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ORIGINAL ARTICLE

Living with dementia from the perspective of older people: Is it a positive story?

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Abstract

Dementia, even at an early stage, may pose problems and challenge one's quality of life. Having accurate knowledge of what one experiences when living with dementia is important for developing proactive care for individuals with dementia and their families. The aim of our Grounded Theory study was to explore what it means for elderly people to live with early-stage dementia. We interviewed 20 elderly people with probable mild dementia and their family members. Living with dementia was often presented as a positive narrative, one that told of only minor problems and which stressed abilities and contentment with life. Being valued, rather than losing one's cognition or identity was central in their experience. More in-depth analyses of participants' narratives revealed, however, that they were constantly balancing their feelings of value and worthlessness, struggling to remain someone of value. This struggle was prompted by threats posed by dementia and by the persons' interactions with others. Superficially, a positive narrative may be understood as a lack of awareness or as denial due to cognitive loss. Our findings suggest, however, that we should look beyond this superficial view and seek to understand the narrative as an expression of one's attempt to counterbalance devaluation.

Introduction

Dementia is increasingly diagnosed at an early stage. Assuming that the number of therapies aimed at slowing the progression of dementia increases in the near future, more and more people with dementia will remain for longer in the early stages of the disease (Sloane et al., 2002). In early-stage dementia, independent living is still possible, but memory loss interferes with more complex activities of daily life and with work and social activities (DSM-III-R, 1987; ICD-10, 1993). Early-stage dementia is a time of transition when individuals pass from being independent to being more dependent. New proactive care modalities to support these persons and their families should be developed (Sloane et al., 2002). At present, in most countries, research and care mainly focuses on managing the disease and not as much on arranging the best conditions for living with early stage-dementia (Grypdonck, 2005).

Research on quality of life of persons with dementia reveals that self-reports of persons with dementia and proxy reports of professional

caregivers may differ (Hoe, Hancock, Livingston, & Orrell, 2006). Persons with dementia apparently rate their quality of life more positively than their caregivers do (Thorgrimsen, Selwood, Spector, & Royan, 2003). These differences in perspectives indicate a need for a better understanding of the lived experience of persons with dementia. Having insight into what one experiences when living with early-stage dementia is required in order to ensure effective care (Grypdonck, 2005); it enables health care practitioners to adapt their care to their patients' perception of reality (Gerhardt, 1990). In this article we report on views of older people living with early-stage dementia and the meaning they attribute to their condition.

In 2000, at the outset of our study, we could identify only nine empirical studies on the experience of living with dementia, specifically studies reporting first-hand perspectives. In recent years a growing number of studies have explored the lived experience of dementia. We conducted a literature

review, the results of which are published elsewhere (Steeman, Dierckx de Casterlé, Godderis, & Grypdonck, 2006). The review of 43 identified studies revealed the following core findings: People with early-stage dementia must deal with many losses—concrete losses, such as losing track of conversations (e.g. Holst & Hallberg, 2003; Phinney & Chesla, 2003); losing track of time (e.g. Nygard & Borell, 1998; Phinney, 1998); forgetting names and events (e.g. Keady, Nolan, & Gilliard, 1995; Phinney, 2002); and loss of practical skills (e.g. Keady et al., 1995; Phinney & Chesla, 2003). These losses threaten their security and autonomy and their ability to be meaningful members of society (Harris & Sterin, 1999). Devaluing interactions increase this threat (e.g. Holst & Hallberg, 2003; Van Dijkhuizen, Clare, & Pearce, 2006). Memory difficulties may make it difficult for persons with dementia to understand their circumstances or to hide their problems from others, causing frustration, uncertainty, and fear (e.g. Clare, 2003; Harris & Sterin, 1999; Holst & Hallberg, 2003). Indeed, those persons with dementia may suffer much in silence (e.g. Keady & Gilliard, 2001; Robinson, Ekman, Meleis, Winblad, & Wahlund, 1997). While some persons keep struggling and may develop depression, other persons with dementia are able to adjust successfully (e.g. Harris & Sterin, 1999; Werezak & Stewart, 2002). These latter persons seem to accept their loss and adopt a positive attitude by trying to make the best of it and enjoy life (e.g. Harris & Durkin, 2002; Keady et al., 1995; Thorgrimsen et al., 2003; Werezak & Stewart, 2002).

Several studies have found that individuals with dementia experience tension between self-protecting and self-adjusting strategies to cope with perceived losses and threats and to preserve their identity. Keady et al. (1995) noted a 'tension between preserving skills and independence while also covering up cumulative losses' (p.16). Pearce, Clare, and Pistrang (2002) described a circular process in which individuals with dementia attempt to manage their sense of self and need for reappraisal and attempt to construct a new sense of self. Similarly, Clare (2003) observed a spectrum of responses to memory difficulties, ranging from self-maintaining expressions to self-adjusting ones. Within Clare's spectrum of coping responses, Van Dijkhuizen et al. (2006) revealed a tension between connectedness with others and the environment and disconnectedness due to cognitive decline. Coping strategies were aimed at maintaining a sense of connectedness and hence a sense of self. MacQuarrie (2005) identified a dialectical tension between agency and objectification.

Integration of dementia into an individual's life is cyclical, since disease progression can bring new difficulties that have to be addressed (e.g. Clare, 2003; Werezak & Stewart, 2002). As they adjust to the cognitive impairments of their loved ones, family

members can either help or hinder the individual to deal successfully with dementia (e.g. Clare & Shakespeare, 2004; Snyder, 2002; Van Dijkhuizen et al., 2006). Similarly, professional caregivers can either support or hinder the efforts of the individual and his or her family to deal with the disorder (e.g. Young, 2002).

Even though today there are a large number of studies on the lived experience of early-stage dementia, we believe our study can further refine and deepen our present understanding of living with dementia. The aim of the present study was to provide a better understanding of what it means for older people to live with early-stage dementia; the long-term goal is to develop a model that promotes proactive care. We explore how these people come to understand their dementia and how they cope with life changes.

Methods

Participants

We conducted a Grounded Theory study (Charmaz, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990) using a sample which comprised (1) older people diagnosed with probable dementia and (2) some of their family members, drawn from five memory clinics in Flanders, Belgium. For the participants with dementia, inclusion criteria were (1) aged 65 years or older; (2) a recent medical diagnosis of probable dementia; (3) a Clinical Dementia Rating (CDR) score of 0.5 (questionable dementia) or 1 (mild dementia) (Hughes, Berg, Danziger, Coben, & Martin, 1982); (4) living at home; and (5) Dutch speaking. Exclusion criteria were (1) severe aphasia, deafness or severe hearing problems; (2) presence of severe psychiatric problems. We included family members in our study sample to help us better understand the social context of the person with dementia's lived experience and for data triangulation. The inclusion criterion for family members was that they had to be Dutch speaking.

Procedure

The memory clinic teams sought out potential participants, informed them about the study, and obtained permission from the participant and/or his family to be contacted by the researcher for further information. The researchers were not affiliated to the memory clinics. Table I summarises the characteristics of the 20 persons with dementia that participated in our study. The sample comprised a range of participants, in terms of CDR-scores, gender, a wide range of ages (69–91 years), diagnoses of dementia, and different kinship ties (son, daughter, spouse, niece).

Table I. Characteristics of the participants.

Person	Type of interview (P = person alone, F = family member(s) alone; P + F = person and family member(s) together)	Sex (F = female; M = Male)	Age	Family member	Diagnosis (derived from medical records)	CDR-score per interview					Reason for drop-out
						1st	2nd	3rd	4th	5th	
A	F	F	81	Daughter	Alzheimer	1	1	2	3		
B	F	F	71	Spouse	mixed dementia: frontotemporal, vascular, Alzheimer	1	1	3			
C	P + F	F	77	Daughters	Alzheimer	1	1	-	-		
D	P + F	M	69	Spouse	(Sub) cortical atrophy	1	-	-	-		Interview too painful
E	P + F	F	91	Son	(Sub) cortical atrophy	1	2	2	-		CDR > 1
F	P + F	M	76	Spouse	Alzheimer	0.5	0.5	0.5	-		
G	P	F	76	Daughter	(Sub) cortical atrophy	0.5	0.5	0.5	-		
H	P	F	72	Daughters and sons	Alzheimer	1	1	1	2		
I	P + F	M	87	Daughters	Alzheimer	0.5	-	-	-		Deceased
J	P + F	F	69	Spouse	(Sub) cortical atrophy	1	1	-	1		
K	P + F	F	82	Daughter	Alzheimer	0.5	0.5	0.5	-		
L	P + F	F	80	Son	Alzheimer	1	0.5-1	-	-		
M	P + F	F	73	Daughter	Alzheimer	0.5	0.5	0.5	-		
N	P	F	78	/	Alzheimer	0.5	0.5	1	-		
O	P + F	F	91	Daughter	(Sub) cortical atrophy	1	1	2	-		Admission to nursing home and CDR > 1
P	P + F	F	76	Daughter	Vascular dementia	0.5	0.5	0.5	-		
Q	P + F	F	80	Daughter	(Sub) cortical atrophy	1	2	-	-		Attention deficit and CDR > 1
R	P + F	F	80	Daughter	Alzheimer	0.5	0.5	0.5	-		
S	P + F	M	75	Spouse	Alzheimer	0.5	1	-	-		Interview too painful
T	P + F	F	77	Niece	Alzheimer	1	1	3	-		admission to psychiatric unit

Ethical considerations

We obtained ethical approval to perform the study from the Institutional Review Board of the Faculty of Medicine, Catholic University, Leuven. Written informed consent from both the persons and their family members was obtained initially; however, at each interview the information was repeated and consent was obtained orally. We also asked permission to inspect the medical records of the persons with dementia. All family members but only nine of the people with dementia were informed of the diagnosis. The remaining people with dementia were told they had memory problems. We opted to use the term 'memory problems' instead of dementia in our initial introduction to the study and when interviewing the persons.

Data collection

We interviewed persons with dementia and their family members together and separately, unless the person or family requested otherwise. To detect changes in lived experiences, we attempted to interview each person three to four times over 1.5 years. The median time between diagnosis and the first interview was 12.5 weeks (Q₁-Q₃: 7-15 weeks). In total, 74 interviews were held, 30 with people with dementia alone, 21 with family member(s) alone, and 23 with the person and family member(s) together. Interviews lasted on average 60-90 minutes. Except for the first few interviews, in which we used a structured outline to guide the discussion, interviews were loosely structured. Subsequent in-depth interviews focused on themes that emerged from the ongoing analyses. During, and immediately after each interview, the interviewer made field notes about the person's non-verbal expressions and his/her perceptions of the interview. Interviews were tape recorded and transcribed verbatim.

Data analysis

Interviews were read entirely to obtain an overall picture of the interview before being coded. The first eight interviews were coded line-by-line. Passages addressing our research question were coded as closely as possible to the actual words of the participants (in vivo coding). By comparing interviews and coded fragments, we developed concepts that were used to guide the next wave of data collection. A central concept emerged, allowing us to focus our data collection and analysis. Throughout the analyses, we clarified the emerging concepts, categories, relationships between categories, and hypotheses by carrying out new interviews, reanalysing previous interviews, analysing cases that differed, and performing a literature review. All data analyses were performed with the NVIVO software package (QSR International).

We used several strategies to increase the trustworthiness of our data. Data triangulation (Kimchi, Polivka, Sabol, & Stevenson, 1991) was accomplished by interviewing the person with dementia and family member(s) separately and together. Analysis triangulation (Kimchi et al., 1991) incorporated methods of Grounded Theory and narrative analysis. More than one person analysed the data. The principal investigator read and coded all interviews. Two other investigators read and coded portions of the interviews. Qualitative research experts and dementia care experts tested the interpretation by a random inspection of the interviews (testing the whole by its parts) and discussed the heuristic relevance of the findings. Peer debriefings prompted us to adapt the interview style, produce suggestions for analysis, validate our findings, and clarify our concepts. Finally, our research and interpretation process was meticulously written out (decision trail).

Data analysis comprised three major phases: a quest to understand the meaning of the initial findings, resulting in a deeper level of analysis; the development of a model around the central concept and analyses of changes over time. In this paper, we describe the first two phases and their results and the research process that led us from the first phase into the next. It is important to know the research process in order to understand our final results and implications for practice.

Results

Analysis of the first 11 interviews revealed a positive story of being valued from participants' reports about living with early-stage dementia. Although our initial analyses advanced the idea that being valued is a central concept for the persons (De Bal, Steeman, Dierckx de Casterlé, Grypdonck, & Godderis, 2004), we remained sceptical about whether living with early-stage dementia was really experienced as positive as participants presented it to be, in other words should be taken at face value? Deeper analyses led us to conclude that a 'balance between being valued and being worthless' more accurately portrayed the participants feelings. Focused analyses led us to propose a model in which the positive story of being valued is, in reality, the person with dementia's expression of a struggle to *remain* someone of value.

Phase 1: A positive story about 'being valued'

Most participants related a positive, but rather superficial, impression of their life history and current situation (see Figure 1). Recurrent themes were the minimizing of memory problems and the emphasizing of remaining competencies related to knowing, doing, being, and self-value.

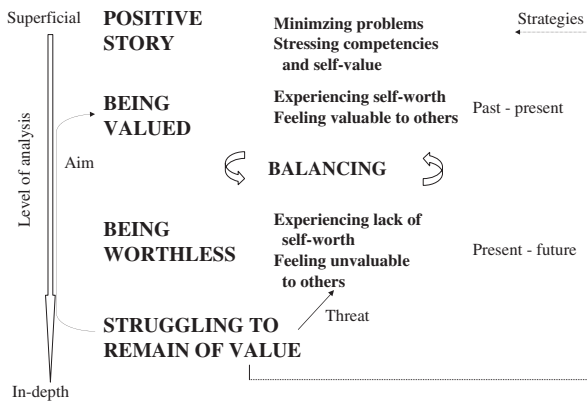


Figure 1. Model of struggle to remain of value.

Minimising memory problems

Although all individuals with dementia admitted to having memory problems, some minimised these problems, particularly with regard to the causes, manifestations, and consequences. Most individuals sought external reasons for their memory problems, relating them to the death of a spouse, disease, loneliness, fatigue, change in environment or habits, the weather, retirement, and hospitalization. Such reasoning supported their view that their memory problems were temporary. Other individuals considered their memory problems to be associated with normal aging. Only a few expected their memory to worsen, or they alluded to becoming demented in the future.

Most individuals perceived their memory problems as manifesting themselves in minor matters: 'Serious matters I don't forget that easily' (interview 10.1). Frequently mentioned memory problems included forgetting recent events, names, dates, and where one had put things, and problems with learning new tasks or information. The persons typically viewed their physical problems as being worse than their memory problems. Moreover, they often considered their situation to be less bad than that of others. They also mentioned that their memory problems fluctuated from day to day, as in having good days and bad days.

The persons usually minimised the consequences of their memory problems. Although their memory problems could potentially interfere with house-keeping or social or leisure activities, they felt that such interference would be negligible and would not greatly affect their contentment with life. They frequently commented that everybody has problems. Individuals mentioned that, should they have trouble managing, they could always count on their spouse or children for help.

Emphasizing the remaining competencies and self value

Instead of focusing on lost competencies, most participants emphasised their remaining competencies related to knowing, doing and being.

Person with dementia (PWD): 'I can read, I can write, I can calculate, I can do all sort of things, I understand everything, I comprehend everything...' (interview 9.2)

PWD (proud): 'I am the granny' (interview 4.1)

Participants put much emphasis on past and present accomplishments. They expressed contentment with their past and their present life, and commented on being loved and valued by family and friends and about being grateful for their help. This is illustrated in the following interview excerpt from a conversation with lady talking about her sons:

PWD: 'I can't complain, because I can still do some things... I can't work anymore as I used to, but I still take care of my dinner and so forth. And I still help with the cleaning. Light chores, nothing too heavy. And my son does everything else'

Interviewer: 'So you get along well?'

PWD: 'Yes, very well! Yes, and they would go through fire and water for me; if I just need or say anything, they are there immediately. They are tremendously kind to me, I have to say, both of them.' (interview 7.1.)

By integrating into our analysis these positive aspects, we identified the central theme of being valued.

Being valued

Being valued can mean experiencing self-worth or feeling valuable to others (see Figure 1). Experiencing self-worth was linked to the person's ability to meet their current life expectations, which was expressed as contentment with their present life:

Interviewer: 'Is there anything else that you would like to tell me, anything that I haven't asked or haven't thought of?'

PWD: 'I'm pleased, still pleased that I am here... I'm pleased that I still am here [in the world]. Many of my friends have died, that's for sure. But that's how life is.' (interview 4.1.)

For other individuals, being valued was manifest in expressions of being loved and being cared for by family and friends. These individuals were grateful that they could always rely on family for help. Some individuals, however, stressed the importance of being autonomous, not being a burden to their family. Autonomous thinking was more prevalent in younger individuals, as shown in the following interview of a 72-year-old woman talking about her children:

'They know if I'm really in trouble, I'll always tell them. Or, at least, if I'm stuck, someone will always come. Yes, they would never abandon. But I don't want to burden them; I want to be independent. That's what I want to be, as long as I can. And I think that is the way it should be.' (interview 3.1.)

In contrast, older individuals showed more flexibility in being dependent on others. Rather than seeing dependence as limiting one's autonomy, older individuals viewed it as a privilege that comes with old age and after years of hard work or having been a good parent.

PWD: 'I don't clean that much anymore. That's my maid (pointing to her son). He does everything. Actually, I don't need to do anything anymore, if I don't want to. But I still try to keep busy, doing one thing or another. Not the heavy work, but I still try to do as much as possible.' (interview 7.1)

Some people indicated that they did not always agree with their family's perception of their memory problems or whether they needed help, but they felt that their family members acted out of good will. Feeling valuable to family and friends was also manifested in the persons' reciprocal expressions. For example, they acknowledged their children's busy life by helping them to manage the household. Individuals with dementia not only wanted to feel valued by their families, but they also wanted to feel valued by society. They stressed qualities such as being social-minded, being a hard and skilled worker, or being a leading figure.

PWD (laughs): 'I used to go to the Federation meetings.'

Daughter: 'She was a member of all kinds of associations. She was a member of the Federation of Large and Young Families; she was a member of its executive committee.'

PWD: 'Oh, I was in charge for many years. (talking about a lady she met) Well, I accosted her, because I know her very well. She said: "But your leaving was a great loss for us". I said: "But you are not so active yourself anymore, are you". "Yes, but", she said, "we lost a lot after you left."

Interviewer: 'And how do you feel when people say those things?'

PWD: 'Then I feel extremely honoured. That's really true. That's a sign that they valued you at that time.' (interview 11.1)

A positive story?

Although memory problems in early-stage dementia may 'objectively' have only limited consequences, we wondered whether living with early-stage dementia was really as positively experienced as our participants described, because the literature suggests otherwise (e.g. Keady & Gilliard, 2001; Robinson et al., 1997). Moreover, the participants' emphasizing of positive aspects, our observations of the person's memory problems, and the contrasting views from family members all suggested that living with early-stage dementia may be more troublesome than was portrayed by the persons.

Throughout the interviews, the persons emphasized positive aspects with striking frequency, as if trying to convince the interviewers. This is exemplified in the following excerpt from an individual who repeatedly talked about her intelligent friends to stress her own value:

PWD: '... this one friend, she is very, very clever; and she also has very clever children—a doctor, gynaecologist—well, I don't know what, very clever children, all of them. Well, and she has to depend on me totally if we go anywhere. And she is an extraordinarily clever person.' (interview 8.1.)

We frequently encountered expressions such as 'not yet' and 'if only it can stay as it is' during the interviews. The use of these kinds of expressions may point to the anticipation of future cognitive problems. Such expressions may also indicate that individuals are aware that their condition is not as normal as they want people to believe. Another plausible explanation is that old age is accompanied by an expectation of a less bright future.

We observed the persons' memory problems throughout the interviews, even when they indicated that they had no problems. Individuals had word-finding difficulties, lost track of conversations, went off on tangents, and repeated the same stories. They also had difficulties answering abstract questions. 'I don't know' or 'I don't know anymore' were frequent responses. At times, individuals motioned for their relatives' to help answer questions. Persons sometimes were insecure about saying something wrong. These problems were more apparent among individuals with a CDR 1 score as opposed to those with a CDR 0.5 score.

When confronted with memory problems during the interview, some persons admitted the problem. Yet most often, the persons would reply in a defensive manner, abruptly changing the subject or providing an excuse for the memory lapse.

Daughter: 'How many grandchildren do you have? Do you remember?'

PWD: 'Five, I guess, or how many?'

Daughter: 'No, six.'

PWD: 'Ah, so. You know, I just answered too quickly.' (interview 4.1.)

The views of participants with dementia contrasted sharply with those of family members. Family members highlighted several problems and pointed to changes in their relatives, often focusing on their relatives' losses. In contrast, the individuals with dementia focused primarily on their remaining capacities: 'My bike is my freedom,' one lady said. Although her daughter agreed, she described her mother's 'freedom' as 'aimless riding'. Family members reported that their relative with

dementia sometimes panicked, showed fear, or questioned the veracity of statements about their memory problems.

The seemingly indifferent attitude of our participants with early-stage dementia also contrasted with those described in the literature, which primarily depicts these individuals as ones living in a cloud of loss and suffering.

Analysis of interviewers' attitudes and preconceived ideas

The apparent discrepancies between our preconceived views and those of family members with those reported in the literature prompted us to re-assess our interpretation that individuals with early-stage dementia generally view their situation positively. One possible explanation is that individuals with dementia experience life positively because their decreased awareness hinders them from acknowledging the negative. This explanation, however, does not account for why our participants so strongly emphasized the positive aspects of their lives. Another explanation is that the participants' positivism serves as a façade to mask their inability or their unwillingness to discuss their disabling memory problems. In this case, the participants' positive outlook may safeguard them from negativism; this may explain why our participants strongly emphasized the positive aspects of their lives.

Our analysis of the first eight interviews supported the latter explanation. In these initial interviews, we found that the interviewers focused on what the persons lost due to their dementia; and by doing so, they may have unknowingly painted dementia as an unacceptable deficit. Also, we observed that the interviewers failed to show genuine sympathy (Morse, Bottorff, Anderson, O'Brien, & Solberg, 2006) for the person. Taken together, these two preconceptions may have caused the persons to be more guarded in their responses. To verify whether these biases promoted positive responses from our participants, we instructed the interviewers to be more sympathetic. In subsequent interviews, the interviewers started by asking the participants about the beautiful things of life, with the aim of showing genuine interest in the participants. In these interviews, the participants communicated more negative experiences and tended to spontaneously acknowledge their memory problems:

Interviewer: 'Can I just ask you about the most important things in your life?'

PWD: 'Well, the most normal things [interviewer decided not to correct]. Something that is normal is that we can live our lives as normal people. Unfortunately, these difficulties that we sometimes have, we are sometimes forgetful. That is all. That is what is most important to us.' (interview 17.1)

Negative case analysis

We noted in our analysis of subsequent interviews and re-analysis of previous interviews that the persons' positive story was not always maintained. This was especially the case after we changed our interview style; positive and negative aspects alternated in the person's story. The degree to which the persons were positive varied, ranging on a continuum between predominantly positive and predominantly negative. Only in two cases the story was predominantly negative.

Analysis of negative aspects also pointed to the central theme of a lack of being 'valued'. Feeling worthless was related to a lack of feeling value for oneself or for others. Losses of competencies were also mentioned. These losses were associated with memory problems, but also with growing old in general, to physical illness, to widowhood, and to retirement. Participants also voiced experiences of devaluation by family members or caregivers, as well as feelings of uncertainty, loneliness, shame, uselessness, losing one's mind, being disregarded, being restricted, being a burden, being a 'poor devil', and being 'written off'. Unhappiness with the past or present life and sometimes questions about their future well-being were voiced. The individuals talked, for example, about fear of becoming a burden, fear of being placed in a nursing home, and fear of losing their mind.

PWD: 'My daughter had spoken to the physician and he said, It would be better if your father didn't drive a car anymore. The problem is, that really beats you . . . it's like them shooting you dead. Or, at least, you're nothing anymore. It's degrading.' (interview 16.3)

Narrative analysis

No single story was entirely negative. In every story, being valued was continually stressed. Questions arose about how to understand this emphasis. To deepen the analysis, elements of narrative research were introduced.

Narrative research offers the opportunity to discover the meaning of the participant's story, even if the participant himself is not necessarily aware of its meaning (Levering, 2001). Narrative analysis takes into account several dimensions: social, psychological, and anthropological (Cortazzi, 1993). The social dimension relates to the role the participant wants to play in the interview, how he or she wants to be seen, and how the story can serve this purpose. Within this dimension, the positive story could serve as a way for individuals with dementia to present themselves as being competent and as meaningful people. The psychological dimension takes into account cognitive processing and considers the story to be a selective reconstruction shaped through cognitive schemata. These schemata are influenced by prior experience,

personal patterns of knowledge, concepts of self, and expectations of the teller. It means that the positive story of the person with dementia can be true to the teller, without being necessarily veridical. The positive story reveals something about the 'untold' self-image, as narratives of personal experience are shaped by patterns of knowledge of the self. The anthropological dimension conveys that what is told, the way it is told, and what is believed of it, is often determined by culture. The positive story could partly be attributed to a general culture shared among elderly people choosing not to complain and to perceive health problems as part of growing old (Westerhof, 2002). It could also be hypothesized that the age gap between the 'young' researcher and the older person with dementia and the negative image of growing old in western society supported the tendency of the older participant to present himself as a full member of society.

Balancing between being of value and being worthless

We used narrative analysis to analyse the interviews again, focusing this time on what was said and how and when it was said. In this round of analysis, we noticed that when persons admitted to problems, they almost immediately stressed competencies or minimised problems.

Daughter: 'I don't think she would know which pill she had taken and which one she hadn't, because she has an entire box of pills. I don't think she could do it.'

PWD: 'No, that is too difficult; I think so too. I would not be able to remember, because I'm so used to it now. I look in the pill organizer to see if I have taken it.'

Interviewer: 'And how do you feel about the fact that you are not able to do so anymore?'

PWD: 'Oh, I can accept it. If I were a poor soul and had to sit here and do nothing, then it would be worse. But I still do my work here and I drive the car. I don't feel written off as a dead loss. It doesn't bother me that I have to take that pill [acetylcholinesterase inhibitor].' (interview 19.1)

This narrative analysis almost always revealed a theme of balancing between being valued and no longer being valued, or becoming worthless. Some participants explicitly expressed this balancing:

PWD: 'It's not that they [her family] will designate me as such [abnormal], but I don't know; it hurts me, because I know I'm normal. [...] Now, I don't dare to say anything anymore, because I think I'm not normal. And that's why I don't say anything anymore.' (interview 9.2.)

We observed this balancing behaviour between retained abilities and lost abilities, between acknowledgment and denial of memory problems, between affirmation of one's competencies and devaluation

implicit in others' remarks. Being confronted by others with one's failings, especially if the person with dementia him/herself does not experience them, threatens one's sense of self value and prompts balancing.

Spouse: '...He used to be very busy, every day doing all kinds of things; and now he often sits there, just sitting. Do you know what I mean?'

PWD: 'Ha, sitting, or reading, or watching television. Not that I sit here all day. You don't have to exaggerate.' (interview 17.1)

On a more abstract level of analysis, we observed individuals attempting to balance feelings of worthlessness in the present with having been of value in the past; with being of value now and no longer being of value in the future; with being of value for oneself and no longer being of value for others (see Figure 1). This balancing behaviour is similar to the concept of identity crisis described by Bergsma (Bergsma, 2002). We considered this concept of identity in our model development, which helped us to understand the individuals' struggle to be someone of value.

Phase 2: The Positive story: a struggle to be someone of value

Our deeper analysis allowed us to understand better the individuals' positive story of struggle to be someone of value (see Figure 1). Persons with dementia balance their feelings of being someone retaining their value and someone losing their value. Within the schema of concept of identity, one is valued if self-imposed norms about knowing, doing and being and social norms or perceived expectations of the environment are met (Bergsma, 2002).

A person's history is very important to consider when dealing with identity disturbances due to illness. A person constantly compares his present self-image with his historical self-image and with his perceived future self (Bergsma, 2002). In our findings, being valued as part of one's identity is mostly built on past experiences, some on present experiences, and very little on future expectations. Limited life expectations in older age, cognitive disorders due to dementia, and few future expectations in view of a deteriorating image associated with dementia, may possibly explain the narrow perspective of individuals with dementia.

The feeling of being valued is threatened. As previously mentioned, threats come from one's own experiences of cognitive loss, as well as from reactions prompted by the environment, and are perceived as devaluing. In terms of identity, these experiences and devaluing reactions may be perceived as normative disturbances, which especially result when one can no longer comply with norms set by society or imposed upon oneself (Bergsma, 2002). Normative disturbances threaten a positive

self-image. The more the self-image deviates from the applied norms, the easier the person may feel socially rejected.

Using several strategies, the person with dementia tries to evade the threat and tries to maintain the feeling of being valued. Some of these strategies include minimizing, rationalizing, normalizing, or somatising problems; affirming one's competencies; denying problems; avoiding confrontation; using humour; training memory; using memory aids; avoiding reflection; and accepting. All were previously seen merely in the context of a positive story. Within the context of a disturbed identity, these strategies allow one to restore identity. They allow the person to remain someone of value. People make comparisons (social comparison theory) and attribute to themselves and others certain qualifications, allowing their position to remain positive in these comparisons (attribution theory) (Bergsma, 2002). The more self-image deviates from societal and self-applied norms, the more the person will tend to comply with these norms (Bergsma, 2002). This may explain why our participants strongly emphasized positive aspects in the stories.

Discussion

This study sought to better understand what it means to function as an older person with probable early-stage dementia. Our findings support the notion that people with dementia are active agents, who do not passively suffer the consequences of having dementia: they interact with their illness (e.g. Keady & Gilliard, 2001; Kitwood, 1990). We observed that people with dementia are aware of loss but also of retention, to such a degree that they work hard at balancing these two aspects of themselves. Central in their experience is being valued, rather than losing their cognition or identity. Despite these feelings, they struggle to remain feeling someone of value, often in the face of many threats posed by dementia itself and by how others interact with the person with dementia.

Three central findings emerged during our analyses: (1) superficially, the individuals' stories appeared mainly positive; (2) further scrutiny, however, revealed that being valued is important to those with dementia; and (3) eventually, deeper analysis indicated that the persons' positive expressions really reflect a struggle to remain someone of value (see Figure 1). The persons' stress on the importance of being valued closely resembles the findings of Harris and Sterin (1999). They identified three core values organizing the identity of people with early-stage dementia: (1) meaningful productivity, (2) primacy of autonomy, and (3) comfort and security. In our study, the persons' feeling of value was linked with doing or having done things of value for others or for society,

to being autonomous, and to being loved and cared for by others.

Our participants' struggle to retain their value is similar to chronically ill persons' search to regain their balanced identity, a search resulting from the illness' threats to one's identity (Bergsma, 2002). In essence, our empirical findings support the idea that dementia, as with any other chronic disease, threatens one's identity and prompts an individual to search for equilibrium.

Our findings are consistent with those of other empirical studies on the lived experience of dementia. Our study supports the idea that the person with dementia struggles to hold on to his identity on the one hand and to adjust to the changes that dementia poses on the other hand (Clare, 2003; Keady et al., 1995; MacQuarrie, 2005; Pearce et al., 2002; Van Dijkhuizen et al., 2006). Our model suggests that individuals with dementia constantly balance being valued and being worthless. Our findings most strongly resemble those of MacQuarrie (2005). She also found that people with dementia simultaneously accepted certain aspects and denied others. She explained this apparent contradiction by positing that tension exists between being an agent and being objectified, a situation arising from one's threatened autonomy. According to MacQuarrie (2005) we should see the individual with dementia as an agent working against objectification. In our model this would be translated into 'agents working against devaluation'. The description of our positive story is similar to MacQuarrie's description of 'Aspects of Resistance'.

Our findings contribute to what is currently known about living with dementia by highlighting the importance of looking beyond the positive facade often displayed by those with early-stage dementia and instead search for the true feelings of these individuals—a struggle to feel valued. The positive story counterbalances devaluation.

Documenting our decision-trail of data-gathering and analysis supports the trustworthiness of our findings. We conscientiously detailed our quest to understand the positive story of individuals with early-stage dementia. This quest revealed that our attitudes towards the individuals during the initial interviews elicited positive stories. Our analyses illustrate how 'the viewer is part of what is viewed rather than separate from it' (p. 524) (Charmaz, 2000). Hall and Callery (2001) stated that 'reflexivity, which addresses the influence of investigator-participant interactions on the research process, and relationality, which addresses power and trust relationships between participants and researchers, have the potential to increase the validity of the findings in grounded theory studies' (p. 258). Incorporation of reflexivity and relationality into our study revealed how we, as researchers with nursing backgrounds, projected our biased image of dementia—one that views the

disorder only as a deficit—onto the interviews. The devaluing effect of this projection most probably prompted the persons' struggle to appear valued, leading to a strikingly positive story. Clare and Shakespeare (2004) also noted a similar 'struggle against being positioned negatively and the rejection of a problem-saturated account of their situation' (p. 226). Changing our interview style by subsequently communicating interest in the person as a complete human being obviously fostered trust in the interviewer. This also gave us the opportunity to balance the threatening aspect of talking about having dementia with the valuing aspect of being heard and being valued as a worthy person who can contribute to science.

The importance of the environment in supporting the self-esteem of the person with dementia is also described in theoretical models, such as Sabat's (2001) social constructionist theory and Kitwood's (1990) person-centred care model, and in Van Dijkhuizen et al.'s (2006) level of connectedness model. Our empirical data contribute to the validation of these models.

We stated earlier that care for people with dementia needs to focus more on achieving the best conditions for living with the disorder. Although our model is still a working model, it already suggests that caregivers need to support people with early-stage dementia, specifically in their search for equilibrium between maintenance and loss, between acceptance and resistance. Caregivers have a major challenge in trying to support the individual with dementia in their need to feel valued, especially because it occurs within a context of increasing loss. The challenge means caregivers must also delicately foster a gradual acceptance of the person's condition without encouraging or promoting surrender. The possible threatening and devaluing effects of the environment are well known (e.g. Kitwood, 1990) and have given rise to the idea of positive interventions (Dewing, 2004). Positive interventions, however, such as including the patient in conversations and decision-making, emphasising the value of remaining or former capacities, and avoiding confronting persons with their deficits, may become counterproductive if not carefully balanced. Overuse of this kind of intervention may result in memory problems being ignored or denied. Hence, the person with dementia may not feel valued as someone who has a problem and that can talk about it (Clare & Shakespeare, 2004). Ignoring memory problems may also result from confronting the patient's memory problems, for example, when overly complex decision-making is encountered. In other words, being too positive and treating the person with dementia as if he had no problem, risks devaluation.

In our study we discovered that our view of dementia as being a limiting deficit is pervasive, despite our preconceptions that we were open-minded and that we deeply appreciated people with dementia. Every caregiver should reflect on his perception of dementia and how this perception is manifested towards the person with dementia. Caregivers should be skilled companions (Titchen, 2000), who guide the person with dementia in their search for equilibrium between loss and maintenance. The positive story we observed in the narratives of this study provides an important clue to this guidance. The content of the person's story may reveal what aspects the person with dementia sees as being of value. How and when the story is told may reveal in what circumstances it is important to feel valued, or conversely, in what circumstances being valued is threatened.

Memory clinics, day care centres, and support groups are examples of care facilities and interventions that may guide the persons in their search for equilibrium. For example people with dementia attending a day care center may be confronted with the threat of being a burden for family. Caregivers may support these persons in counterbalancing this threat by pointing out how their willingness to attend the day care center can be seen as a way of caring for their carers, by seeking actively to relieve the caregiver burden.

Our working model needs further elaboration and confirmation. Questions need to be explored about when and how the balancing and struggle are prompted, how cognitive loss and the struggle to find equilibrium are interrelated, how aging relates to the process, and how family members support or hinder the individual with dementia's efforts to feel valued. Theoretical sampling of caregiving situations that may support or hinder being valued would provide valuable information on specific care interventions for this population.

In conclusion, the present study advances our knowledge about the experience of living with early-stage dementia in a number of ways. Firstly, the findings point to a similarity between the experience of living with early-stage dementia and that of living with chronic disease in general. Finding an equilibrium between maintenance and loss so that one can continue to exist (be valued) is central in the experience of living with chronic disease. Secondly, our findings show that the experience of living with early-stage dementia differs from the general experience of living with a chronic disease. Dementia specifically affects cognitive functions, which play a central role in coping. The positive story related by persons with dementia, if taken at face value, may be a symptom of impaired coping. Our model reveals, however, that having a positive outlook is a

specific way to cope and live with dementia. It also reveals how important it is for a person with dementia to remain a person of value. Thirdly, this study underscores the importance of reflexivity. Reflexivity, not only of the researcher but also of the caregiver is important when interacting with individuals with dementia.

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