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HOW DEMENTIA AFFECTS PERSONAL DIGNITY: A QUALITATIVE STUDY ON THE PERSPECTIVE OF INDIVIDUALS WITH MILD TO MODERATE DEMENTIA

ABSTRACT

Objective This article examines how dementia affects personal dignity in individuals with mild to moderate dementia from their perspective. **Method** In this qualitative cross-sectional study, in-depth interviews were carried out with 14 individuals, aged 50-94, with mild to moderate dementia who lived at home. Verbatim transcripts were analyzed making use of the principles of thematic analysis. **Results** Although mild to moderate dementia resulted in a diminished sense of personal dignity, in general participants still felt reasonably dignified. The decline in personal dignity was generally caused by cognitive impairments resulting in diminished autonomy and changes to the individual's former identity. However, the intensity with which the decline in personal dignity was experienced depended to a large degree on the social context of the individual, with a marked difference between the private sphere of the home and the external, social environment. The study gives recommendations how others can help to sustain personal dignity in people with mild to moderate dementia. **Conclusion** Given the considerable impact the social environment has on the personal dignity of people with mild to moderate dementia, it is important in caregiving not to confine attention to health-related or even any individual aspects alone, but also to take interpersonal aspects into consideration.

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INTRODUCTION

As the population of western societies ages, an increasing number of individuals will suffer from dementia (Ferri *et al.*, 2005). During the first years of the disease trajectory, people with dementia generally still live at home; in the Netherlands, for example, this applies to 70% of the 245,000 dementia patients (Deltaplan Dementie 2012-2020). However, as dementia research has focused primarily on the biomedical aspects of the disease (Steeman *et al.*, 2006), knowledge on how to effectively meet the care needs of individuals living at home between the initial diagnosis of dementia and potential institutionalization is rather limited (The, 2013; Norman, *et al.* 2004). Although there has been some criticism of the unilateral biomedical approach to dementia research from the 1990s onward, coupled with the call for a stronger focus on psychological and social aspects of the disease (de Boer *et al.*, 2007; Steeman *et al.*, 2006; Kitwood, 1997; Kitwood and Bredin, 1992), studies dealing with the subjective experience of individuals with early-stage dementia have only been slowly forthcoming (Heggestad *et al.* 2013a and 2013b; The, 2013; De Boer *et al.* 2007).

Even though the first-person voice of individuals with dementia has long been neglected, more recently there has been an increased awareness of the importance of taking into account the views, needs and concerns of these individuals (Heggestad *et al.* 2013a and 2013b; The, 2013; Clare *et al.*, 2008; De Boer *et al.* 2007; Clare, 2003). Qualitative studies can provide much-needed insight into the personal perspective of those afflicted with dementia. By doing so, these studies provide an essential tool for increasing our knowledge of how to deliver effective, targeted care for people with dementia, and their partners, who are faced with the daily challenges of living with dementia (The, 2013; Dröes *et al.*, 2006).

Qualitative studies which have explored the subjective experiences of individuals afflicted with dementia, indicate that a key element of the dementia experience is the struggle to preserve one's identity or sense of self (Sabat *et al.* 1999) and to maintain a meaningful life. Multiple personal losses and changes such as increased dependency (*e.g.* Cotrell and Hooker, 2005; MacQuarrie, 2005; Gillies, 2000), loss of autonomy (*e.g.* Holst and Hallberg, 2003; Harris and Sterin, 1999) and gradual loss of abilities or competencies (*e.g.* Harman and Clare, 2006; Cohen-Mansfield *et al.*, 2000) can affect the sense of self and the self-esteem of those suffering from dementia (Fazio and Mitchell, 2009; Harman and Clare, 2006; Sabat *et al.*, 1999). Additionally, a number of studies have indicated that the way in which individuals with dementia are treated by others has a significant impact

on their experience of the disease (e.g. Langdon *et al.*, 2007; O'Conner *et al.*, 2007; Kitwood 1997) and that the views of and treatment by others can perhaps be seen as the primary cause of the loss of self and self-esteem (Sabat *et al.*, 1992). For example, Clare (2003) found that memory failure tended not to deflate the individual's sense of self-esteem in and of itself, but rather indirectly through the humiliating remarks made by others. In another study, Harman and Clare (2006) discovered that being treated differently by others since developing dementia was one of the most acutely felt experiences. A study by Steeman and colleagues (2013) showed that people with early-stage dementia struggled with their sense of being valued. Thus, perhaps even more than cognitive problems themselves, the reactions of others to these problems and the individual's altered status within society may have a negative impact on people suffering from early-stage dementia.

From research among patients with cancer and chronic illness we know that existential concerns related to changes in the self due to disease, as well as the social ramifications of the disease (e.g. embarrassment, role changes, loss of independence and stigmatization), can have a significant impact on one's sense of personal dignity (Van Gennip *et al.*, 2013; Chochinov *et al.*, 2002). Personal dignity is a concept that has emerged rather recently within the context of palliative care (Chochinov *et al.* 2002), care for patients with severe chronic illnesses (Van Gennip *et al.*, 2013; Slettebø *et al.*, 2009; Söderberg *et al.*, 1999), acute care for older people (Jacelon, 2003), care for nursing homes residents (Oosterveld-Vlug *et al.*, 2013; Hall *et al.*, 2009; Pleschberger, 2007; Franklin *et al.*, 2006) and within the context of vulnerable and marginalized individuals or groups (Jacobson, 2009). Personal dignity is a type of dignity that is subjectively experienced by an individual and relates to a sense of worthiness (Leget, 2012; Jacobson, 2009 and 2007; Jacelon *et al.*, 2004; Nordenfelt, 2004). It is distinguished from universal human dignity, which is considered intrinsic to humankind (Kant, 1981) and which is associated with human rights. Personal dignity, on the other hand, is contingent and contextual, and can be influenced both by an internal aspect, which is the worth and self-respect one ascribes to oneself, and by an external aspect, which is the worth and value ascribed by others (Franklin *et al.*, 2006).

Patients whose personal dignity has been severely damaged, frequently express a sense of worthlessness, of no longer being of any use or value to others. Such feelings can lead to the conclusion that their lives have become superfluous (Chochinov *et al.*, 2002), sometimes resulting in the desire to terminate life prematurely (Ganzini *et al.*, 2007; Georges *et al.*, 2006; Jansen-van der Weide *et al.*, 2005). It is therefore not surprising that preserving personal dignity is an important aim in caring for individuals who suffer from severe chronic illnesses.

In light of the findings of previous research on the subjective experience of individuals diagnosed with dementia, it seems likely that these individuals are particularly at risk of suffering a loss of personal dignity as the result of the impact the disease has directly on their identity and sense of self, as well as indirectly via negative social interactions and experiences. A moral obligation to sustain the personal dignity of patients suffering from dementia is recognized in the ethics of dementia care (Gove *et al.*, 2010). With severe dementia, maintaining the patient's personal dignity has become chiefly the moral concern of caregivers, who are for example responsible for the personal hygiene and appearance of the patient. Before entering the stage of severe dementia, however, individuals are aware of the progressive decline in their abilities and actively try to cope with this decline (Sørensen *et al.*, 2008; De Boer *et al.*, 2007). During this stage, individuals themselves may have concerns with regard to maintaining their personal dignity. However, research on how people with dementia actually experience their personal dignity is scarce. It is only very recently that empirical research has begun to address the question how having dementia may impact personal dignity (Tranvåg *et al.*, 2014; Heggstad *et al.* 2013a).

A solid sense of personal dignity is essential to the individual's overall experience of well-being. Maintaining personal dignity should be a central focus of effective and targeted care for individuals afflicted with dementia. Investigation of the factors that contribute to and strengthen personal dignity needs to incorporate data gathered from those afflicted. This study aims to explore how dementia may affect personal dignity of individuals with mild to moderate dementia who live at home, asking which factors pose a threat to personal dignity and which factors preserve it. This insight can contribute to a deeper understanding of the (care) needs of people with dementia and point the way to providing the type of care required to help them remain dignified human beings.

METHOD

Recruitment and sampling

The participants for this study were recruited from among the 6,824 respondents participating in the Advance Directive Cohort Study (ADC study 2005 - 2011), a study focusing on individuals who had signed one or more advance directives (i.e. a will-to-live statement, a refusal-of-treatment document, an advance euthanasia directive, and/or a durable power of attorney for health care). The respondents of the ADC study were sent a self-administered questionnaire every 1.5 years. In total five surveys were conducted (Van Wijmen *et al.*, 2010).

We selected those individuals who had indicated on the ADC that they had been diagnosed with Alzheimer's disease or some other type of dementia. We also selected individuals who were no longer capable of filling in the questionnaire due to cognitive problems (this could be indicated on the back of the questionnaire) because we wanted to include individuals with moderate dementia as well. We contacted those individuals, or their relatives, first to see if it was still possible to hold a face-to-face interview. Over a 5-year period, 188 (2.75%) of the respondents participating in the ADC study indicated that they had some form of dementia. Of these, 62 (33%) had given permission to be approached for an interview study. We sent a letter explaining the content and purpose of the interview study to the eligible respondents, and we telephoned them one week later to ask if they were willing to participate. In total, 14 respondents with mild to moderate dementia participated in our study. The remaining respondents were either too demented to be interviewed, had died, could not be located, or were not willing or able to participate. The study was approved by The Medical Ethics Committee of the VU University Medical Center. Participants granted their informed consent before the start of the interview.

Interviews

The interviews took place between 2007 and 2012. This rather lengthy time span was the result of selecting participants from the ADC cohort study over a number of years. However, recruitment and participation in our study took place immediately after the respondent had indicated on the ADC questionnaire that he or she had dementia. We interviewed the participants at their homes for 60-120 minutes.

Although 'dignity' can, at a certain level, be seen as a rather abstract concept, it also relates to concrete experiences and feelings (Oosterveld-Vlug *et al.*, 2014; Van Gennip *et al.*, 2013). Some previous research has emphasized that while people with dementia may have trouble in answering questions that appeal to their intellectual capacities, they are generally able express to their feelings and experiences properly (Nygård, 2006; Moore & Hollet, 2003). All participants in our study were able to sensibly communicate their experiences with regard to personal dignity. Because individuals with dementia are particularly vulnerable informants, establishing a relationship of trust and creating a safe, secure environment in the interview situation seems particularly significant in studies involving those with dementia (Hellstrom *et al.*, 2007). An environment that is perceived as unsafe or insecure may influence the ability of individuals suffering from dementia to articulate their feelings (Clarke and Keady, 2002). During our study, we paid considerable attention to the manner in which the interview was conducted, taking ample care to put the participants at ease. We permitted the presence of a familiar person during the

interview ($n=9$) if this was the desire of the participant. The interviewer did, however, take measures to limit the influence of the third person by instructing them to limit their role to giving encouraging and supportive comments and not to interfere during the interview unless necessary. We subjectively determined the level of dementia during the interview based on participants' statements and our observations.

The in-depth interviews started with a general question about what dignity meant to the participant personally and what aspects affect personal dignity. Since the aim of this study was to identify the participants' subjective experiences of personal dignity, the interviewer introduced the concept of 'dignity' without providing for a formal description or definition. The interviewer followed up on the answers provided by the participants with further questioning in a conversational manner. The interviewer took the cognitive impairments of the participants into consideration, adjusting language and questions to the cognitive level of the participant. While the interviewer did not suggest any themes possibly related to personal dignity, the interviewer did from time to time check whether the participant was still talking about things actually affecting personal dignity and not, for instance, things that were merely annoying or difficult. To ensure that all aspects relevant to the objective of our study were covered during the interview, the interviews were guided by a topic list providing cues (Britten, 1995). The topics related to the participant's sense of dignity at present, situations and factors affecting dignity, and the participant's concerns for the future with regard to dignity.

Data Analysis

All interviews were audio recorded and transcribed verbatim. We conducted a thematic analysis to identify themes within the data and to establish meaningful categories, their relation to each other, and to the core concept of "personal dignity" (Boyatzis 1998; Braun and Clarke, 2006). The analysis of the first eight interviews contributed to an earlier study which resulted in the development of the Model of Dignity in Illness (Van Gennip *et al.*, 2013). All interviews were re-analyzed for the purpose of this study, focusing on the research question how dementia affects personal dignity. In this analysis we made use of the codes and themes established in this previous study while keeping an open mind for new themes in the data.

The interview transcripts were read several times to become familiar with the data. Next, text fragments were coded making use of Atlas/ti software. To ensure reliability of the coding procedure, some interviews were independently coded by the first and third authors, which revealed a high consensus. Discrepancies led to a more precise definition of some codes and resolved the issue of selective attention. Constant comparison was used to maintain a close connection between the data and codes (Strauss & Corbin, 1990). Inter-subjective reliability was sought throughout the analytic process.

The interview transcripts, case summaries and evolving code list were discussed by a research team consisting of six experienced qualitative researchers. The quotations used within the article were translated from Dutch to English by a native English speaker who has lived in the Netherlands for a number of years and is experienced in translations.

We used the domains of the Model of Dignity in Illness as a structuring principle for our results. In this model, three domains of the self are defined through which disease can affect personal dignity: (a) the individual self: the subjective experiences and internal qualities of an individual; (b) the relational self: the self within dyadic, reciprocal interactions with significant others; and, (c) the societal self: the self seen as a social object in the eyes of the generalized other and society.

RESULTS

The characteristics of the participants are summarized in Table 1. The age of the participants ranged from 50 to 94. Of the participants, 57% was male. Most participants lived at home with their partner.

Table 1. Participants' characteristics

P.	Sex	Age range	Educational level	Diagnosis	Place of residence	Alone/ with partner
1	F	80-84	Primary school	Dementia *	Residential home	Alone
2	F	65-69	Vocational education	Alzheimer's disease	Home	With partner
3	F	50-54	Vocational education	FTD	Home	Alone
4	M	50-54	Basic professional training	Alzheimer's disease#	Home	With Partner
5	F	85-89	High school	Dementia*	Home	With partner
6	M	70-74	Vocational education	Alzheimer's disease	Assisted living commendation	With partner
7	F	85-89	Primary school	Dementia*	Home	Alone
8	M	85-89	Masters degree	Alzheimer's disease	Home	With partner
9	M	65-69	Basic professional training	FTD	Home	With partner
10	M	90-94	Masters degree	Alzheimer's disease	Home	With partner
11	M	80-84	Bachelors degree	Dementia*	Home	With partner
12	M	80-84	Masters degree	Alzheimer's disease	Home	With partner

13	M	80-84	Basic professional training	Brain damage	Assisted living commendation	Alone
14	F	85-89	Bachelors degree	Alzheimer's disease	Home	Alone

*undifferentiated dementia

The Individual Self: how is dignity affected at the intrapersonal level?

Almost all participants noted that, to a greater or lesser extent, the disease had affected their identity. They did not feel like the person they were before the onset of dementia, or they felt that something – a part of themselves – had been lost. Closely related to the partial loss of personhood, and often mentioned in conjunction with a diminished sense of personal dignity, was the loss of autonomy. As a result of cognitive decline, participants experienced increasing difficulty in understanding and grasping situations, leading to a loss of control and dependency on others for guidance and decision making:

"Dignity means you can be yourself, you're still in control of your own thoughts, you can do what you want, with friends and people around you, with enough dignity to still know who you are. But I'm not like that anymore." (cries) "It's difficult to put into words. Now I just give in to others who...don't exactly decide for me, but still...I'm no longer independent. That's the way I feel about it." (female, age between 80 and 84)

While changes in identity and loss of autonomy diminished participants' personal dignity, as the above quote shows, participants generally described their dignity as still reasonably intact and, in general, they still found meaning in their lives. For many, a key factor in the preservation of their personal dignity was the on-going ability to carry out their daily routine and perform normal chores, and their engagement in meaningful activities within the safe and secure environment of their own homes:

"Yes, digging in the garden... . It really does me good. I worked in the garden yesterday or the day before, it's a bit cluttered, but I like a cluttered garden. And it makes me feel so much better. I was completely...my body ached and I was so sad. But then I went and worked in the garden and came out feeling healthy." (female, age between 65 and 69)

"Yes, I'm a real homebody...you feel so safe and free in your own house. Every day, I'm just so pleased with my home. And that we live here." (female, age between 80 and 84)

While almost all participants stated that if things could remain as they were right now they would continue to feel dignified, they expressed concerns for the future. Participants focused on the present to cope with the consequences of the disease and maintain their personal dignity:

I: How can dignity be maintained? P: I live from day to day. My day is divided in three. When I get up in the morning, OK, I'm easily satisfied. And satisfied is good enough for me. And then lunch and it's afternoon and then it's evening and then I go to bed and think when I wake up tomorrow I'll just see what the day brings. I don't plan anything beforehand, no future, nothing. I just do what I feel like doing. And that works fine for me. I don't have a lot of problems, and when I do I just say so. And I...well, I just take it as it comes, because I don't know today how I'll react to a situation tomorrow, that might be different tomorrow. (female, age between 65 and 69)

The Relational Self: how is dignity affected at the interpersonal level?

With the development of disorientation in time and place and memory problems, dependency on others for assistance and guidance gradually increases. While complete dependency on others (especially for activities such as eating and toileting) was considered undignified, many participants noted that at present they were grateful for the help they received and that the assistance from their partner, or others close to them, actually helped them to sustain their personal dignity. For many, their sense of personal dignity was maintained by the acceptance and respect provided by their partner:

I: Does this mean that you still have your dignity? P: Yes, my wife has made that possible, that's a fact...and my children, too, and the rest of my social circle. They're the ones who could take dignity away from me. (male, age between 85 and 89)

I: Who or what could help you maintain your dignity in the future? P: That would be my partner. And good friends. If I say something odd or can't understand something, that's OK. (female, age between 65 and 69)

Paramount in maintaining dignity was the fact that the care participants received from their partner enabled them to remain in their own home, rather than having to move into a care facility:

"I feel fairly dignified right now, but there's always that nagging sense of dread that someday my dignity will vanish. Maybe I still feel dignified because we have a wonderful home, and because I have my partner who of course does a superb job taking care of everything. That gives me a sense of dignity. If that ever stopped I don't know if I could maintain my dignity. Dignity means people still respect you, but somewhere there's the fear that that won't always be the case. And I think that's why I tend to withdraw into my shell, not to do anything, I don't have any job or chores to do. I just sit at my computer for a while or lie down on the bed and read a book." (male, age between 65 and 69)

Most participants realized the need for assistance with their thought processes, such as help with planning, decision-making and remembering. Through assistance with the thought process and the structure provided by caregivers, the participants could continue to manage and experience a sense of mastery and agency. In other words, caregivers could provide a certain framework through which it was possible for the participants to maintain a more or less normal life:

I: So your wife helps you to maintain your dignity? P: That's what she does all the time because that's just the way she is. And that's what you call a happy marriage, you know...in my opinion, this is a happy marriage. Wife of participant: He lives for his intellect, and he uses my memory. P: Yes, that's right. Wife: That's how you're able to function. P: I consciously use her memory, or at least I realize that I make clever use of her memory. Wife: Compared to a year ago it's... P: ...increased. Wife: ...I have to put my memory to work more and more often to... P: ...refresh mine. Don't forget this, remember to do that. (male, age between 85 and 89)

While grateful for the help and assistance received, at the same time participants attempted to maintain their personal dignity by claiming a certain agency within this shift from active to passive subject, for instance by perceiving the assistance they received as self-initiated or by actively delegating certain tasks they were incapable of executing themselves:

P: Dignity is making your own decisions. I: Can you give me some examples? P: Uhm...well, deciding what things I need from the shops, what I want to wear. Still being more or less in charge of what happens in my own home, although I do have people to help me and I'm very grateful for that, we work together. I: You give the instructions and they do the job? P: Yes, although I'm not really the boss, but they pretend I am. (laughs) (female, age between 50 and 54)

Another aspect important to the acceptance of increased dependency on others was the opportunity and ability to reciprocate. Participants said their personal dignity was not diminished by having to call in the help of others if they felt they still had something to offer and the relationship could remain one of give and take. Some participants experienced a decline in their sense of personal dignity in situations where the balance had shifted and they had become the needy one in the relationship. Such perceptions were often associated with the feeling that one was no longer the person one once was:

I: So your sense of dignity would improve if your daughter were to become pregnant, because then you could help her? P: Yes, I could give her advice, tell her how I did things and how to do this or that. That's your dignity as a mother and I think that dignity would diminish if you can no longer mother. To tell the truth, they're the ones who have to mother over me now. (female, aged 50 and 54)

Contact with other people who have dementia, for example at the day-care center, was perceived as a relationship of equality in which meaning to each other's lives could be given. Additionally, being part of a community in which one is respected helped to maintain personal dignity:

"People here know me... people at the shopping mall never talk as if I wasn't there, not even when I'm in my wheelchair, they don't talk over my head, they talk to me. That gives me a safe cocoon, even though I might start acting crazy in the future, but they know that I belong there and that I used to be normal." (female, age between 65 and 69)

The Societal Self: how is dignity affected by the external world?

While participating in the close circle of family, friends and the home was generally experienced by participants as enhancing their personal dignity, situations in the world beyond this safe and familiar environment were described by many as a threat to personal dignity. In addition to the fear of disorientation and getting lost, there was also the fear of losing one's dignity in front of strangers. While most participants felt dignified when among family and close friends because they felt understood and accepted, in public places many felt ashamed of their behavior:

I: The symptoms of Alzheimer's disease you are experiencing, do they affect your sense of dignity? P: Well, it depends. Not when you're in a familiar situation, that's OK. But when I'm in a shop and I act rather odd, that's really embarrassing.

You can't compare the two... Yes, it really hits you. You feel like you're not whole anymore. And you notice it, you can feel what you're missing. You start to feel insecure, then you start to stammer and you think 'oh God, no'. You get tongue-tied, you get nervous. That's happened to me a couple of times. I just break out in a sweat. I feel like a complete idiot, just standing there stammering, it really bothers me. (female, age between 65 and 69)

Furthermore, some participants had experienced that others did not take their illness and difficulties seriously. Being viewed as a pretender was a painful, undignifying experience:

P: I ask them 'What was your name again, I've forgotten it?' And then they give me an odd look as if to say 'Don't you remember that?'. I: Is there a sense of disbelief, that people don't really believe you're ill? P: Yes, some people say I should be tested again. That's just because other patients have gone downhill faster. They're all older than I am, I'm still younger than they are. (male, age between 50 and 54)

Some participants had experienced incidences of being infantilized or patronized, as is evident in the story of this woman who paints at the day care center:

"I think my painting is just O.K. and they say 'Oh, how wonderful!'. And I think, don't say that, it's about what I think and whether I should change something, yes or no - I don't like that. I think, don't say that because it doesn't help, in fact it makes me feel worse, I'm not that stupid or that far gone. Of course, they still have to figure that out, there are a lot of people there who are much worse than I am and it's good that they over compliment them, but don't do that to people who can still function well. As if we're that far gone, I don't need that." (female, age between 50 and 54)

These negative experiences in the external world contributed to the desire on the part of the majority of participants to retreat to the safe environment of their homes and their intimate circle of close friends and loved ones:

I: Would it be correct to say that you avoid feeling a loss of dignity by withdrawing into your shell? P: I think so, yes, that's right. I go to the swimming pool every day, there's always the same group of people, mostly women, two or three other men, it's familiar territory so I go there. I just stay a short while, then I get out and come home as quick as I can and then don't do anything else unless my wife tells me to,

that we have to go shopping or go to the activity center, things like that. If it weren't for her, I wouldn't ever do anything again. I think it's because I'm afraid that otherwise...eh... that I may destroy my dignity or something like that. (male, aged 65 and 69)

DISCUSSION

The participants in this study conveyed that the decrease in their autonomy and changes to their sense of self, due to cognitive impairment, did result in a diminished sense of personal dignity. However, overall, they expressed that they still felt reasonably dignified. A key factor in maintaining a sense of personal dignity was the belief that life is still meaningful. Carrying out daily routines and chores, and engaging in pleasurable activities in and around the home, such as gardening or listening to music, all gave meaning to life. A sense of personal dignity could be maintained by focusing on the present and being grateful for what one still has and what is still possible, that is, by lowering one's expectations of one's capabilities and by deriving satisfaction from the smaller pleasures in life. A study exploring how individuals with Alzheimer's disease who lived at home coped with the changes they faced in daily life and social relations also found that individuals adjusted their activities, attitudes and values as part of a comprehensive coping strategy to preserve personal worth and dignity (Sørensen *et al.*, 2008).

In order to maintain daily routine, individuals with dementia become increasingly dependent on others, specifically caregivers, either professionals or family and friends. Amongst the elderly in general, changes in the relationship with others, most notably the loss of autonomy and a concomitant dependency on others, is perceived as a threat to one's dignity and a serious cause for concern and anxiety (De Boer *et al.*, 2007). The individuals in the present study were well aware that only through the assistance provided by others, generally their partner, were they able to participate in activities that helped them preserve their personal dignity. Many of the accounts given in this study illustrate the vital role played by the partner in helping out with chores, providing structure in daily life, keeping schedules and appointments, serving as a source of memory – in short, making a more or less normal life possible. In general, the participants in the present study accepted this relationship of dependency and expressed gratitude for the help they received, as long as they maintained a sense of agency and felt that they were taken seriously, listened to, and that their wishes were respected. The opportunity for reciprocation, however, was also considered to be a key element in maintaining personal dignity, as a perceived inequality in the relationship between the caregiver and the

receiver of this care was experienced by the participants in the study as emotionally painful.

For individuals with dementia, their partners or others close to them further help them sustain their personal dignity by providing a sense of continuity of identity. Participants in this study stated that being amongst those who knew them when they were still healthy, fully capable individuals helped them feel dignified because those people still regarded them as complete individuals rather than as patients suffering from dementia. Because they felt that they were still seen as "full" people by those close to them, they considered their mistakes, failures or shortcomings resulting from their cognitive impairment to be less shameful. Additionally, the home environment was seen to play a significant part in the maintenance of personal dignity. In their homes, participants not only felt free, autonomous and safe, but many of them experienced a close emotional attachment to their homes. The home itself served as a reminder and symbol of one's life and achievements; it confirmed their identity, their success in life, and it was generally a source of pride. Thus, the significance of the house extended well beyond its basic functionality as a dwelling, becoming a symbol of the identity the participant had built up over a lifetime.

The present study found that in individuals with mild to moderate dementia the sense of mastery they were able to maintain within their home environment, with the aid of their partner, often disintegrated in the outside world. The participants expressed a strong need to preserve normalcy, and their perceived failure to consistently behave in normative ways evoked feelings of shame and made them aware that part of their former self had been lost. They reported being confronted by an array of negative reactions, such as incomprehension regarding their incapacities or being patronized, all of which had a significant negative impact on their sense of personal dignity.

It appears that, especially during the earlier stages, individuals with dementia feel highly self-conscious, helpless and ashamed of their perceived deviations from social norms. Some participants in our study stated that they withdrew from social interactions in order to prevent loss of personal dignity. Social withdrawal is also described in other studies on the subjective experiences of dementia as a strategy to prevent embarrassment. Ostwald (2002) found that particularly those who still exhibited a relatively high degree of cognitive functioning preferred to limit their social contact with others as a way of coping with their dementia. A study by Clare (2003) also indicates that people with early-stage dementia avoided situations in which they might feel challenged by their difficulties with memory loss and thus feared they would not appear to be "normal" when interacting with others. Research by Husband (2002) has revealed that upon receiving the diagnose of dementia, the most common concerns expressed by patients were the fear of others finding out that they had dementia and the fear of social

embarrassment; the most frequently observed effects were social withdrawal and hyper-vigilance for evidence of cognitive failure.

Some authors have stressed that staying active and socially involved is important for individuals with dementia and should be stimulated by caregivers to prevent a passive and isolated lifestyle (Sørensen *et al.*, 2008; Harris and Durkin, 2002). While being engaged in meaningful and useful activities was mentioned by our participants as important in sustaining their personal dignity, at the same time they chose to discontinue certain activities. Social withdraw can be seen as part of a comprehensive coping strategy for those with dementia, aimed at avoiding situations in which they might fail and thus protecting their sense of personal dignity by not exposing themselves to potential humiliation. Caregivers must recognize and respect the positive benefits of social withdrawal in maintaining personal dignity as perceived by the individual, and consider the complexity of this aspect when developing programs for individuals requiring care.

Personal dignity is foremost a relational concept; it can be either given or taken by others within interpersonal interactions. The present study indicates clearly that the way others view and treat individuals with dementia has a significant impact on their sense of personal dignity. The intensity with which a decline in personal dignity was experienced depended largely on the social context of the individual. One of the most striking findings of this study was the difference between the impact of the inner circle (partner, relatives, close friends) and that of the outer, external world in terms of shaping the experiences and perception of individuals with mild to moderate dementia.

The need to initiate appropriate social-psychological support for those with dementia as early as possible is being increasingly recognized, especially as no bio-medical cure for the disease is currently available (The, 2013). Active support from family members and from professional caregivers is required to preserve a sense of personhood, personal worth and personal dignity in those suffering from dementia. Our findings can provide insight into the ways in which these goals can be achieved. First of all, individuals with dementia require practical assistance with everyday tasks, routines and activities. In providing this care, it is important that the caregivers show respect for the individual's sense of agency and autonomy, that they inform the individual and take their wishes into account when possible. Additionally, they should recognize that the person receiving care or assistance generally wants to reciprocate and should be given the opportunity to do so. Individuals receiving care should be treated as worthy individuals rather than impaired and needy patients, individuals who, in their own way, can still give, not just receive. Secondly, it is important to provide emotional and psychological support to those with mild to moderate dementia by confirming their worth as complete individuals with a past and present self. Being at home in the presence of one's partner can provide a sense of belonging (both to a tangible place and to another person), and through the association

with the past can be a confirmation in itself. It can also be beneficial to provide caregivers with insight into the active role they can play by focusing their interactions on supporting the lifelong characteristics of the self instead of focussing on the "diseased self" based on symptoms and problems, as stressed by Fazio and Mitchell (2009). Tranvåg *et al.* (2014) identified the acknowledgment of the individual's own life-projects and life-history as a crucial dignifying aspect. Personal dignity can be reinforced, for example, by allowing individuals with dementia to talk about past achievements and significant events in their lives, giving them the opportunity to confirm their identity to both themselves and others. This awareness can be of particular importance to professional caregivers who may not have prior knowledge of the individual.

The results of this study indicate that the care provided by the partner and continuing to live at home may both play a crucial role in the maintenance of dignity in individuals with dementia as perceived by themselves. Taking care of an individual with dementia can, however, be a heavy burden for non-professional caregivers (Etters *et al.*, 2008), and, as a result, tension between what is in the best interests of the patient and the interests of the family caregivers can arise. However, promising intervention programs have been developed that can alleviate caregivers' distress and delay institutionalization in demented patients (Olazarán *et al.*, 2010; Mittelman *et al.*, 2006). Additionally, appropriate pharmacological and non-pharmacological treatment of behavioral and psychological symptoms in dementia (BPSD), such as depression, irritability and agitation, may help to postpone institutionalization (Finkel, 1996).

Not all individuals suffering from dementia have a partner or other relative who is willing and/or able to care for them. Moreover, not all partners or other caregivers are able to provide sensitive, supportive care: abusive treatment, anger and irritation can seriously undermine their sense of personal dignity and self-esteem. Thus, homecare is not always the best solution for individuals with dementia. Furthermore, for many of those suffering from dementia, institutionalization is ultimately inevitable as the disease progresses. At that point, it is particularly relevant to determine how dignity can be maintained within the new, institutional social context. A recent study by Heggstad and colleagues (2013a), based on a participant observation study combined with qualitative interviews among nursing home residents with dementia, identified a range of challenges in dementia care within nursing homes which may actually harm the residents' personal dignity. Residents described feelings of homesickness, for example, and felt that they were not treated as distinct and autonomous individuals. The authors conclude that by recognizing the person behind the diagnosis, by confirming each and every resident as a whole and unique individual, and by creating a more homelike, less institutional environment based on the concept of person-centred care as described by Kitwood

(Kitwood 1997; Kitwood & Bredin 1992), it is possible to protect and preserve the residents' identity and thus their personal dignity to a greater degree.

Special dementia care units using a 'homelike' framework, that is highly individualized, relationship-oriented care, seem promising in sustaining the dignity of patients with dementia (Öhländer, 2009). It is worth noting that the aspects that characterize this type of care as described by nurses working within this framework closely resemble the dignity sustaining factors mentioned by the participants in our study, i.e. demonstrating an attitude of acceptance, always being available for support in order to prevent feelings of inferiority, and protecting the residents from disrespectful treatment by others. Additionally, nurses tried to encourage residents' sense of agency where possible (Zingmark *et al.*, 2002). Thus, the relationship-centred care offered within homelike care units appears to be an effective substitute for the dignity sustaining care otherwise provided by a partner.

Limitations of the Study

The present study is one of the few studies to date which have begun to systematically explore the effects of dementia on the individual's sense of personal dignity, and contributes to the limited body of research literature concerned with the personal perceptions and experiences of individuals with dementia. As the study reflects the perspective of individuals who demonstrated a certain degree of resourcefulness in coping with their situation and who could rely on supportive partners or other caregivers, the results are necessarily only part of the entire range of possible patient perspectives. Furthermore, as the study included only participants with mild to moderate dementia, it cannot provide insight into patients' perceptions and experiences with regard to the concept of personal dignity throughout the further course of the disease as cognitive degeneration progresses. The findings of this study can therefore not be extrapolated to apply to the later stages of dementia.

Because people with dementia are vulnerable informants the presence of a familiar person during the interview was allowed if this was the participant's desire. While measures were taken to limit the influence of the presence of a third person, their presence might have induced socially desirable answers, although we did not have this impression. The participants were not submitted to a formal testing procedure to establish level of cognitive impairment. Finally, the level of dementia of the participants was subjectively determined during the interview.

CONCLUSION

The present study shows that cognitive impairment resulting in diminished autonomy, limited ability and changes to identity did diminish the sense of personal dignity in individuals with mild to moderate dementia. The extent to which this was experienced, however, depended on the social context of the individual, with a strong demarcation between the sheltered, familiar environment of the home and the outside world. Given the social vulnerability of people with dementia because of their dependency on others and the considerable impact social interactions have on their sense of dignity, it is important in caregiving not to confine attention to health-related or even any individual aspects alone, but also to take interpersonal aspects into consideration. Amongst other aspects, this study highlights the importance of remaining at home as long as possible in cases where this is feasible for the well-being and sense of personal dignity of individuals with dementia. In order to facilitate this, it is vital to provide sufficient support to both individuals afflicted with dementia and their partners or other caregivers early in the diagnostic process and through the on-going process of adjustment to the diagnosis of dementia.

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