Chapter 3

The lived-experiences of early-stage dementia and the feared suffering
An explorative survey

Published [in Dutch] as:
ABSTRACT

This qualitative exploratory survey aims to investigate the personal experiences of elderly people with early-stage dementia with regard to their illness and the extent to which they experience their situation as ‘suffering’. In the Netherlands insight into this suffering is relevant for the ongoing debate on euthanasia and physician-assisted death in early dementia. Participants in the study were 24 elderly persons (mean age 76.3 years) diagnosed with early-stage Alzheimer’s disease. The semi-structured interviews were transcribed verbatim, and subjected to qualitative analysis. The elderly were found to be very capable of sharing experiences about their disease. They indicated not experiencing their situation ‘as a whole’ as one of dreadful suffering The gradual progression, which is distinctive of Alzheimer’s disease, also allows people to adapt and adjust to their changing situation. As a result, the actual experiences of the disease can deviate from their anticipatory beliefs in a positive sense. The experiences of the participants proved to be less negative than the ideas ‘healthy’ elderly often have about a life with dementia. The results from this study emphasize the importance of listening to the voices of people with dementia. Communication with elderly persons with Alzheimer’s disease is quite possible in the early stages and essential for the adjustment of advance care planning to their actual wishes and needs.
INTRODUCTION

‘Life is like sand
that we sieve, but
when you have long passed
three score and ten years
you see in your sieve
but a few grains remain’

This poem, written by an 86-year old woman with Alzheimer’s disease, says something about her down-to-earth outlook on life, but at the same time it raises the question how those ‘few grains’ that are left are experienced by a person in her situation. In our society the image of dementia, of which Alzheimer’s disease is the most common type, is mainly negative. Being confused, not being able to remember anything, growing increasingly dependent on others, but also the loss of personality and identity, are a few of the often-mentioned associations when people think of dementia. This image leads to fear (Laforce and Maclean, 2005). And this fear causes people to find ways to avoid this feared suffering. Some people therefore draw up an advance euthanasia directive in case they do develop dementia.

Research into the experiences of people with dementia has increased over the last decade (Clare, 2002; Dröes, 2007; Gilmour and Huntington, 2005; Macquarrie, 2005; Macrae, 2008; Phinney, 2002; Sorell, 2005; Steeman et al., 2006). Recent overviews of the literature on experienced dementia from the patient’s perspective demonstrate that the impact of dementia on people’s everyday life is significant. On the other hand it becomes clear that the illness is not endured passively and that the people who are experiencing it are continuously adjusting in an effort to integrate the disease into their life (Steeman et al., 2007; De Boer et al., 2007). The effects of adjusting (adaptation) and learning to deal with the disease (coping) on the experiences of people with dementia are largely neglected in the literature. To what extent do people with dementia suffer due to their disease?

These questions are also important in the context of the ongoing debate about physician-assisted suicide in the case of dementia. The media and the popular press regularly call attention to the unbearable prospect of a life with dementia, as for example in 2008 following the suicide of Flemish author Hugo Claus. The 2002 report of the Dutch Health Council (Gezondheidsraad) also suggests that people in the early stages of the disease can (still) be painfully aware of their situation and can suffer unbearably and hopelessly under the prospect of their future deterioration (Gezondheidsraad, 2002). Based on this assumption and in view of the increased possibilities of early diagnosis of dementia in recent years, one would expect to see, after the euthanasia act (Wet toetsing levensbeëindiging en hulp bij zelfdoding, 2001) came into effect, an increase in euthanasia among people with early-stage dementia, who are still able to autonomously express their desire to die. However, this was not the case. The number of reported physician-assisted suicides based on dementia is very limited and totals only 22 cases since 2003 (broadcast NOVA television,
2 January 2010); these were all people in the early stages of dementia. One potential explanation for the limited number of cases of euthanasia in dementia may be found in the reserve of physicians, although this relates mainly to the situation of elderly people in advanced stages of dementia who have an advance euthanasia directive (Hertogh et al., 2007a; Van Delden, 2004). It is also possible that physicians do not understand or recognize requests from people with early-stage dementia as such. A third explanation might be that the number of actual requests for assisted suicide by people with dementia is not as high as it was expected or thought to be. So far the perspective of the persons with dementia has received little attention in this context. Despite the increased literature on how people with dementia experience and assess the consequences of their illness, their views on possible ‘experienced suffering’ have been largely ignored (Steeman et al., 2007; De Boer et al., 2007). Participants in the debate on this issue are predominantly healthy elderly people who are afraid they may develop dementia in the future, but do not have it (yet).

This article reports on an exploratory field study into the way in which elderly people in the early stages of dementia experience their situation and illness. The central question was to what degree they suffer due to their illness. The study focuses on elderly persons because dementia is very common in this group. We have furthermore chosen to focus the research on dementia of the Alzheimer type, as this is the most common type of dementia.

METHOD

Participants
The participants in this study, all elderly people with Alzheimer’s disease according to the DSM-IV criteria (American Psychiatric Association, 1994), were recruited in various ways. The first selection took place on the basis of a large existing database of people with dementia in the Amsterdam region, which was used in previous research on the needs of people with dementia. For this database people were recruited through various care and welfare organizations (Van der Roest, et al., 2009). In addition, participants were recruited through the memory clinics of the University Medical Centres of Leiden (LUMC) and Amsterdam (VUmc). Inclusion required a diagnosis of Alzheimer’s disease and a score of at least 2 and no higher than 4 on the Global Deterioration Scale (GDS) (Reisberg, et al., 1982). Also, potential participants had to be willing and able to consent to participation in the study. The partners or other family members of the participants were also asked for their consent. Exclusion criteria were: severe depression (based on the Cornell Scale of Depression in Dementia (CSDD) (Alezopolous, 1988) or the Geriatric Depression Scale (Yesavage, et al., 1983), or severe language problems (based on the language items of the CAMCOG (Cognitive and self-contained part of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) (Derix, et al., 1991; Roth, et al., 1986). Exclusion was only necessary in the case of one participant whose command of the Dutch language was insufficient to be able to conduct an adequate interview. Data collection took place on the basis of the principles of constant comparison and the purposive selection of participants (‘purposive sampling’) (Patton, 1990) who would be able to provide specific information on the subject of investigation, i.e. elderly
persons with an advance directive and ‘younger’ elderly. Data saturation was reached after 24 interviews (Boeije, 1990). The participants were 14 men and 10 women, all home-dwelling, in an age range of 63 to 89 years old with an average age of 76.3 (SD=7.3), and GDS scores between 2 and 4. Six of the 24 participants had an advance directive at the time of the interview. In five cases this was a standard document as drawn up by the Dutch Right-to-die society (NVVE) [see: http://www.nvve.nl] or a very similar document drawn up by the participant. One participant had formulated a text himself, which included a non-treatment directive and specific wishes with regard to pain relief. The study was examined and approved by the Medical Ethics Committee of VU University Medical Center.

**Interviews and data collection procedure**

The perspectives of the participants in the early stages of Alzheimer’s disease were inventoried using semi-structured exploratory interviews. An interdisciplinary team specialized in medical as well as psychological and psychosocial aspects of dementia care compiled a topics list that covered various aspects of experience and possible suffering. This topics list consisted of: memory problems (description, perceived change, experience, adaptation), limitations due to the memory problems (changes in activities), limitations in social life (change in social contacts/social roles, reaction of environment, support from and communication with environment), self-esteem (dependency, being a burden, feeling useful), and view of the future (development of memory problems, view on care, advance directives, suffering). The interviews took place in the homes of the participants and were conducted by the first author of this article. The participants were given ample space to tell their own story; the interviewer emphasized the importance of their experiences and formulated the questions as openly as possible in order to explore the different subjects on the topics list in-depth. The interview, varying in length from 45 to 90 minutes (average: 1 hour), was preceded by an informal introduction. In most cases the participant’s partner or other representative was present during the introduction as well as the conclusion of the interview, but left the room for the actual interview with the person with dementia. All interviews were tape-recorded and transcribed verbatim.

**Analysis**

The transcripts were subjected to qualitative analysis. The process consisted of reading and rereading the interviews to identify and code themes. In the analysis we utilized the qualitative software Atlas.ti. (Scientific Software Development, 2008). The interviews were coded using a list of codes. The first version of this list was drawn up based on themes included in the interview protocol. Based on two interviews that were to be coded, three researchers (MdB, CVH, RMD) independently assessed the applicability of the categories. Subsequently any differences of opinion were discussed and the code list was adjusted where necessary. All remaining interviews were analyzed and coded independently by two researchers (Mdb, CH, RMD, CJ, JE), in varying combinations. Any discrepancies were discussed until consensus was reached on all themes and coded text fragments.
RESULTS

The analysis of the interviews yielded three themes that are relevant with regard to obtaining more insight into experienced suffering as a consequence of the disease. These themes were named: awareness and attribution of the cognitive problems, the experienced consequences of the cognitive problems in everyday life, and coping with these consequences, including the perspective on the future. The results are supported by quotes from the interviews; each of the quotes is followed by a participant number that indicates which of the participants made the statement. These numbers and the background characteristics of the participants are reflected in table 1.

Table 1 Background characteristics participants interviews

<table>
<thead>
<tr>
<th>Participant</th>
<th>GDS*</th>
<th>Gender</th>
<th>Age</th>
<th>Education level**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>Male</td>
<td>80</td>
<td>Higher</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>Female</td>
<td>89</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>Female</td>
<td>86</td>
<td>Lower</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>Male</td>
<td>79</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>Female</td>
<td>74</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>Male</td>
<td>82</td>
<td>Higher</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
<td>Male</td>
<td>79</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>8</td>
<td>4</td>
<td>Male</td>
<td>80</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>9</td>
<td>4</td>
<td>Male</td>
<td>72</td>
<td>Higher</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>Female</td>
<td>69</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>11</td>
<td>2</td>
<td>Male</td>
<td>81</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>12</td>
<td>2</td>
<td>Female</td>
<td>71</td>
<td>Higher</td>
</tr>
<tr>
<td>13</td>
<td>2</td>
<td>Male</td>
<td>85</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>14</td>
<td>2</td>
<td>Female</td>
<td>70</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>15</td>
<td>4</td>
<td>Female</td>
<td>67</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>16</td>
<td>4</td>
<td>Female</td>
<td>88</td>
<td>Higher</td>
</tr>
<tr>
<td>17</td>
<td>4</td>
<td>Male</td>
<td>65</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>18</td>
<td>4</td>
<td>Male</td>
<td>83</td>
<td>Lower secondary</td>
</tr>
<tr>
<td>19</td>
<td>4</td>
<td>Female</td>
<td>72</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>20</td>
<td>3</td>
<td>Male</td>
<td>73</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>21</td>
<td>4</td>
<td>Male</td>
<td>76</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>22</td>
<td>4</td>
<td>Male</td>
<td>63</td>
<td>Higher</td>
</tr>
<tr>
<td>23</td>
<td>4</td>
<td>Male</td>
<td>70</td>
<td>Higher secondary</td>
</tr>
<tr>
<td>24</td>
<td>4</td>
<td>Female</td>
<td>76</td>
<td>Higher secondary</td>
</tr>
</tbody>
</table>

* GDS = Global Deterioration Scale (Reisberg)\(^{18}\)

** (Lower = primary school; Lower-secondary = pre-vocational secondary ('vmbo') or similar; Higher-secondary = intermediate vocational/higher general secondary/pre-university ('mbo/havo/vwo') or similar; higher = higher vocational/higher ('hbo/wo')
Awareness and attribution of cognitive problems
The extent to which the interviewed participants expressed themselves about the fact that they were experiencing cognitive problems varied. Although a majority acknowledged having memory problems, some participants indicated they hardly had any memory problems, or were not held back by them (box 1, quote 1). Several interviewees were aware they had been diagnosed with dementia, or Alzheimer’s disease and they also used these words (box 1, quotes 2,3). Only when the participant him/herself used the terms ‘dementia’ or ‘Alzheimer’s (disease),’ did the interviewer adopt this term. The response to questions about the cause of the memory problems/dementia was diverse. Participants said, for example, that the problems had started as a result of a cerebral haemorrhage, TIA, or polio; others attributed their memory problems to old age (box 1, quotes 4, 5). Most of the participants who acknowledged having memory problems also spoke about what this meant for their everyday life, and they also demonstrated being aware of the risk of deterioration in the future. There were also elderly persons, however, who did not show any awareness of the unavoidable deterioration. A few individuals had expectations of being cured of the disease or their cognitive problems diminishing or disappearing over time (box 1, quote 6).

Box 1: Awareness and attribution of memory problems

1. ‘but I think it’s not too bad, these memory problems [...] maybe it was worse before, but now I only have no problems at all’. (10)

2. ‘I mean, it feels like you, well let me use the word then, are ‘demented’.’ (3)

3. ‘[...] yes, it’s Alzheimer’s’. (17)

4. ‘[...] but well, they [neighbours] all lived to an old age. They have the same problems I have, I think’. (3)

5. Researcher: ‘And when we talk specifically about your memory problems, do you have any idea where it comes from?
   ‘Well, maybe my age ... is starting to play tricks .. that could be it’. (8)

6. ‘I also still have the crazy idea that I am going to be well again’. (12)

Experienced consequences
The interviews provided a varied image of the experienced consequences of the memory problems/dementia in the everyday lives of the participants. Three sub-themes emerged from the analyses: experiences of loss, self-esteem and being appreciated by others, and suffering.

Experiences of loss
The immediate consequences of the cognitive problems were expressed especially in the many losses that accompany the disease. Although some were reserved, every single participant gave examples and indicated the emotions this stirred up in them. The loss that was mentioned most frequently was the diminished capacity to remember things (box 2, quote 1). Even without formulating it concretely, various participants made it clear that several activities of daily living were lost to them as a result of their memory problems (box
More concretely they mentioned: the loss of communication (box 2, quote 3), the loss of independence/autonomy (box 2, quotes 4,5), and the loss of social contacts (box 2, quote 6). These losses sometimes made the participants feel they no longer belonged (box 2, quote 7).

Box 2: Experiences of loss as a result of cognitive problems

<table>
<thead>
<tr>
<th>Quote</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ‘I’m not saying I can’t, well ehm, that I can’t remember anything ehm anything at all anymore. But it’s not like it used to be.’</td>
<td>(11)</td>
</tr>
<tr>
<td>2. ‘Short and sweet, what I do think is that I am really going to miss more and more things, ehm, of what we used to discuss sometimes or what we did, like .. just those kinds of things .. the normal things to do in everyday life, you know’. Researcher: ‘You miss the things you can no longer do’? ‘Yes, that’s what I miss..I don’t get around to them anymore or I forget them or.. in short. something like that’.</td>
<td>(1)</td>
</tr>
<tr>
<td>3. ‘Well, I used to rattle on forever, so to speak, and I can’t anymore’.</td>
<td>(4)</td>
</tr>
<tr>
<td>4. ‘But that [having to quit driving] I felt was really – that that was a great sacrifice for me, really, I was heartbroken about it’.</td>
<td>(24)</td>
</tr>
<tr>
<td>5. ‘[…] look I always worked, like, our our home finances, you know, so to speak so ehm paying and so on and so on and so on … I usually did that’[…] ‘but I don’t do that anymore now.’</td>
<td>(22)</td>
</tr>
<tr>
<td>6. ‘Researcher: ‘But have your contacts changed?’ ‘Yes, you are more ehm lonely actually.’</td>
<td>(9)</td>
</tr>
<tr>
<td>7. ‘But then, I feel like .. God yes, ‘you don’t belong anymore’, you can’t live in that life anymore, how can I put it’.</td>
<td>(3)</td>
</tr>
</tbody>
</table>

Self-esteem and being appreciated by others

The initial reaction of the majority of the participants was that they did not view or value themselves differently as a result of the memory problems/dementia. For those participants who did, it concerned feelings of embarrassment or frustration about forgetting things or getting stuck in communication (box 3, quote 1). As the interview progressed several participants, despite their initial denial, did provide different examples of how their self-esteem is affected. They indicated, for example, that the memory problems negatively impacted their sense of self-worth (box 3, quote 2), and ‘no longer feeling useful’ also proved to have a negative effect on feelings of self-worth (box 1, quotes 3, 4). Several participants indicated the importance of social contacts. Interacting with and being appreciated by elderly persons in their environment turned out to have both positive and negative effects on the way in which the participants experienced their situation. Examples of positive experiences based on social contacts become clear from the stories about travelling together, enjoying nature together, or playing cards with friends. Negative experiences were generated mainly by the lack of understanding from the environment and the changing attitudes of some people around them (box 3, quote 5).
Box 3: Self-esteem and being appreciated by others in relation to memory problems

1. Yes .. it’s hard you know, and then you want to bring something to mind, but you don’t remember anymore, you know. And that frustrates me, yes’. (23)

2. ‘Obviously it is a feeling like ‘why don’t I know these things anymore’, ‘am I still somebody.’’(3)

3. ‘Well, because I ehm sit in my chair all day, and ehm actually ehm am no help at all with all kinds of, a lot of, not-not with household ehm things, but still with ehm, with all kinds of, maybe small errands ehm that I used to do, and that, I ehm, that ehm that has gone completely downhill, I have, ehm, turned into nothing more, ehm, than a chair sitter’. (13)

4. ‘... at the moment I feel I simply don’t .. how can I put it.. ‘somebody who is in the closet’.
   Researcher: ‘Somebody who is in the closet, what do you mean by that?’
   Participant: ‘Well, someone who observes life from afar’. (3)

5. Researcher: ‘And do you also feel that the people around you have started appreciating you differently?’
   Participant: ‘Ehm, yes, they won’t show it, but they do anyway in a different way’.
   Researcher: ‘And how can you tell?’
   Participant: ‘The way they .. they try to talk to you. Well, that goes fine for a while and at some point it goes a little less fine or whatever and then they quit, or … that’s the kind of thing that happens.’
   Researcher: ‘So they treat you differently than before?’
   Participant: ‘Yes, yes, they don’t want to, but it happens.’
   Researcher: ‘And what is that like for you?’
   Participant: ‘Well, it’s not fun, but there’s nothing I can do about it’. (4)

Suffering
The participants were asked to give their opinion on the generally negative image in our society in which dementia is associated with a situation of suffering. The participants’ first response to this question was always negative. ‘Suffering’ in the broad sense of the word was deemed ‘too heavy’ a word and elderly people used more subtle wording, such as ‘no fun’, ‘annoying’, ‘unpleasant’ or ‘frustrating’ to describe their negative experiences (box 4, quote 1). Several participants spoke about how they initially avoid discussing their negative experiences and feelings (box 4, quote 2). By putting the participants at ease, taking the time and stimulating them as much as possible to express their own experiences, the participants opened up and several of them mentioned feelings of discomfort, anxiety, pain and sorrow over the course of the interview (box 4, quote 3). A number of them explicitly indicated, as the interview progressed, they were suffering, especially due to the experiences of losses and the accompanying negative emotions, but they immediately put the severity of this suffering in perspective (box 4, quote 4). Also, several participants expressed concern about the wellbeing of their partner or other family members who cared for them (box 4, quote 5).
CHAPTER 3

Box 4: Suffering due to memory problems

1. ‘Ehm ... no, that is o- o- overstating it a little suffering under but ehm annoying is what I think think it is’. (17)

2. ‘You also don’t make a show of it. You try to hide it as much as possible’ … ‘I do believe that does make you suffer, yes, but you try to gloss over that as much as possible’. (4)

3. ‘Well yes naturally it has an effect on you, you know, I mean you ehm it bothers you constantly and that’s why you really always are a little sad about the whole thing you know so ehm ..’ (24)

4. ‘Yes well yes, I think – I do think I suffer because of it yes, because I obviously hate it, and and and you ehm depend well depend a little more on others, you know and ehm on yourself also, that the things you think like ‘oh god what what what- how how did that go again’ and that sort of – that this forgetfulness, that is the worst for me, and that makes you suffer, yes. ... But I act like it’s a tragedy, but it is.’ (24)

5. Participant: ‘And ehm, but yes, I, and then I do think, where is this going? That is a real problem for me’. 
Researcher: ‘Yes’.
Participant: ‘That really bothers me tremendously. It ehm, all the more for my husband too. But he says that he [copes] terribly well (?), but I can already tell that he suffers enormously under it’. (14)

Coping with the experienced consequences

The interviewed participants described different ways in which they tried to accommodate the consequences of their cognitive problems. Several of them indicated not (yet) being too inconvenienced by the consequences, or having the idea that it bothered others more than it bothered them (box 5, quotes 1,2). A few individuals indicated not feeling the need to talk about the consequences of the memory problems (box 5, quote 3); others, on the other hand, opted to do just that (box 5, quote 4). The interviewees frequently indicated how the experienced consequences of the cognitive problems were accompanied by various emotional reactions, which they either expressed immediately, or not (box 5, quotes 5-7). One of the participants indicated mostly avoiding difficult situations (box 5, quote 8). In different ways the participants formulated how they tried to embrace their (constantly changing) situation by accepting the changes, putting them into perspective, resigning themselves to them or staying positive (box 5, quotes 9-12). Others described how, once they started experiencing the memory problems and their consequences, they adjusted their views on the impact of the problems in a positive sense compared to what they thought before developing the disease (box 5, quote 13). Although some participants had an advance directive documenting their wishes regarding future care and treatment, most of them said very little about it. One of them clearly postponed the applicability of this directive (box 5, quote 14).
Box 5 Coping with the experienced consequences of cognitive problems

It’s not too bad
1. How does this affect you [your memory problems]?  
   ‘Ehm, very little actually, very little. What I I I actually have no memory problems. I only have problems that my, my life- my age ehm are possibly explained by my age.’ (6)

2. Participant: ‘[...]my memory problems. so far i myself don’t have a problem with it.’  
   Researcher: ‘It doesn’t bother you much is what you are saying?’  
   Participant: ‘Well, maybe it bothers other people more than it bothers me ...’. (2)

Talk /not talk about it
3. Participant: ‘...I do not talk about myself, I don’t like to speak talk about it’.  
   Researcher: ‘No, you don’t feel the need to?’  
   Participant: ‘No, because I feel it’s bad enough that I have it’. (17)

4. Participant: ‘Does it help you that everyone knows that?’  
   Researcher: ‘Yes, yes of course. I am no ehm, yes it is better that they do know how I think and what I do and that they know why I don’t say anything sometimes.’ (21)

Emotional reactions
5. ‘Well yes naturally it has an effect on you, you know, I mean you ehm it bothers you constantly and that’s why you really always are a little sad about the whole thing you know so ehm . ((coughs)) yes it does cause you ehm mental sorrow also’. (24)

6. ‘I have just become terribly emotional because I fight it, the powerlessness’. (14)

7. ‘Yes, inside I am angry then, but I try not to show it, you know because then you are really wrong of course’. (4)

Avoidance
8. ‘You obviously already start cutting off certain things, you know, when you think ‘well, I’m not getting into that, because I will only mess up, so try to avoid it’. (24)

Accepting/ putting into perspective
9. Participant: ‘I was a very keen driver, I still am, but unfortunately I am no longer allowed to drive’.  
   Researcher: ‘No’.  
   Participant: ‘But that I felt was really – that that was a great sacrifice for me, really, I was heartbroken about it. O well, yes but I am also down-to-earth I think ‘I’ll just do it then’ if that is the worst thing you have to give up, then it’s not so bad [...] ‘And I try to talk to myself, you know. I do that often.”

10. ‘Yes, yes some resignation ... actually... I suppose’. (1)

11. ‘I try to remain positive as long as I can’. (20)

12. ‘I simply have to accept that I that I that .. that it ... is left behind, let me put it that way. You know. You can get upset about it, and I did at first, but it hurts you more than anyone else, and then I just accept it’. (5)

Changing/not changing view
13. Participant: ‘No, I feel, feel experience it yourself, that I, actually, ehm, while when you are facing it, facing it, you dread it, but when you are in the middle of it then it’s not too bad’.  
   Researcher: ‘Really? Before you developed memory problems, you had very different ideas about it, then ..’
   Participant: ‘Well, then you look at it from the outside and then you think, well it must be bad to have that. And now that you experience it every day, I don’t see it as a major problem anymore’. (7)

14. Participant: ‘There is a whole text that I ehm don’t really want to experience this’ ... ‘You know. And that I want to ehm well yes be put out of my misery in that case’.  
   Interviewer: ‘For this moment also?’  
   Participant: ‘Well, that is a bit premature I think’ .. ‘Because I still feel quite good’. (21)
DISCUSSION

By engaging elderly people in the early stages of Alzheimer’s disease in conversation we have gained an idea of how they experience their situation and illness, and the extent to which they suffer under the consequences of their dementia. The experiences of elderly people with Alzheimer’s disease prove to be dependent on the degree in which they are aware of their cognitive problems, the specific consequences this has for them and especially the way in which they cope with these consequences.

The interviews in this study demonstrated that the majority of the participants were aware - in varying degrees - of the fact that they had memory problems: acknowledgement of the problem, including putting a name to it using the words ‘dementia’ or ‘Alzheimer’s’, was not exceptional. In addition there were elderly persons who indicated not being troubled by memory problems, or who described them as something that is ‘normal for our age’. Recent research demonstrates that apart from neurobiological factors (cognitive decline), psychological (f.e. coping strategies, personality) and social factors (f.e. social network, reactions from and interaction with others) also influence the degree to which people with dementia are aware of their situation (Clare, 2002; Steeman et al., 2007; Phinney, 1998; Clare, 2004). The influence of psychosocial factors also emerged in our study because participants opened up during the interview as they became more at ease with the interview situation and the interviewer: initial denial was replaced by explicitly naming the problems and it regularly resulted in great candour about personal experiences with Alzheimer’s disease.

The many negative experiences and related emotions described by the participants in our study demonstrate that the effect of this disease on the lives of the elderly who suffer from it is considerable. What was remarkable was that talking about this still seemed to be taboo. Several participants initially did not speak directly about their negative experiences. Only in the course of the conversation, as they started to feel more at ease, did the subject come up. One possible explanation is that elderly people with dementia in an unsafe environment are afraid to show too much of themselves and their painful experiences for fear of being rejected or disqualified, as also suggested by Clare (2002) and Steeman et al. (2007). However, the experiences of the participants appeared to be less negative than is often assumed (De Boer et al., 2007). The participants in this study indicated they did not experience their situation ‘as a whole’ as one of dreadful suffering; the word ‘suffering’ was generally considered ‘too heavy’. They mentioned various ways in which they tried to deal with the challenges the disease confronts them with, for example ‘talk about if often’, ‘avoid difficult situations’ or ‘try to stay positive’. In spite of their negative experiences they did not appear to undergo the disease passively, but every individual in his own way tried to face up to the constantly changing situation. In part thanks to the gradual progression of the disease there is room for adaptation and coping. This means that the experiences of elderly persons with Alzheimer’s disease seem to be different from those suggested by the negative image that exists in society.

A possible limitation of the current study could be that we talked primarily to elderly people who, either on their own initiative or together with their family, actively sought help when
the first symptoms manifested themselves; for these were participants who for the main part had been diagnosed in memory clinics, or were recruited through care and welfare organizations. Possibly the experiences of these elderly persons reflect a different, more positive image than the image of the still very large group of elderly people who are in the same stages of the disease, but who do not seek help for their problems early on. However, in view of the candour of the participants in this study and the variety of experiences they described we are of the opinion we have gained a solid insight into the experiences of elderly persons in the early stages of Alzheimer’s disease.

The research demonstrated, among other things, the feasibility of talking with them about the way in which they experience and assess their situation. When entering into such a conversation it is important to take the time, to put the person with dementia at ease, and give them ample room to tell their personal story. The trust that this creates between researcher and person with dementia in this study resulted in a high degree of candour regarding personal experiences. Several participants appreciated the interview so much that they took the initiative to inquire about the possibility of follow-up conversations immediately after the interview, or they contacted the researchers again by telephone some time after the interview.

A second important finding from this study is that the gradual deterioration that characterizes Alzheimer’s disease at the same time provides room for adjustment (adaptation) and for learning to deal with the consequences (coping). This means that the experiences of elderly people with this disease can differ in a positive sense from the negative ideas that ‘healthy’ elderly people often have about how they would experience the disease if they were ever to develop it. It also means that the current wishes of people with Alzheimer’s disease with regard to care and treatment may deviate from the ideas they had before they were diagnosed and may have recorded in an advance directive. It therefore appears that the well-known phenomenon of the ‘disability paradox’ also occurs in dementia (Albrecht and Devlieger, 1999; Hertogh et al., 2007b). Furthermore, attention has also been given in the literature to the difference in how quality of life is assessed by the patients and by proxies, with the patients often having a more positive judgement than their loved ones (Sands et al., 2004; Ready et al., 2004). For this reason it is essential to keep communicating with people with dementia themselves about their experiences and wishes. It is quite conceivable that changes in the wishes and needs of people with dementia once they have been diagnosed, may contribute to only few of them making a request for physician-assisted suicide. This could explain the limited number of cases of euthanasia/physician-assisted suicide in dementia.

The findings of this study emphasize the importance of involving elderly people with dementia in research. It is eminently possible to talk to these persons in the early stages of dementia, which is essential in planning the type of care and treatment that best fits their current wishes and needs.
REFERENCES


