Advance directives in dementia care

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2011

document version
Publisher's PDF, also known as Version of record

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Download date: 10. Jun. 2022
Thoughts on the future
The perspectives of elderly people with early-stage Alzheimer’s disease and the implications for advance care planning

Accepted for publication as:
ABSTRACT

Background
Early diagnosis in dementia is promoted to allow patients to engage in advance care planning (ACP) while still competent to do so and thereby extend their autonomy into futures in which they lack decision-making capacity. However, engagement of people with dementia in ACP is lagging. The aim of this study was to investigate the thoughts of people with early-stage Alzheimer’s disease (AD) with regard to future care and treatment and the implications for ACP.

Methods
A qualitative study using explorative semi-structured interviews was conducted with 24 individuals diagnosed with early-stage AD.

Results
Participants were found to be very capable of sharing their experiences, often becoming more open and talkative in the course of the interview. For participants, thinking about the future involved an ongoing process of balancing feelings of fear and hope, but the overall tendency among this group was to try to live one day at a time and avoid worrying about the future.

Conclusions
Although ACP is considered to be a key element of high quality palliative and end-of-life care, engagement in ACP by people with early-stage AD on their own initiative is limited. Additional interventions are essential in order to stimulate and support people with early-stage AD to initiate actions with regard to ACP. The development of alternative models for ACP in dementia care is recommended. However, the advisability of ACP in early-stage AD is not without dispute. Ethical issues, such as whether steering people towards ACP is justified, should be addressed in further research and the role of advance directives needs to be reconsidered.
INTRODUCTION

Over the past decade, multiple articles have appeared on the experiences of people with dementia, their awareness of their condition and coping behaviors (Clare, 2002; De Boer et al., 2007; Steeman et al., 2007; Pearce et al., 2002). Despite the insights that have been generated, the literature does not include a focus on the way people with dementia think about and prepare for the future. In dealing with the growing population of people with dementia, timely care and support services, as well as advance care planning (ACP), seem to be gaining ground.

ACP is a process of enabling patients to express wishes with regard to their future healthcare in consultation with family members and healthcare professionals. Advance directives can be seen as a potential outcome of this process. However, the number of advance directives made by people with dementia has traditionally been lower than for people with other incurable diseases, such as cancer (Mitchell, 2004). A follow-up study of ACP by people with mild cognitive impairment or Alzheimer’s disease showed that only a minority of these individuals (39%) went on to complete ACP (designation of durable power of attorney or execution of a living will) within 5 years of learning their cognitive diagnosis (Garand, 2010). Furthermore, levels of advance planning among persons with mild cognitive impairment and early Alzheimer’s disease do not exceed those of healthy elderly (Lingler et al., 2008).

However, timely engagement in ACP of people with dementia is considered important as they progressively lose the capacity to make meaningful decisions about their current and future medical care. Given the progressive nature of dementia, early diagnosis is advocated in order to allow people with dementia – while they are still competent to do so – to engage in ACP, as a means to exercise their right to self-determination and to extend their autonomy into a future of decision-making incapacity (Dworkin, 1986; Alzheimer Europe, 2005). Although early-diagnosis as a facilitating factor for ACP is becoming more common, the engagement in ACP of people with dementia, including the writing of advance directives, lags behind. Insight into the perspectives of people with dementia with regard to the future and ACP is therefore vital in determining the value and possibilities of ACP in dementia.

The purpose of this article is to explore the views of people with early-stage AD with regard to the future and the implications for ACP.

METHODS

A qualitative survey was conducted based on semi-structured interviews (Fink, 2003), covering multiple facets of the experiences of living with dementia. However, this article focuses specifically on thoughts on the future and ACP. Only people with Alzheimer’s disease were included, as this is the most frequent and paradigmatic form of dementia among elderly people. The study was approved by the Medical Ethics Committee of the VU University Medical Center.
Participants and instruments
Participants were recruited through the Memory Clinics of the University Medical Centers of Leiden (LUMC) and Amsterdam (VUmc) and an existing database of people with dementia (van der Roest et al., 2009). All participants were diagnosed with early-stage Alzheimer's disease based on the DSM-IV-criteria (American Psychiatric Association, 1994). To be included in the study, an individual had to have a severity score of ≤ 4 (= early dementia) on the Global Deterioration Scale (GDS) (Reisberg et al., 1982), live within the community, and have a partner or other family member willing to take part in the informed consent procedure. Exclusion criteria were determined by GPs or medical specialists and involved severe depression as measured by the Cornell Scale of Depression in Dementia (CSDD) (Alexopolous et al., 1988) or the Geriatric Depression Scale (Yesavage, 1983) or severe language problems as measured by the language items of the CAMCOG (the cognitive test of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)) (Derix et al., 1991; Roth et al., 1986). One person was excluded because his mastery of the Dutch language was insufficient to be interviewed; none of the participants had to be excluded for depression.

An iterative process of data-collection and analysis was followed, which provided the opportunity for recruiting specific information-rich cases (i.e., purposive sampling) (Patton, 1990). This led to the recruitment of additional participants with advance directives and a close monitoring of the age distribution. Furthermore, follow-up interviews were carried out with 4 of the 24 participants who had received their diagnosis less than 3 weeks prior to the first interview in order to see whether their views had changed over time as a result of coping and adaptation processes. Recruitment was continued until saturation was reached; none of the individuals with dementia (or their family members) who were approached refused participation in the study.

Interviews
Semi-structured interview guides were constructed by an interdisciplinary team of specialists in medical, behavioural, psychosocial and ethical aspects of dementia care. The interviews involved a face-to-face conversation with participants, which had an explorative character with open-ended questions about different aspects of living with dementia, including thoughts about the future (with a focus on health and care), and involvement in ACP. Written consent was obtained from both the participants with AD and their partners or other caring family members. As the focus was on the views of people with AD, participants were preferably interviewed without any proxies present. However, occasionally additional information provided by proxies after the official interview triggered participants to spontaneously elaborate on their experiences, in which cases any additional expressions of participants were also taken into account in the analysis. On average, both the initial and the follow-up interviews lasted one hour. All interviews took place in the participant’s own home.
Analysis
All interviews were tape-recorded, transcribed verbatim, and qualitatively analyzed with the use of Atlas.ti software (Scientific Software Development, 2008). Analysis incorporated an iterative process of reading and re-reading the transcripts in order to code the transcripts and to identify emergent themes. An initial categorization system was established based on the topics of the interview. After independent coding of the first two interviews by three researchers (MdB, CH, RMD), the applicability of categories was discussed and modified where necessary. Every other interview was analyzed and coded by the first author (MdB) and one of the other authors (CH, RMD, CJ, JE) independently. After comparison and discussion of discrepancies, consensus was reached on all themes and coded text segments.

RESULTS
In total, 24 community-dwelling individuals diagnosed with early-stage Alzheimer’s disease were included (14 men and 10 women) and interviewed. Their mean age was 76.3 years (SD = 7.3), ranging from 65 to 89 years. Of these participants, 6 had an advance directive at the time of the interview. [As a point of reference, 10% of older people have an advance directive in the Netherlands (Rurup et al., 2006)]. In 5 cases, the advance directive contained a standard written statement created by the Dutch Right to Die Society (NVVE) or a self-made document similar to this, comprising both an advance directive for euthanasia ADE and a non-treatment directive. One participant had a self-formulated document which included non-treatment and pain-relief wishes (not euthanasia) in the case of endless suffering from a very severe illness, without specifically mentioning situations involving dementia.

The final outcome of our analysis of the interview material revealed that thinking about the future is an ongoing process of balancing hopes and fears, influenced by several subjective (personal) and objective (external) factors, and resulting in different outcomes for ACP. The interrelationship between these aspects is summarized in Figure 1. Next, all aspects depicted in the figure will be illustrated with examples from the participants’ verbatim accounts.

Figure 1 The process of thinking about and planning for the future

<table>
<thead>
<tr>
<th>Thoughts on the future</th>
<th>Planning for the future</th>
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<tbody>
<tr>
<td>Subjective attribution</td>
<td>living one day at a time</td>
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<td>burden on others</td>
<td>relying on others</td>
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<tr>
<td>experiences</td>
<td>ACP? (advance directives?)</td>
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<td>FEARS</td>
<td>balancing</td>
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<td>HOPES</td>
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<td>Objective information</td>
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<td>support</td>
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<td>treatment</td>
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Thoughts on the future
Although all participants in our study acknowledged they had memory problems, their attribution and awareness of future decline with regard to these problems differed. Some were aware of the fact they had dementia, others attributed their problems to other medical events (e.g. cerebral haemorrhage), or considered their problems to be age-related. In spite of these differences in awareness and attribution, all participants expressed both hopes and fears when thinking about the future. In general, thinking ahead was found to be limited in participants.

Future fears
The most obvious fear is the fear of future decline (box-1:quote-1). In addition, some people seemed to fear losing control the most (box-1:quote-2). Upon further exploration of this fear, participants proved to be especially afraid of becoming more dependent on others, being admitted to a nursing home, and not being able to take care of the partner (box-1:quotes-3/4). In some cases participants based their fears of the future upon information provided by the hospital (box-1:quote-5). Negative views of the future were also fostered when the participant involved had a personal relationship with someone diagnosed with dementia (box-1:quotes-6/7).

Future hopes
Besides fears of the future, positive feelings regarding the future were also present in participants. They tended to hold on to their hopes of things remaining the way they were or not deteriorating over time (box-1:quotes-8/9/10). Others expressed their hopes for improvement of their memory problems, either spontaneously or through the use of medication (box-1:quotes-11/12). Hoping for stabilization of the illness and its consequences was found both in participants who were aware of their memory problems and in participants who (initially) denied or trivialized (part of) these problems. Many hoped or expected future support from their family (box-1:quotes-13/14). At the same time, there were participants who realized this support in the future was not a certainty they could rely on (box-1:quote-15).

Balancing hopes and fears
Often participants expressed a combination of both hopes and fears with regard to the future and appeared to be in a constant process of trying to balance these feelings. In this process, the overall tendency was not to think about the future too much and to let nature take its course (box-1:quote-16/17/18/19). Multiple participants expressed how they had lowered their expectations of the future as they grew older (box-1:quote-20). Others explained how with aging they stopped thinking about the future and started focusing more on accepting the present and living life from one day to the next (box-1:quote-21/22). Rather than fearing the anticipated negative future, participants tended to resign themselves to this future.
Box 1 Quotes from participants on thoughts on the future

<table>
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<tr>
<th>Future fears</th>
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<tr>
<td>1. ‘I would think that, yes, to reconcile yourself to that, if you are that crazy, that you eh no longer realize what you are doing, that it is hard for me to cope with.’ (female, age 70)</td>
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<td>2. ‘...then I won’t be aware of it anymore, that I am like this. That scares me a lot. Yes.’ (female, age 70)</td>
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<td>3. ‘If you you would have have to ask your relatives your relatives, like my wife, a lot more would find that unpleasant, yes. To put it mildly. Perhaps even annoying, terribly annoying.’ (male, age 82)</td>
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<td>4. ‘...that I would end up (crazy) in a rest home or nursing home, nursing. Hhhhm. Well, that would be horrible. I find it horrible to think about, I don’t want that.’ (male, age 76)</td>
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<td>5. ‘Well, if it is true what the VU (hospital) says with regard to these memory problems, then obviously my future looks a little dismal.’ (male, age 76)</td>
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<td>6. ‘...so the way my mother [diagnosed with AD] died, I don’t want to die like that...’ (female, age 72)</td>
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<td>7. ‘...I hope it won’t be like it was with my cousin, you know, because I also have Alzheimer’s...’ (male, age 73)</td>
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<th>Future hopes</th>
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<tr>
<td>8. ‘Well, that it takes that long, my future eh I do hope that as long, as long as, the years I still have, that it stays like this.’ (male, age 82)</td>
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<td>9. ‘And eh, yes, I hope that it won’t go any further.’ (male, age 81)</td>
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<td>10. ‘I hope it turns out alright.’ (male, age 70)</td>
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<td>11. ‘I also have the silly idea that I will actually still get better.’ (female, age 72)</td>
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<td>12. ‘I do hope that at some point I will hear they have found something.’ (female, age 67)</td>
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<td>13. ‘Oh, my children will...and my husband for sure...he is a lot of help.’ (female, age 89)</td>
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<td>14. ‘I think that my wife, my wife is still going strong and that she will continue to take care of me and eh, well that’s what I’m counting on eh actually.’ (male, age 85)</td>
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<td>15. ‘How much longer eh can you ask them to to help you.’ (female, age 70)</td>
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<th>Balancing hopes and fears</th>
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<tr>
<td>16. ‘No, I just let sit back and wait. At this age, and when you are not so fit anymore, then you can’t start thinking about the future.’ (female, age 86)</td>
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<td>17. Interviewer: And how do you see your future? Yes... it will ...yes, well, I try not to think about the future. What happens happens, so it will probably be...only the future will tell.’ (female, age 89)</td>
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<td>18. ‘Let things take their course. Yes, I don’t think...there are so many things it’s best not know in advance.’ (male, age 80)</td>
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<td>19. ‘Eh, I don’t look ahead, no. I try not to go into that now if ... anyway, there is absolutely no point in doing so.’ (male, age 80)</td>
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<td>20. ‘But, well, I am 88, so what can you expect of the future...it all takes care of itself, I’ll just wait and see what happens.’ (female, age 89)</td>
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<td>21. ‘I can’t really say anything about that [the future] yet no, what can you say about it...no, no, no, no, I accept things as they are now.’ ‘No, no, no, no, because you are...look...you’re not 18 anymore, you accept everything much more easily now. Well, you’re old, aren’t you?’ (female, age 74)</td>
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<tr>
<td>22. ‘I let come what may...’ And, I don’t don’t look ahead, no. I also try not to bury myself too much in it... after all, there is no point in doing that’ ‘Yeah, I have come to terms with it...sort of.’ (male, age 80)</td>
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Planning for the future

Planning for the future was, like thinking about the future, also marginal among participants. Most tried to make the best of today. An example is provided by the following quote of a woman who explained how she was holding on to the belief that suffering was a great waste:

‘But it’s a crying shame, isn’t it?...then you throw away a whole, a whole part of your life you then throw away..’ (female, age 72)
Advance care planning
In line with living life one day at a time and not thinking about the future, future care also did not seem to be on the minds of the participants with early-stage AD. Spontaneous remarks about ACP were generally not made, regardless of whether the person involved did or did not have an advance directive.

Reasons participants gave for not planning for the future varied from ‘we’ll cross that bridge when we get there’ to relying on partner or children to organize future care (box-2:quote-1). However, questioning people about their thoughts triggered some to express remarks in the direction of ACP. They made statements like wanting to be put to sleep if they became totally demented with a life they thought would be not worth living, without being able to specify the exact moment for this wish to take effect (box-2:quote-2). Another participant made clear he wanted to fight and seize every opportunity with both hands to get better (box-2:quote-3). Participants also appeared to adjust to their situation by revising their former views on living with dementia (box-2:quote-4).

Advance directives
The most frequent reaction among participants to questions about advance directives was that it was not something that had their attention. Several individuals stated they had never heard about these documents or their possibilities (box-2:quotatation-5). Others did seem to have planned for the future as they had completed an advance directive prior to diagnosis, formulating their wishes regarding future care and medical treatment. However, these participants did not seem to differ from the overall group of participants in terms of awareness, suffering or preparing for the future. Moreover, among the participants that had an advance directive, several were found to be unaware of this fact. Occasionally partners helped participants remember their advance directive in the final part of the interview, which made it possible for some participants to then share their thoughts about it.

One of the participants explained the advance directive was more a concern of his wife than of himself, and refrained from elaborating on his own opinion on advance directives or ACP (box-2:quote-6). Another participant seemed well aware of the wishes expressed in the advance directive, even without being helped to remember. Although this participant acknowledged he was in the situation described in his directive, he currently interpreted this situation differently thereby postponing the applicability of the directive (box-2:quotatation-7). Occasionally interest was shown in advance directives: some participants asked for information, others indicated they themselves or their spouses were busy drawing one up. One woman indicated she did not want to end up like her mother who had been demented, but stated she thought drawing up an advance directive was not necessary yet. There appeared to be a pattern in the type of participants showing interest in advance directives, as they were mostly aware of their diagnosis and the expected decline, and often influenced by examples of other family members with dementia.
Box 2 Quotes from participants on planning for the future

**Advance care planning**

1. [reaction when asked whether participant had thoughts about future care that she might want] ‘No, do you [husbands]? [husband intervenes: well yeah, no, that we haven’t put it on record] we also have children who...who think [husband: you can’t burden them with this either] no...but they can make sure that care is provided or what ever else.’ (female, age 89)

2. [participants explanation about when she wanted to end her life] ‘......if the suffering becomes too much’ Interviewer: ‘When will this moment be?’ ‘you have to experience that moment.’ (female, age 86)

3. ‘No, I think, think experience it myself, that I, in fact, eh, while if you look at it at it from a distance, then you dread it, but once you are faced with it, it’s not too bad.’

4. ‘It contains a whole story about me, eh, not really wanting to go through this. You know. And that I would want then, eh yeah, to get an injection’...’Well, I think it is still a little premature. Because I still feel quite good.’ (male, age 76)

**Advance directives**

1. Interviewer: ‘Do you have such a document[an advance directive]?’ ‘No, no. Never heard of it, even. This is the first time someone tells me this.’ (male, age 82)

2. Interviewer: ‘Did you draw it [advance directive] up together with your wife?’ ‘Oh yes, sure... especially her ... it is her initiative, because I was already not .. so close to .. to that problem, so to speak.’ (male, age 80)

3. ‘It contains a whole story about me, eh, not really wanting to go through this. You know. And that I would want then, eh yeah, to get an injection’...’Well, I think it is still a little premature. Because I still feel quite good.’ (male, age 76)

**The interview process**

Most interviews involved a process of gradual disclosure of experiences and feelings. Although some participants were persistent in denying their memory problems and associated feelings, in other cases deeper feelings were initially concealed from the interviewer, but surfaced when involvement and rapport between the participant and the interviewer increased as the interview progressed. This process is illustrated by quotes 1-4 in box 3, stemming from different parts of a single interview and presented in chronological order. They show how initial trivialization of worries about the future changed into more open and even emotional expressions later on in the interview.

Box 3 Quotes from participants illustrating ‘the interview process’

(1) Interviewer: ‘Do you have any idea what your future will look like?’ ‘... no, I I don’t worry about it at all.’ (male, age 65)

(2) ‘No, I can’t look into the future.’

(3) ‘... well eh, yes, it does not bother me daily, but eh when you ask me then then then I do think to myself yes enough is enough.’

(4) ‘I have gone crazy so eh so’

Interviewer: ‘That must be hard for you’

‘Yes, it hurts me.’
The follow-up interviews

Four participants were interviewed so quickly after the disclosure of their diagnosis of Alzheimer’s disease, that they might have had insufficient time to accept the bad news and adjust to the new situation. Even though some of them increasingly opened up over the course of the interview, we suspected their thoughts about the future could possibly change over time. These four participants were re-interviewed after 6 to 18 months to detect any changes in views and to see whether any actions with regard to ACP had been taken in between the first and the second interview. It was found that these participants had not essentially changed their views with regard to the future and only one of them had taken steps forward in planning future care (see box 4).

Box 4 Quotes from participants illustrating ‘the interview process’

Interview 1: ‘Well, we do already have the points, don’t we [of the advance directive]’... ‘And now we’re going to, we were actually hard at work doing that already, we have discussed it extensively together eh, but no it has eh some day soon we will also... the doctor eh’. Yeah, you just have to do that, you know, persevere. And not eh postpone it. No, that is within a few weeks it will be written down on paper, ok.’ (male, age 73)

Interview 2 (after 15 months): Interviewer: ‘Did you also put that [wishes with regard to medical care in the future] on record?’ No, but we have already discussed it, and we have spoken to the doctor X about it, haven’t we.’

Although the participant had discussed his wishes about future care and treatment with his physician, this had not (yet) resulted in any form of ACP.

DISCUSSION

The focus of this study was to investigate how people with early-stage AD are thinking about the future and to explore the implications for ACP.

The main outcome of our interviews is that thinking about the future (in terms of health and care) seems limited in people with early-stage AD. It involves an ongoing process (see Figure 1) of balancing feelings of fear and hope. This process is influenced by subjective (personal) and objective (external) factors. Subjective factors identified in our research were: the attribution of problems, prior experiences with dementia among acquaintances, and feelings of burdening others. Objective factors included (availability of) information and support and/or treatment received.

The limited interest in the future may be associated with the lack of awareness which is often described as a clinical feature of Alzheimer’s disease. Traditionally, the lack of awareness is often explained as a neurological consequence of anosognosia (unawareness of a disease or deficit, rooted in cerebral physiology) or (early) impaired executive function. Alternatively, it might also be explained (at least in part) psychologically. Participants in our study were found to initially conceal their thoughts and feelings about the future, which became apparent from the fact that several people opened up about their thoughts over the course of the interview. This process of gradual disclosure suggests a more psychosocial,
rather than a primarily neurological, explanation for people’s initial reticence. In this sense, our findings support the theory that (un)awareness can be seen as a result of an interplay between biological processes and psychosocial factors (Clare, 2002; de Boer et al., 2007; Dröes, 2007). The initial concealing of one’s feelings about the future can then be interpreted as coping behaviour, aimed at the preservation of the self (Steeman et al., 2007, Pearce et al., 2002). Thus, the domination of feelings of hope for stabilization or even improvement of symptoms over awareness and fears of the expected future decline, can be described as a self-protective mechanism. This line of reasoning is in accordance with literature stating that dementia is considered a threat which people try to keep outside their consciousness (Dröes, 2007; Harman et al., 2006; MacQuarrie, 2005; van Dijkhuizen et al., 2006).

Despite the initial reaction of participants to stay away from thinking about the future, it was possible, over the course of the interviews, to elicit some thoughts with regard to the future. Some participants clearly wanted to avoid a future with (severe) dementia, but at the same time they did not view their current situation as one they would want to end. In discussing their wishes with regard to future care and treatment, it was also found to be difficult for participants to formulate their desires precisely and to pinpoint the exact moments they wanted these desires to take effect. Participants were found not to be very familiar with either the existence or the possibilities of advance directives. Where we expected participants who already had an advance directive prior to their diagnosis of AD to have a more clear opinion about their wishes for future care and treatment, their thoughts on the future were found to be not substantially different from those of participants without an advance directive. Furthermore, those participants that had an advance directive could only provide limited information about its content. Nonetheless, thinking about ACP was not avoided altogether. In some cases, people’s attention was drawn towards ACP as a result of the topics addressed in our interviews. This led some participants to ask for additional information about advance directives and their possibilities. For others, it meant a renewed focus on an already initiated process of making steps towards ACP, without these ‘steps’ being translated into concrete actions like discussing matters with their physician or relatives, or writing an advance directive.

A potential limitation of our study is that most participants were recruited from memory clinics. This means that they sought help for their condition and received diagnoses of early-stage AD, which is not necessarily common practice for all people who experience the first symptoms of cognitive and memory deterioration (Werner, 2003). This may have resulted in selection bias, in the sense that the participants in our study were perhaps more aware of their situation than the general population of people with early-stage AD. Also, the number of follow-up interviews was limited and restricted to participants who were diagnosed shortly before the first interview. Follow-up interviews with all participants could have produced more robust conclusions, but this was not possible within the timeframe of the study. Another potential criticism regarding the study is that it focused on people with early-stage AD only. Still, the results on thinking and planning for the future may also apply to older adults in general or older adults with other chronic diseases. However, the results in a population of people with early-stage AD remain particularly important because of the
differential implications for ACP between this population and other elderly people, particularly in terms of the former’s progressively diminishing capacity to be involved in this process.

Our study shows that ACP is not matter-of-course for people with early-stage AD. Considering the limited ‘window of opportunity’ (before incapacity gains the upper hand) and the lack of spontaneous actions in the sphere of ACP of people with early-stage AD, we therefore conclude that an uptake of ACP in early-stage AD necessitates the development of additional interventions to stimulate and support individuals in this respect. Our research provides some indications that such interventions may be successful, insofar as we found that just bringing up the subject of ACP in a research-interview setting stimulated people with early-stage AD to express their thoughts about the future and in some cases drew their attention towards ACP. Support for the possibilities of ACP in dementia care can also be found in the principle that diagnosis of dementia does not imply incapacity (Kim et al., 2002). At the same time, we should think carefully about the implications of promoting ACP in the early-stages of AD. We might consider whether it is morally justified to stimulate and steer people with early-stage AD towards ACP, in a phase when they are primarily trying to cope with their condition and have a tendency to keep their focus away from the future. In addition, it must also be recognized that the urge to manage and control the future is not equally present in all people (Winzelberg et al., 2005), and a patient’s informed decision not to be involved in ACP should always be respected. This makes it important to carefully assess the attitudes of people with dementia towards ACP and their desires with regard to its content. Secondly, we feel that the role of advance directives in the context of ACP might need to be reconsidered in view of the fact that people’s thoughts with regard to their general well-being change over the course of chronic diseases. Our results showed how people with early-stage AD also downgrade their expectations of life and postpone the applicability of their directive, thus illustrating how discrepancies can arise between people’s previous and current wishes, resulting in the well-known ethical dilemma of how to balance the patient’s current interests against his earlier advance directive (Hertogh et al., 2007; Dresser, 1992). This calls for further research into ACP in the early-stages of AD and the ethical issues it evokes. First, longitudinal research into the changes and/or stabilities of people’s preferences is recommended. A second recommendation involves the development of models for ACP in which advance directives do not form the primary outcome.

ACP is considered by many to be a key element of high quality palliative and end-of-life care for people with incurable, progressive illnesses. In the case of Alzheimer’s disease active engagement of the patient is restricted to the earlier stages, due to progressive lack of decision-making capacity. This requires the timely start of ACP in order to guarantee active involvement of and meaningful communication with the person with dementia. However, this research shows that engagement in ACP of people with early-stage AD on their own initiative is limited. Therefore, additional interventions, with a proactive character, are essential in order to stimulate and support people with early-stages of AD to initiate actions with regard to ACP. Starting conversations with both the patient and his/her relatives about ACP at an early stage offers such a possibility as it initiates an ongoing process of monitoring and discussing their perspectives and wishes in this respect (Teno, 2003). In the light of the
growing consensus about the limitations of advance directives (e.g. Gillick, 2010; Sudore, 2010; Messinger-rapport, 2009), discussing the patient’s wishes on a continuous basis in cooperation with the family, is increasingly suggested as an alternative. The designation of a durable power of attorney may also be a possible outcome of ACP. Anticipating the future and advance care planning involves a broader concept than the mere signing of a form or ticking a checklist of interventions to be accepted or denied (Hertogh, 2011). Further development and testing of models for ACP in dementia care, in which realistic goals of care are central, is essential in order to adequately adjust the care to the needs and the wishes of the people involved.
REFERENCES


