulate and steer people towards ACP remains a delicate question, which will be discussed later. Also, the role of advance directives in the context of ACP may need to be reconsidered in view of the results that show that the thoughts and wishes of people with early-stage AD may also change over the course of the disease. This leads to the ethical dilemma of how to balance the patient’s current interests against his earlier directive.

**Part II  Advance directives in dementia**

Research question 3 (Chapter 5)

*What are the relevant problems addressed in the ethical debate on advance directives in cases of dementia?*

*How do these problems relate to what is known from empirical research on the validity and effectiveness of advance directives in the clinical practice of dementia care?*

Chapter 5 summarizes the essence of the ethical debate on advance directives in cases of dementia. This debate was shown to focus on the dilemma of how to respect the wishes and interests of an incompetent person with dementia and yet do justice to the wishes expressed in his/her advance directive. In summary, the points of view within this debate vary between two extremes. On one end of the spectrum the validity of advance directives is disputed because the person with dementia is viewed as another person. [Parfit, 1984]. The reasoning is that if an advance directive can never be applied to a person who did not prepare it, and if the person with dementia is viewed as a different person from the one who once prepared the advance directive, then the directive can never be applicable to the
person with dementia. Those on the other end of the spectrum hold that the preferences laid down in an advance directive represent the individual’s appraisal of where his/her critical interests lie, and this should prevail over the interests of the incompetent person with dementia, thereby arguing for the primacy of ‘precedent autonomy’ [Dworkin, 1986]. In the more nuanced approaches overriding an advance directive can be justified in cases of a good quality of life of the person with dementia based on experiential interests [Dresser, 1995] or when the person is still able to express his/her current wishes based upon their ‘capacity to value’ [Jaworska, 1999].

While the ethical debate focuses on how to respond to the current wishes and/or interests of a patient with dementia if these differ from those formulated in an advance directive, the focus in actual practice seems to be different. The very limited empirical data (9 studies) about the Dutch situation, gathered through experts and a PubMed search, show that the main factors in medical decision making in such cases are not found in the patient’s perspective, but in the medical judgement of the physician and the influence of relatives of the patient. Insight into the actual experiences of people with dementia themselves regarding advance directives is lacking altogether in empirical research. Empirical research did show that, although physicians and relatives seem to have a positive attitude towards the validity of advance directives, ADEs are seldom complied with and appear to have only marginal influence on the decision-making process.

Research question 4 (Chapter 6)

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 aimed at obtaining insight into the current practice regarding ADEs in cases of incompetent patients with dementia in Dutch nursing homes against the background of the introduction of the euthanasia law. This law formally allows physician-assisted death in incompetent patients, provided that an advance directive is present [De Boer et al. 2010]. The results presented here are based on a questionnaire that was completed by 434 elderly care physicians (ECPs) in the Netherlands, of whom 90% indicated having at some point treated a patient with dementia who had an advance directive. Half of the participating ECPs indicated they had currently had one or more (1 or 2 on average) of such patients. According to the ECPs a request for euthanasia is included in the directive in approximately 50% of all cases. Most physicians worked in a nursing home that has a policy on euthanasia, but less than half of these ECPs indicated this policy included information on euthanasia in the specific case of dementia. When information on euthanasia in dementia was included, it most commonly (63%) stated that ADEs of patients with dementia are not complied with, although they are taken into account in the form of a restricted policy of treatment (limitations on life-sustaining treatments). In 16% of the nursing homes with a policy on euthanasia in dementia the ECP indicated the policy held that ADEs in cases of patients with dementia are never complied with. Most ECPs (88%) agree with the policy of the nursing home. In the majority of cases ECPs indicated they inform the family, and wherever possible also the patient him/herself, of the policy of the nursing home. Also, 73% indicated that it is
standard practice to inquire about the presence of advance directives at admission of the patient. According to the majority of ECPs (90%) advance directives are discussed during admission with the patient (34%), his family (90%), the nursing staff (63%) or fellow ECPs (29%). Despite the legal recognition of ADEs of incompetent patients with dementia, the present study revealed no cases of performed euthanasia based on an ADE. Although 5 cases of euthanasia/assisted suicide of patients with dementia (other forms than Alzheimer’s disease) were reported in the study, these involved competent patients who were capable of discussing their situation and expressing their wishes. Physicians therefore did not have to rely on an ADE. This led to the conclusion that the possibilities offered by the euthanasia law have not resulted in an increase in euthanasia among this group of patients in nursing homes.

The research described here revealed several explanations for the reticent attitudes of ECPs in complying with ADEs of incompetent patients with dementia. Of all ECPs taking part in the study, 73% disagreed to a certain extent with the statement that the presence of dementia can be a valid reason for life-terminating actions, provided that a written directive for euthanasia is present. This opinion might be explained by the reported difficulties in determining the ‘unbearableness’ of the suffering and choosing the appropriate moment to carry out the ADE. An additional explanation may be found in the policy statements of the nursing homes. In the majority of cases this policy holds that ADEs of patients with dementia are not complied with, but that these directives are taken into account, mostly by applying a limited treatment policy. Comparison of previous research from 2002 [Rurup et al. 2005] with the data of the present study shows that ECPs seem to have adopted a more tolerant attitude towards compliance with ADEs of patients with dementia in comparison to the situation before the euthanasia law: more ECPs think it conceivable that they might comply with an ADE of a patient with dementia in the future. However, in practice this latent tolerance has not resulted in more compliance with ADEs of patients with dementia. In comparison with data gathered before the introduction of the euthanasia law [Rurup 2005] this present study shows that ADEs are still rarely complied with and never in the case of patients with advanced dementia. This finding is also consistent with the reports of the review committees to which cases of euthanasia must be reported [Regional Review Committees Euthanasia 2003-2010]. None of these reports describes a case of euthanasia based on an ADE of a patient with dementia who has become fully incompetent. The main reason why these tolerant attitudes are not reflected in actual practice seems to be that the majority of ECPs specifically emphasized that a patient with dementia has to be competent in order for them to consider complying with an ADE, in which case the ADE is mainly supportive of the actual wish. The underlying arguments for the overall reticent behaviour of ECPs towards compliance with ADEs of incompetent patients with dementia may result from the more fundamental problem of the lack of meaningful patient-physician communication. Such communication is considered essential in cases of requests for euthanasia and these conversations cannot be captured in or replaced by an ADE. The paradoxical nature of this situation raises questions about the feasibility of ADEs in advanced dementia and of enforcing the law on this point: ADEs were developed for situations in which the patient is no longer able to actively communicate a request for euthanasia, but exactly this lack of
communication seems to be the crucial factor in the non-compliance with ADEs. The relevance of this kind of meaningful patient-physician communication in case of requests for euthanasia will be addressed in more depth later on in the discussion.

Research question 5 (Chapter 7)

*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?*

The decision-making process around ADEs of patients with dementia was presented in chapter 7 by highlighting the experiences of both ECPs and relatives of patients with dementia who had an ADE. Data on the experiences of ECPs are derived from the general part of the questionnaire that was completed by 434 ECPs, the 110 case-histories provided by the ECPs in the questionnaires, and 11 additional interviews with ECPs. The experiences of relatives were gathered through 8 face-to-face interviews with relatives of deceased patients with dementia.

Although 110 ECPs described a case in which they had treated a patient with dementia and an ADE, none of them reported compliance with the ADE. In many cases (64%) ECPs were of the opinion that the ADE applied to the patient’s current medical condition. The actual wish of the patient was clear in only a limited number of cases (22%); in 6 cases the ECP indicated the patient would have wanted euthanasia. In the interviews ECPs emphasized that without the patient confirming his/her earlier wishes for euthanasia as put down in their advance directive, compliance with the ADE was inconceivable for them. The absence of meaningful communication as a reason for not complying with an ADE was not pre-structured as an optional answer in the questionnaire, as such directives are essentially intended for situations in which the patient is no longer able to actively communicate his wishes. Other reasons for not complying with the ADE, as indicated in the questionnaire, included difficulties in determining the ‘unbearableness’ of the suffering of patients with dementia, the limitations of the nursing home policy and the personal opinion of the ECP.

According to ECPs relatives of patients with dementia were also reluctant with regard to compliance with the ADE; in only 16 of the 110 described cases did relatives want euthanasia to be performed. In the majority of cases (63%) relatives opted for limitations on life-sustaining treatments instead of compliance with the ADE. In the interviews, relatives themselves indicated that ADEs were drafted well before the first signs of dementia emerged. Although there were relatives who indicated that completing a directive was a relief for the patient, they also reported that the document was not much discussed afterwards in those cases. It was found that relatives were not always ready for euthanasia; instead, decisions were made to forgo life-prolonging treatment. Both relatives and ECPs felt that the presence of the ADE supported such decisions.
METHODOLOGICAL CONSIDERATIONS

Search strategies literature review
To search the international literature for articles about living through dementia from the patient’s perspective a broad spectrum of terms was used in the search strategy. However, 22 of the 50 papers included in the study came from other sources. Although most of these papers that were found elsewhere were registered in the searched databases, only a comprehensive list of search terms would have retrieved them, and this would also have resulted in many non-relevant papers. Therefore, it is important to note that one should not rely solely on predefined, protocol-driven search strategies, but also use secondary search strategies, like citation tracking, which is common practice in literature studies [Greenhalgh 2005]. Using these strategies and consequently looking beyond the databases is likely to produce most of the relevant literature.

A limitation of the literature search was that it did not specify different types of dementia, nor was it limited to any particular type. As a result this overview of living through dementia does not allow for specifying possible differences in personal experiences based on types of dementia. In addition, the results of the literature review cannot be generalized to all stages of dementia, as the personal experiences described all come from people who, despite their condition, are still able to communicate their feelings relatively well, which indicates they are not (yet) in the advanced stage of the disease. On the other hand, it should be noted that it is in the earlier stages that people are thought to be most involved in their own care and planning for the future [Werezak 2002]. For this reason it seems to be the most appropriate group to investigate, and this makes the results of this review very relevant.

Perspectives of the patient
The results presented in chapters 2 and 3 concern the perspectives of 24 elderly people with early-stage Alzheimer’s disease. A potential limitation is that most of these participants were recruited from memory clinics. This means that they - themselves, or together with their relatives - actively sought help for their condition and were informed of the diagnosis of early-stage Alzheimer’s disease. Although early diagnosis is increasing and also promoted by organizations such as Alzheimer Europe, not all people who experience the first symptoms of cognitive and memory deterioration are inclined to seek help [Werner 2003]. This may have caused the study population to be more aware of their situation than the population of elderly persons in the same stage of the disease who are not seeking help. Whether the population studied also represents this latter group therefore remains to be determined.

Four of the participants with dementia were interviewed shortly after diagnostic disclosure, which means they may have had insufficient time to accept the bad news and adjust to the new situation. They were re-interviewed after 6-18 months to detect any changes in views and action with regard to advance care planning. Although these additional interviews revealed no changes, more profound conclusions might have been possible if all participants had taken part in follow-up interviews. Unfortunately, the lack of time and a limited budget prevented us from conducting these interviews. Nonetheless, the interviews as conducted in this study provide adequate insight into the thoughts of people with early-stage Alzheimer’s
disease, and their focus on future care and treatment is what makes them most interesting. The implications and recommendations based on these results will also be relevant for people with early-stage Alzheimer’s disease who are less inclined to seek help.

**Perspectives of physicians and relatives**
The perspectives of elderly care physicians (ECPs) and relatives of patients with dementia and an ADE are described in chapter 7. In addition to the 110 case histories provided by ECPs, which are a fair representation of actual practice, it was possible to conduct a sufficient number of interviews with ECPs (11) to reach saturation of data. However, the response on the qualitative interviews with relatives (8) lagged behind. The sensitivity of the subject made ECPs hesitant to approach families and also resulted in relatives refusing to participate. Although these qualitative data should be interpreted with caution, they are thought to provide relevant insights into a variety of experiences and allow conclusions to be drawn.

**Response to questionnaire**
The questionnaire was distributed among all elderly care physicians (ECPs) in the Netherlands who are members of the Dutch Association for Elderly Care Physicians (VERENSO). However, the only available address file also contained an unknown number of approached ECPs who had no medical responsibility for patients with dementia and whose response was therefore not relevant for this study. Some ECPs indicated they had no responsibility for patients with dementia, but this information was not available for the remaining group of non-responders. The latter ECPs were also included in the calculation of the response, which could therefore be an underestimation of the actual response. A significant positive characteristic of the responders was that they all had considerable work experience, which gave them the advantage of having experienced the situation around ADEs in dementia both before and after the introduction of the euthanasia law.

Another limitation was that not all ECPs answered the questions on the number of patients with an advance (euthanasia) directive they (had) treated. This was perhaps due to the time lag between the moment of data collection and the time-period focussed upon. Difficulties remembering or retrieving exact numbers of patients with an advance (euthanasia) directive resulted in relatively small numbers of responders for those questions. However, in view of the sensitivity of the research subject, the overall response was fairly high and the conclusions of the present study are based upon reliable answers from an acceptable number of ECPs.

**Attitudes**
Part of the results presented in chapter 6 are based on questions about the attitudes of ECPs on ADEs in dementia care. This may have led to socially desirable answers, which possibly do not reflect their behaviour in actual practice. However, the research was also case oriented: ECPs were questioned about their behaviour in real cases. Furthermore, additional interviews were held with a selection of ECPs and family members, which made it possible to ‘look beyond’ attitudinal aspects. On the other hand caution is necessary when interpreting
the data, because insight into the behaviour of ECPs in actual practice was not obtained through observation but gathered indirectly through questionnaires completed by ECPs themselves.

KEY ISSUES

The euthanasia law in practice

Despite the legal status that written advance directives received with the introduction of the euthanasia law in the Netherlands in 2002, results of this study show that this law has not resulted in an increase of euthanasia among incompetent patients with dementia in Dutch nursing homes. As explained in the introduction of this thesis, the legal status of advance directives was realized in article 2, paragraph 2, which holds that an oral request may be replaced by a written advance directive when the patient is no longer able to express his actual wish (first requirement of due care – see table 1 introduction); the remaining requirements (2-6) of due care should be met in a ‘corresponding way’. However, as explained in the introduction, how this should be interpreted in practice was, and still is, not clearly documented. The most obvious difficulty is in the 4th requirement, which says that the physician has to come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient’s situation. How to meet the requirement of ‘unbearable suffering of the patient’ (2nd requirement) ‘in a corresponding way’ is another point of discussion in the case of an incompetent patient with dementia. Many ECPs in the present study indicated their patient with dementia was suffering; a previous study among ECPs in nursing homes showed even larger percentages of suffering [Rurup 2005]. In addition, a recent review on dying with dementia shows that people with dementia often also develop multiple physical symptoms in the end stages of dementia such as pain, shortness of breath, discomfort and restlessness [van der Steen 2010]. These results all emphasize that suffering in dementia is an issue that cannot and should not be denied. However, suffering as such is not sufficient reason to actively terminate a patient’s life. Without the possibility of meaningful conversation about this suffering with the patient with dementia, ECPs indicated experiencing difficulty determining the un bearableness of the suffering and they proved reluctant to actively end a patient’s life. Physicians in the present study have indicated and emphasized time and again the importance of communication with the patient in ‘weighing’ the suffering, which is also expressed in the 4th requirement of due care in the euthanasia law. Put differently: the suggestion made by the ministers of Justice and of Health, Welfare and Sports that, in cases where dialogue and communication between physicians and patient are no longer possible, the ECP’s 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 physician that there is, indeed, unbearable suffering and no reasonable alternative , [Tweede Kamer, 2000-2001, 26 691, nr. 24], is not consistent with what happens in actual practice. All in all it seems very hard to meet all of the requirements of the euthanasia law in cases of incompetent patients with dementia, as the crucial factor for ECPs to consider complying
with an ADE of a patient with dementia is the possibility of meaningful communication with the patient about their wish for euthanasia. In fact this undermines the nature of ADEs as they were specifically developed for situations in which the patient is no longer able to actively communicate a request for euthanasia. At present, euthanasia seems to be the ‘privilege’ of competent patients with dementia who are still able to discuss their wishes. The essence of meaningful communication also implies that planning care in advance should start in the stages in which communication with the patient with dementia is still possible. In addition, conversations about advance care planning should be continued on a regular basis with the patient until incompetence of the patient results in relatives having to take over this task.

**Advance care planning (ACP) in dementia**

People in the early stages of Alzheimer’s disease in this study - the stages in which communication is still possible - tend not to think about the future or plan for future care and treatment. An explanation for this behaviour was found in the fact that people in the early stages of Alzheimer’s disease are primarily trying to cope with their condition. Against this background the question was posed whether it is ethically justified, under all circumstances, to stimulate and steer people towards advance care planning. First of all, not everyone has the same view on autonomy or desire to manage and control his/her future [Winzelberg 2005]. Forcing people in the direction of planning future care and treatment in a situation in which they tend to do the opposite does not seem respectful. However, without the active involvement of patients with dementia in planning their care (in advance), family members or other informal caregivers could be left with the difficult task of having to make medical decisions without knowing what the patient him/herself would have wanted. Although it is suggested in other research that having and expressing views on end-of-life care is possible even up to the advanced stages of dementia [Godwin 2009], active involvement of patients with dementia in advance care planning will diminish in the course of the disease. This means that waiting too long could result in missing any chance there might be for ACP. It is this limited window of opportunity that could justify interventions to stimulate thinking about ACP in patients with dementia in these early stages when they are mainly trying to cope with their condition. Of course such interventions should always be attuned to the needs and wishes of the patient, which could also mean respecting a patient’s wish not to be involved in ACP or delegate end-of-life decisions to their family and health professionals. At the same time, the limited knowledge about advance directives as expressed by some of the participants in this study along with the interest that some of them showed in the subject, support the initiation of interventions aimed at ACP in order to at least provide an opportunity for people with dementia and their families to get involved in planning care in advance. A timely start in exploring the ideas of the patient will allow others to better represent the interests of the person with dementia as the disease progresses and decision-making capacity diminishes. The professional caregiver who is most closely involved with the patient seems to be the most appropriate person to initiate such a discussion about advance care planning. It should aim at stimulating and supporting patients and their families/proxies to think ahead and formulate the patient’s future wishes and goals of care.
Such a role could be taken up by, for example, general practitioners, geriatricians or case managers in dementia care. It requires an active role of these caregivers, which may be time-consuming and calls for high quality communication skills. Based on the needs and values of the patient, a treatment plan should be developed by physicians in collaboration with the patient, his/her family/proxies and/or case managers. Such a treatment plan should be reassessed regularly, especially when the patient’s health status changes. This makes advance directives, being static documents, less attractive as the primary outcome of advance care planning. However, they could still be regarded as a secondary outcome of ACP in the form of a ‘useful formal expression of the essential, qualified communication process’ [in der Schmitten 2011]. Alternatively, they could be used in the form of more versatile documents identifying a surrogate decision maker and ascertaining how much flexibility the surrogate should have with health care decisions [Messinger-Rapport 2009]. However, requests for euthanasia cannot be laid down in such directives. All in all it seems obvious that models for ACP in dementia should be developed and that information about the possibilities and limitations of advance directives in general and advance directives for euthanasia in particular should be part of discussions about ACP.

**Advance directives (for euthanasia)**

The research described in this thesis focussed on advance directives for euthanasia. It showed that the effects of these directives in the care for incompetent people with dementia in the Netherlands appear to be limited today. The fundamental reason for the non-compliance is that elderly care physicians will not consider complying with advance directives for euthanasia unless there can be communication with the patient about his request for euthanasia. Euthanasia is only possible in ‘the context of a relationship with trust and mutual understanding’ [Hertogh 2010]. One of the ECPs in this study addressed the issue that drawing up an ADE can raise false expectations in the patient and/or their family. At present, the role of advance euthanasia directives seems restricted to the earlier stages of dementia, in which the patient is (still) able to communicate about his wishes for euthanasia. In those cases the advance directive for euthanasia may support the patient’s actual wish. In the more advanced stages of dementia the presence of an advance directive for euthanasia will at best result in a non-treatment policy. Considering the limited effects of advance directives for euthanasia and the possibility of raising false expectations among those composing such a directive, informing patients and families/proxies about the limitations of advance directives for euthanasia seems essential.

Information about other forms of advance directives, such as non-treatment directives also seems in order, as their static character seems to contradict the dynamic process of advance care planning. More generally there is growing consensus about the limitations of advance directives [Hertogh 2011; Gillick 2010; Sudore 2010; Messinger-Rapport 2009; Perkins 2007; Kirschner 2005; Seymour 2004]. On the one hand these limitations concern practical problems, for example in terms of specifying (medical) situations or the fact that they are often not available when needed (documentation problems). On the other hand more fundamental problems are described, such as the fact that people tend to change their preferences with changing situations, and the difficulty relatives have interpreting the
patients wishes. This is why advance care planning (ACP), in which discussing the patient’s wishes on a continuous basis in cooperation with the family, is increasingly suggested as an alternative. Anticipating the future and advance care planning involves a broader concept than just signing a form or ticking a checklist of interventions to be accepted or denied [Hertogh 2011]. In this respect the role of advance directives as part of ACP in dementia care needs to be reconsidered.

CONCLUSIONS

Based on the findings of the presented research it may be concluded that the experiences of people with early-stage Alzheimer’s disease are not necessarily as negative as the widespread assumption of the general public suggests. The gradual progression of the dementia (especially distinctive of Alzheimer’s disease), allows people who are affected to adapt and adjust to their changing situation, which may also result in an adjustment of previous thoughts regarding a life with dementia. Consequently, a situation may arise in which a person with dementia considers a previously written advance directive no longer applicable to the situation it was meant for, without being able to revoke or adapt the directive (any longer) because of incompetence. It was found that people with early-stage Alzheimer’s disease tend to live by the day and stay away from thinking about the future, which implies very limited initiative on their part to engage in advance care planning. This leads to the conclusion that the help and support of others is needed in order to stimulate people with early-stage Alzheimer’s disease to participate in planning future care. However, it must be noted that there is a limited window of opportunity for this engagement in advance care planning, as active participation of the person with dementia decreases over the course of the disease. As the interviews in this study were limited to people with early-stage dementia of the Alzheimer’s type these results should not be generalized to other, less common, types of dementia. On the other hand, it cannot be ruled out that people with other types of dementia have similar coping strategies, which would make interventions on advance care planning relevant for them also.

At present the effects of advance directives for euthanasia in the care for incompetent people with dementia in the Netherlands are limited. Although advance directives for euthanasia may be supportive of the wishes of competent patients with dementia who also actively request euthanasia, in the case of incompetent people with dementia their effect seems to be limited to a supportive role at best in setting limitations on life-sustaining treatments. It is concluded that despite the opportunities the euthanasia law in the Netherlands provides to comply with advance directives for euthanasia of incompetent patients with dementia, this has not (yet) resulted in changes in Dutch nursing home practice: advance directives for euthanasia are still rarely complied with and never in patients with advanced dementia. The crucial factor for the non-compliance with ADEs seems to lie in the fact that the actual wish of the patient and the possibility to communicate about this wish remain essential for ECPs in considering life-terminating actions in patients with dementia. This makes it difficult for physicians to deal with article 2, paragraph 2, which
holds that an oral request may be replaced by a written advance directive as long as the remaining requirements of due care are met in a ‘corresponding way’. Besides elderly care physicians, relatives of patients with dementia were also found to be reluctant to comply with advance directives for euthanasia. Whether the small sample of relatives interviewed in this study represents the larger group of relatives of patients with dementia and an advance directive for euthanasia remains to be determined. Although most nursing homes in the Netherlands do have a policy on euthanasia, it does not always specify euthanasia in dementia based on an advance directive. Nonetheless, whenever such a clause is present it often holds that advance directives for euthanasia are respected by setting limitations on life-sustaining treatments. Considering the essence of meaningful communication with patients about their ADE and the fact that ECPs have no legal obligation to comply with ADEs, this implies that, in current practice in the Netherlands, euthanasia in dementia seems to be reserved for patients in the early stages of the disease who are still able to actively communicate their wishes.

IMPLICATIONS AND RECOMMENDATIONS FOR DEMENTIA CARE PRACTICE

‘Living through dementia’
For caregivers in dementia care as well as for the general public it is important to take note of the conclusion of this research that the experiences of people with early-stage Alzheimer’s disease do not coincide with the widespread assumptions of the general public. It is important to provide more accurate and nuanced information to patients and families, but adequate sources of such information are still to be developed (see recommendations for research). Information about living through dementia should be available not only to (potential) patients with dementia and their relatives but also to professional caregivers and the general public.

Anticipating a future with dementia and advance care planning
Thinking about and planning for the future could support living through and coping with dementia. Getting people with dementia to be actively involved in anticipating their future requires 1) active support from relatives and caregivers; 2) the establishment of a relationship of trust between the patient and the physician and 3) a timely start of such an intervention, preferably following the diagnosis, because of the decreasing possibilities of active involvement of the person with dementia (limited window of opportunity). Here physicians who diagnose the patient (physicians of memory clinics, general practitioners, elderly care physicians), but also case managers could (or should) step in. It is recommended that people with dementia are guided in the process of planning their future by means of ‘advance care planning’, but this demands the development of adequate models for implementing advance care planning in dementia care (see recommendations for research). It is important to realize that anticipating the future and planning care and treatment in advance is a dynamic process, in which preferences and goals (for care) can be adapted or
changed regularly, which at the same time points to the limitations of advance directives as a potential outcome of this process.

**Advance directives (for euthanasia)**

Given the fact that an advance directive is static in nature, it does not seem to be the most appropriate instrument for planning care in advance. For those who do consider drawing up an advance directive it is essential that they are informed by physicians of the practical and ethical limitations of using such directives in planning care and treatment in advance. Also, physicians should monitor people’s wishes over time and regularly evaluate the content of the advance directive. Given the central role of general practitioners and elderly care physicians in the practice of advance directives, it is recommended they, together, develop a ‘standard’ for how to deal with advance directives. Furthermore, physicians should guide and stimulate patients and relatives to engage in the broader process of advance care planning, of which advance directives can be a potential, but not the primary outcome.

On a different level, limiting the period of validity of advance directives in an attempt to stimulate people to regularly reassess their advance directive could also be considered. Such a limitation is not part of the current legislation in the Netherlands, but it would be advisable to include this option in the next evaluation of the euthanasia law.

**Clarification of nursing home policies**

Many of the ECPs in this study indicated that the nursing home where they worked had a policy with regard to euthanasia. A study into the impact of written ethics policies on euthanasia showed that care providers felt positively supported by the euthanasia policy during the euthanasia process [Lemiengre et al. 2010]. Although the number of nursing homes that have a policy on euthanasia and assisted suicide has increased since the changes in the legal system (the introduction of the euthanasia law in 2002) [Pasman et al. 2009], it was concluded in this study that only half of these policy statements included information about euthanasia in the specific case of dementia. In order to ensure clear communication about euthanasia in dementia towards patients and their relatives, it is therefore recommended that all nursing homes clarify, and put into writing, their policy on euthanasia in dementia.

**RECOMMENDATIONS FOR FUTURE RESEARCH**

**Providing information about ‘living through dementia’**

Based on the conclusion that experiences of people with early-stage Alzheimer’s disease do not coincide with the widespread popular assumptions, it seems very important to develop adequate sources of information for the general public about what life with dementia is like. At present, most of the available information is provided or interpreted by people who do not (yet) suffer from dementia [de Boer et al. 2007]. For a more nuanced picture of living through dementia, existing and new sources of information should be consistent with the experiences of patients with dementia themselves. An example of an initiative taken by
people with dementia is the ‘Scottish Dementia Working Group’ (www.sdwg.org.uk), which tries to improve attitudes towards people with dementia. Other initiatives, e.g. in the Netherlands, are the ‘meeting centres’ (www.ontmoetingscentradementie.nl) or the ‘Odensehouse’ (www.odensehuis.nl), although these organizations focus mainly on people who actually have dementia (and their relatives), and less on the general public. A possible aid in providing information to the general public could be videotapes in which future health states are visualized. A study of Volandes et al. describes such a ‘video decision support tool’, which was found to increase the patients’ understanding of the dementia [Volandes, 2009; Volandes, 2007]. In the Netherlands the ‘Dementia experience’ (www.dementieexperience.nl) has been developed, which uses simulation to let people who do not have dementia experience the disease. In addition, there is the ‘Alzheimer Experience’ (www.alzheimerexperience.nl), where also the perspectives of those around the person with dementia are shown. However, the use of such videotapes and simulations should be applied with caution: as a source of information for caregivers and the general public they can be useful, but for people who have recently received a diagnosis of dementia and their families they might be rather confrontational. Research, preferably in consultation with organizations like the Alzheimer Associations, is needed to develop adequate sources of information.

**Advance directives for euthanasia – practical guidance**

One conclusion of this study was that advance directives in general and advance directives for euthanasia in particular have limited effects in the care of incompetent patients with dementia. In addition, elderly care physicians were found to experience difficulties dealing with article 2, paragraph 2 of the euthanasia law. At the same time the data showed that, at present, elderly care physicians are regularly confronted with patients with (advanced) dementia who have an advance directive, often including a request for euthanasia. Taking into account the conclusions as described above, it is therefore recommended that the Dutch association of elderly care physicians (VERENSO), in cooperation with the Royal Dutch Medical Association (KNMG), compose a detailed practical guide with regard to the possibilities of euthanasia in dementia. Such a document may not only provide insight into the matter for elderly care physicians, but it could also provide clarity to patients and their families about the feasibility of advance directives for euthanasia in cases of dementia. Special attention should be given to the interpretation of the requirements of due care, and the importance of advance care planning in dementia care.

**Advance care planning – developing models**

Advance care planning involves a broader concept in which realistic goals of care for the future rather than just treatment decisions are central. It focuses not only on end-of-life decisions and situations in which the patient is incompetent, but also on the whole trajectory of the disease. Advance care planning in dementia care should at least incorporate the following essential elements: 1. a proactive character, as involvement in the future on the initiative of people with dementia is limited; 2. a timely start, shortly after diagnosis - given the limited window of opportunity - in order to guarantee active involvement of and
meaningful communication with the person with dementia; 3. involvement of physicians and relatives in relation with the person with dementia; 4. a focus on clarification of needs, values and treatment goals of patients which will form the basis of the care plan; 5. periodical evaluations on a continuous basis especially in case of (medical) changes in the lives of patients. Such an approach involves changes in the actual practice of dementia care and requires active engagement in advance care planning and decision making of physicians who diagnose patients with dementia (specialist in memory clinic, elderly care physician, general practitioner). While some view such a development in the direction of a more proactive role of physicians towards patients and relatives as part of ‘the triadic caregiving relationship that is so essential to elderly medicine’ [Hertogh 2010], others interpret it as medical paternalism in the sense that physicians are too directive in their communication [Helton 2006]. This process obviously requires further development of models of advance care planning in collaboration with physicians as well as patients and their relatives. Models of advance care planning should, after careful development, be implemented and studied in actual practice with respect to their feasibility and effectiveness, and the satisfaction of all involved.

Longitudinal research
To adequately research models of advance care planning, a longitudinal study should be set up, involving people with dementia, their relatives, and physicians. Such research will not only yield insight into the feasibility and effectiveness of, as well as satisfaction with advance care planning, it also provides an opportunity to detect any changes in the wishes of people with dementia with regard to euthanasia and other end-of-life decisions. At the same time it would be interesting to investigate the effects of advance care planning on the willingness of physicians to perform euthanasia in patients with dementia. Perhaps the more ‘intense’ relationship between physicians, patients and their families in advance care planning models could help physicians optimize the meaningful communication about requests for euthanasia so essential for them. Whether this will lead physicians to think about the possibilities for euthanasia toward the later stages of the disease remains to be seen (and researched).

The aim of all research should be to contribute to better care for people with dementia and their relatives.
REFERENCES


