

Dignity and care for people with dementia living in nursing homes

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Abstract

This article presents and discusses findings from a qualitative study on how the dignity of patients with dementia is preserved or harmed when they live in a nursing home. The results build on participant observation in two nursing home wards, combined with qualitative interviews with seven relatives of patients with dementia. The most important issue for relatives was that their family member with dementia was confirmed as a relational human being. However, relatives experienced lack of resources and task-centred care as threats to confirming, relational care and to patients' dignity. Findings from participant observations confirmed this. In this article, we argue that care which focuses on the residents' personhood, combined with a relational focus, is of great importance in maintaining the dignity of people with dementia living in nursing homes.

Keywords

Dementia, dignity, nursing home, person-centred care, relationship-centred care.

Introduction

In Norway there are 70 000 people who suffer from dementia and 40% of these live in nursing homes (Engedal 2010). Dignity is one of the key concepts in the care of this vulnerable patient group (Gastmans 2013, McIntyre 2003, The Nuffield Council On Bioethics 2009), and can be seen as a moral touchstone (Moody 1998). Dignity is also a central theme on the political agenda in Norway. In 2010, the Norwegian government introduced what they called, "The Dignity Guarantee," where they stated that all older people should be guaranteed dignity-promoting care when they need it (Norwegian Ministry Of Health Care Services 2011). Dignity as a concept also plays a crucial role in understanding human rights (Andorno 2009, Nordenfelt 2004) .

Despite this focus on dignity in national and international statements and legislation, the concept of dignity is rarely defined and is a vague concept (Seedhouse & Gallagher 2002).

To clarify the meaning and importance of dignity in health care practice, we need to explore what patients and their relatives experience as promoting dignity, and what they experience as a threat to dignity.

Background

Both empirical and theoretical research have considered how to understand the concept of dignity. The relationship between theoretical and empirical research can be seen as a dialectical process, with each side informing the other (Gallagher *et al.* 2008). We can consider empirical research in the light of theories of dignity and vice versa.

The literature review, below, builds on regular systematic searches in MEDLINE, CINAHL, Academic Search Premier and SocINDEX (from March 2009 to August 2013) on dignity in relation to dementia and dignity as a concept. In addition, we carried out snowball sampling, following up original articles which were cited by articles that we found through the more systematic search.

Theoretical analysis of the concept of dignity. Theories that focus on human dignity often see it an expression of an intrinsic value related to human worth, but also as a subjective or relative value related to a person's experiences of how he or she is met and treated as a human being (Edlund 2002, Jacobson 2009b, Nordenfelt 2004, Van Der Graaf & Van Delden 2009). In this study, it is this latter understanding of dignity – as a subjective experience– that has been the main focus.

A major contributor to our understanding of the concept of dignity in the care of older people is the Swedish researcher and philosopher Lennart Nordenfelt (2004, 2005). He distinguishes between four notions of dignity: dignity of *menschenwürde*, dignity of moral stature, dignity

of merit and dignity of identity (Nordenfelt 2004, Nordenfelt & Andrew 2005). *Dignity as menschenwürde* is related to human worth, and is, according to Nordenfelt, universal and inherent. Nordenfelt claims that an individual has this kind of dignity despite diseases like dementia, and it cannot be lost as long as the person exists. There are some, though, who claim that dignity related to human worth may be lost when a person suffers from dementia, as they relate human worth and dignity to the ability to reason (Cooley 2007). *Dignity of moral stature* depends on an individual's moral value, and may be understood as a kind of virtue that depends on the thoughts and deeds of a subject. Dignity of moral stature may be high or low, and depends on the moral values of one's actions. Some may claim that this kind of dignity is at threat when an individual suffers from dementia, as they think that cognitive impairment affects the person as a moral agent, but this is a contested argument, and depends on how one defines a moral agent (Cooley 2007, Sharp 2012). *Dignity of merit* depends on social rank or formal position, and is a kind of dignity one receive because of this rank or position. Dignity of merit may be related to a position or rank one is born into, such as a king. However, dignity of merit may also be something one can achieve through education and work, for example, the position a priest may have in a community. This may be seen as an archaic notion of dignity, and we will argue that this kind of dignity is not the most relevant for people with dementia. *Dignity of identity* represents a person's subjective experiences of dignity and is related to integrity, autonomy, self-respect and social relations. This kind of dignity may be taken away or threatened by external events or by the acts of other people, for example, if an individual is humiliated or treated as an object. Injury, illness and old age can also be experienced as threats to the dignity of identity. According to Nordenfelt, dignity of identity is the most important notion of dignity in relation to ageing and illness, and therefore in relation to individuals with dementia.

Pullman (1999) distinguishes between *basic dignity* and *personal dignity*. Basic dignity is much the same as what Nordenfelt calls *dignity related to menschenwürde*, and is a kind of dignity that is irreducible. Pullman’s ‘personal dignity’ is similar to Nordenfelt’s *dignity of identity*. It is a dignity that is socially constructed and changeable. Personal dignity can be affected by health and physical and intellectual capacity, and can therefore be threatened when a person gets a diagnosis of dementia and moves into a nursing home (Pullman 1999).

Jacobson has developed a general theory of dignity and describes dignity as the two phenomena *human dignity* and *social dignity* (Jacobson 2009b). *Human dignity* is the same as Nordenfelt’s *dignity of menschenwürde* and Pullman’s *basic dignity*. *Social dignity* is influenced by social interactions and may be understood as Nordenfelt’s three latter forms of dignity and what Pullman calls *personal dignity*. Social dignity can be divided into two forms of dignity: *dignity-of-self* and *dignity-in-relation*. Both forms of social dignity are contingent, and may be violated or promoted. According to Jacobson, dignity can be violated through rudeness, condescension, disregard, objectification and abjection (Jacobson, 2009).

Table comparing how the different categories of dignity correspond:

(Nordenfelt 2004)	(Pullman 1999)	(Jacobson 2009b)
Dignity of menshenwürde - dignity related to human worth	Basic dignity – dignity related to human worth	Human dignity – dignity related to human worth
Dignity of moral stature	Personal dignity	Social dignity
Dignity of merit	Personal dignity	Social dignity
Dignity of identity	Personal dignity	Social dignity

The discussion about whether and how dignity, human worth and moral agency are related to or dependent on the ability to reason is beyond the scope of this article. The focus here will be *dignity of identity, personal dignity and social dignity*, as we see these as the most proper forms of dignity related to people with dementia living in nursing homes.

Dementia and dignity. There has been a focus in research on how to balance ethical principles when maintaining the dignity of people with dementia living in nursing homes (Buzgová & Ivanová 2011, Jakobsen & Sorlie 2010, Lejman *et al.* 2013, Manthorpe *et al.* 2010, Orulv *et al.* 2007). Other researchers have focused on the challenges related to decision-making or coercion when caring for people with dementia (Helgesen *et al.* 2013, Jakobsen & Sorlie 2010, Jaworska 1999, Koppelman 2002). Most of the studies have been carried out from the perspective of health professionals, rather than patients or relatives.

Person-centred care and the importance of valuing the individual patient's personhood have been emphasized in earlier research on dignity and dementia (Buron 2008, Edvardsson *et al.* 2008, Kaldjian *et al.* 2010, Lorentzon & Bryan 2007, McIntyre 2003, Palmer 2013, Woolley *et al.* 2008). Person-centred care focuses on seeing the person behind the diagnosis of dementia and treating that person as a unique individual (Kitwood 1997). According to Kitwood, person-centred care is the opposite of task-centred care. The Nuffield Foundation's report "Dementia: ethical issues" also underlines the importance of person-centred care, stating that treating a patient with dignity is a matter of "*showing respect for the personhood of the individual, recognising her value as a person, equal to anyone without dementia*" (The Nuffield Council On Bioethics 2009) .

Nolan *et al.* (2008), however, think that the original intent of person-centred care, as introduced by Kitwood, has been lost in later research and political statements. They criticize the way the concept has developed into something more individualistic, where the goal of care

has become autonomy, individuality and “successful aging”. This, they think, only represents a new form of ageism. They suggest that relationship-centred care may be more appropriate for people with dementia (Nolan *et al.* 2004 p.33). In relationship-centred care, the interdependence of relationships is taken into account. This means that we see every person as belonging to social relations, not merely as individual, independent human beings (Nolan *et al.* 2008, Nolan *et al.* 2004).

Research on dementia and either person-centred or relation-centred care, often mentions dignity, but does not go into any further discussion of the relationship between either type of care and the concept of dignity. We believe that this article contributes to increased understanding of the connection between dignity and person-centred or relationship-centred care. This article also contributes new knowledge on how relatives of people with dementia experience the promotion or loss of their loved ones’ dignity.

Aim

The aim of this study was to gain more knowledge about how people with dementia, and their relatives, experience that dignity being maintained or harmed in nursing homes. We present findings from participant observation and from interviews with relatives. Through this, we try to clarify the relevance of dignity in the care of people with dementia who live in nursing homes.

We have already presented and discussed findings from interviews with patients in another article (authors anonymised, 2013a).

Design and method

The study builds on phenomenological and hermeneutic scientific philosophy. What is important, though, is that we did not use a phenomenological method. We distinguish

between phenomenology as philosophy of science and phenomenology as a method. The aim, adopting a phenomenological perspective, was to take the participants' subjective experiences seriously and to focus on how dignity as a phenomenon may appear in the life-world in a nursing home (Zahavi 2003). In this article, we focus on the *relatives'* subjective experiences of dignity in nursing home care and on material from participant observations on how dignity may appear in interactions between carers and residents in two nursing home wards.

According to hermeneutics, new knowledge builds on previous knowledge and develops as a circle or a spiral (Gadamer 2004). How we understand and interpret the subjective experiences of the research participants, and how we understand and interpret our observations of daily life, will always depend on our pre-understanding (Alvesson & Sköldbberg 2009). The pre-understanding in this study built on the first author's experiences of working in a Norwegian nursing home, combined with the three authors' knowledge of previous research in the field. This pre-understanding formed both the interview guides and the analysis of the data material.

Participants

A criterion for including the patients in the field notes was that they lived in the unit where the participant observation was carried out. All the patients included in the interviews or in the analysis of the field notes were suffering from dementia. The dementia diagnosis of the participants was confirmed by the general practitioner (GP) responsible for assessing the residents' diagnosis, or through reports from the nursing journals in which the residents' different diagnoses were documented. Eight residents (aged 79–99) were included in the field notes from the special care unit, and seven patients (aged 78–93) were included from the general unit. None of care workers declined being included in the research

Seven relatives of patients living in the two units were included in interviews. The inclusion criteria were that they should be relatives of residents in the units, and that they should give their written consent to participation. From the special care unit one husband (83 years old), one daughter (56 years old) and one daughter-in-law (59 years old) were included. From the general unit, one daughter (51 years old), one son (49 years old), one wife (86 years old) and one niece (64 years old) were included.

Research context

Two nursing homes units, one of which was general unit and one a special care unit, were selected to guarantee a variation in terms of size and location.

The first unit, (nursing home 1), was a special care unit where eight people suffering from dementia lived. The residents had their own private rooms, with their own personal belongings. They also had their own toilets and bathrooms connected to their rooms. There was a living room in the unit that the residents shared with each other. The staff had their own office in the unit..

The other unit, (nursing home 2), was a general or somatic unit, where people with and without dementia lived together. All the residents had their own private rooms with their own toilets, but there were only two bathrooms in the unit that the residents had to share with each other.

Data collection

Participant observation. The first author was in the units between 07.30 am and 10.00 pm, three to four days a week, participating as an “assistant” in the daily life in the wards. The first author observed and participated during the daily meals, during toileting and in bathing situations, and sat down with the residents in their living room, listening to them and

participating in informal conversations with both the residents and the staff. The first author wrote down observations and the informal conversations in field notes

Participant observation took place between March and December 2010, and lasted for 88.25 hours in the special care unit, and 96.25 hours in the general unit.

Interviews. The interviews with the relatives lasted from one hour to one-and-a-half hours. We used a thematic guide in the interviews based on open-ended questions as well as questions which built on our pre-understanding. Themes that emerged through the first analysis of the field notes were included in the interview guide. Among the themes that were focused on in the interview guide were how relatives experienced the patient moving into the nursing home, what they thought to be most important in order to maintain the patients' dignity, and in what way they saw the dignity of their loved ones being jeopardized when living in a nursing home.

The interviews took place in a meeting room outside the nursing home unit, so that patients or staff would not disturb the interview.

The interviews were conducted between March and December 2010.

The strength of triangulation. By combining two different methods (observation and interviews) in data gathering, one may get richer and more valid data. Triangulation made it possible to follow up themes from the field notes in the later interviews, by incorporating the themes from observations in the interview guide. It was also possible to follow up themes that emerged during the interviews in later observations. If the same theme emerged both in the interviews and in the field notes, the theme could be consolidated. Findings from interviews could also be challenged and confronted with findings from the field notes. The field notes gave important contextual insights into the field, and made it possible to situate the findings from the interviews in a wider framework.

Research ethics.

The head nurse informed the residents, their relatives and all the health care workers about the research project, both orally and in a letter. In addition, the first author had an information meeting with the care workers before the research project began. Residents received information about the research project continuously throughout the project. In addition, an information sheet about the research project was posted on an information board in the nursing home unit. The first author wore a nameplate with her name and the title 'researcher' so that research participants would not be confused about her role.

The head nurse obtained written consent from all residents who were competent to give their own consent. If a resident was assessed as not competent to give his or her own consent, consent was obtained from a proxy. How the consent was assessed is describe thoroughly in another article (authors anonymised, 2013b). When the patients were assessed as not competent to give written consent, they were given the opportunity to give their verbal assent to participate in interviews, in addition to written consent from a proxy. If consent was not obtained, the resident was not included in the interviews or in the field notes. Written consent was obtained from all relatives who participated in interviews. The health care personnel could abstain from participating. Health care personnel gave their written consent, and residents gave their assent in situations where the first author assisted in delivering personal care, like bathing and toileting. It was important to be sensitive to the residents' verbal and nonverbal reactions to the researcher's presence and participation. If a resident seemed to be distressed when the first author assisted in delivering personal care, the first author withdrew from the situation. We saw the consent process as an ongoing process, as discussed in previous research (Dewing 2007, Wilson 2011). This means that the first author had to renegotiate the consent throughout the research process.

We informed all the participants that they could withdraw from the project at any time, and that withdrawal would have no consequences.

Challenges related to ethical concerns that arose in the course of the project have been more thoroughly described in a previous article (authors anonymised, 2013b).

The study was approved by the Regional Committee for Medical Research Ethics (REK sør-øst 2009/2222).

Any names used in the article are fictitious.

Issues of rigour.

As a participant observer, one participates with the research participants in their daily life.

This means that one may influence the participants. When the care workers are aware that the researcher is observing them, and know that the focus is on dignity and care, this may influence how they behave in the caring situation and may affect the findings. To strengthen the quality of the research, it is therefore crucial that the researcher adopts a reflexive attitude throughout the research process (Houghton *et al.* 2013, Jootun *et al.* 2009, Wilson 2011). The first author therefore had to be aware of and reflect over how her role as a researcher in the field could influence the observations and hence the findings (Fangen 2004).

The fact that the first author had worked in nursing homes before made it easier to get access to the field. Knowledge about the field enabled the researcher to communicate with the patients in a good way and to be more sensitive to and aware of reactions from the research participants (Hem *et al.* 2007). While the first author's previous experience was a valuable asset, this type of 'insider' status can also present a challenge. If one is too close to the field

one may be blinded to new insights and to the power structures within the practice (Hem *et al.* 2007, Wilson 2011). It may be difficult to achieve an analytical distance to the field, and roles can get ‘mixed up’ if one ‘goes native’ in the field (Fangen 2004). The first author handled these challenges by being as descriptive as possible in the field notes, by focusing on open-ended questions in the interviews, and by questioning and discussing the method and findings with the two other researchers throughout the project.

Data analysis

First we read the material inductively and, to the greatest extent possible, with an open mind to get an overall impression of the field notes and the interviews, without being too influenced by our preconceptions. The first author coded the subthemes that emerged from this open reading into matrices to systematize the material. Some parts were sorted into several subthemes. After we had coded the data material according to the subthemes, the more deductive part of the analysis started. Subthemes that emerged through the first ‘open’ reading were abstracted to theoretical themes that could be related to earlier research on dignity.

Examples of subthemes were the significance of a *relational and confirming care* that confirms both the relational needs of the patient and his or her personhood. With a *confirming care* we mean a care where the individual is acknowledged and taken seriously as a human being. Another subtheme was *task-centred care*. The subthemes were abstracted to the theoretical themes *dignity related to confirmation of identity* and *dignity-in-relation*, or *dignity promotion through person-centred* and *relationship-centred care*.

However, analysis in qualitative research is not a linear process. It is more like a journey where the researcher moves back and forth in the material, between the whole and the parts, in line with the hermeneutic approach. According to Wadel, data analysis is like a ‘round-dance’ between theory and empirical data (Wadel 1991).

The first author did the main analysis, and consulted on the interpretation of themes and quotations with one of the supervisors and co-authors. The model below shows the three-step analysis, which can also be understood in the light of Kvale and Brinkmann’s three steps of analysis (Kvale & Brinkmann 2009). The first step represents what the informants said, or raw data from the field notes; the second step represents the common sense level or the subthemes; and the third step represents abstraction to theory.

Self-understanding level	Common-sense level	Theoretical level
G: Confirmation – they need to be confirmed all the time, so that they may feel that they are individuals, and human beings.	A relational and confirming care	dignity related to confirmation

Findings

Our findings show that relatives think the most important thing for ensuring that people with dementia live a life in dignity, is that they are taken seriously as equal human beings, and that their relational needs are met. To live a life in dignity they need a confirming, person-centred and relational care. According to the relatives, confirming the residents as whole human beings and meeting relational needs depends on the attitudes of the health care workers, as well as on the time and resources available for communication and personal care.

Findings from the field notes agreed to some extent with the findings from the interviews with the relatives, but variations between the two different nursing home units were more evident in the field notes than in the interviews. One difference observed by the first author was that the care workers in the special care unit seemed to know more about the residents’ life stories, and they used these life stories in communication with the residents to confirm them or to calm them down. In the general unit, the staff were more concerned with practical tasks and somatic needs than in the relational needs of patients.

The importance of confirming, person-centred and relational care

What was most important to maintaining the dignity of the residents, according to the relatives, was that the residents were seen and taken seriously as relational human beings, and not merely as objects needing physical care. When asked if she could describe a good and caring nurse, one relative replied:

M (relative nursing home 1): Someone who is calm. Gentle, and has time to sit down ... listening. I actually think that's the most important thing they can give. If they manage to help them with showering, I don't think that's the most important thing. (...)

Another relative emphasised the importance of meeting the residents' emotional and relational needs, and of taking them seriously as human beings:

G (relative nursing home 1): Because I think it's really important that the staff should be a little bit ... (...), what do you say, 'including' for each individual. (...) We want extra emphasis on emotional support. So – not only a person who walks around and gives them food and makes their beds and follows them to the toilet and takes them out for a walk. So – we should have more emotional care, we want something more.

I: Do you think this is about being seen?

G: Yes, for those who live here, yes. Oh, absolutely! To be taken seriously as a human being; to be taken seriously.

Later in the interview, this relative also emphasised the importance of confirming the person with dementia:

G: Confirmation – they need to be confirmed all the time, so that they may feel that they are individuals, and human beings.

How the patients were treated in the caring relationship and the carers' attitudes towards the residents were important. The relatives highlighted the importance of treating individual patients with respect for their personhood, not merely as members of a patient-group, as one daughter said:

S (relative nursing home 2): She's [her mother; our comment] respected as the person she is; they don't treat her as a 'demented person' in a wheelchair who isn't able to move.

I: Is this about meeting the physical needs, you think?

S: Yes, it's everything; how they care for her skin, the physical care, the way they talk to her; it's everything.

I: And how do they talk to her?

S: Like a grown-up human being.

The first author also observed how carers used knowledge about the residents' life-stories and encouraged the resident to tell stories from their lives to confirm their personhood. The story of Helene, one of the nursing assistants, and Dagny, one of the residents, demonstrates this.

(From the field notes from the special care unit, nursing home 1):

Helene, one of the nursing assistants, sits down and is eating with the residents. It is winter and cold outside, and as she sits and talks with the residents, Helene starts to talk about 'puttees'. 'We should have "puttees" when we are walking outside now,' she says. She turns to Dagny and says: 'You know what a "puttee" is, Dagny. We didn't know what it was until you told us. That's something we have learned from you.' Dagny starts to explain to me [the researcher; our comment] what a 'puttee' is. She seems to enjoy telling me about something I did not know about. 'It's a kind of leggings,' she says. In addition, she tells about how they used 'puttees' when they walked to school as children during wintertime. She smiles when she tells this to me.

Here Dagny had the opportunity to participate in a conversation and talk about who she was and who she had been. She had the opportunity to feel that she was an expert on something and not only 'a demented person' with cognitive deficits. Helene needed to know Dagny and her preferences to know what themes she could bring into the conversations with Dagny to confirm her.

Time and resources in the care relationship. What the relatives experienced, however, was that resources for proper interpersonal care in the nursing home unit were scarce, and that the caregivers were often busy. They wished that the health care workers had more time to see and listen to each of the patients. Almost all the relatives talked about lack of resources in the nursing homes, and they thought this was a threat to dignifying care:

G (relative nursing home 1): They don't have time, you know. They are running from one thing to another. They wish they could have more time for activities; that's what they say. But they can't sit down, one to one. (...) So it's a question of resources.

And when the first author asked one of the relatives if she thought anything could be better in the nursing home unit, she answered:

M (relative nursing home 1): No, not given the staff situation they are in at present. If something were to be better, they would need to have more staff so that they could have more time. Because that is what it is all about, they do not need more time for the physical care, but what I am thinking about, maybe they should have had more time to sit down. (...) I know that is very important for my mother. Moreover, they [the caregivers: our comment] say that to calm her down, someone should sit down with her alone. That is how she is. However, I know there are staff reductions everywhere

The first author also observed that it was crucial for the residents that carers had time to listen to them to confirm them, especially if the residents became restless or anxious. As the situation described below shows (from the field notes from the special care unit, nursing home 1, with the same resident as mentioned earlier):

Today Dagny is restless and anxious. Several of the carers have tried to calm her down, but not even her daughter has managed. When Elise, one of the nursing assistants who know Dagny well, arrives at the evening shift, she says that she will take care of Dagny. After the report, Elise follows Dagny into her room. After an hour, they come out to the living room, and Dagny is much calmer. Later I ask Elise what she did to calm Dagny down. She says, "It's about diversion. Diversion, diversion and diversion, again and again. And if talking about one subject doesn't help, I have to move on to another. But it's very time-consuming."

This shows how both time and knowledge of the person are important factors in confirming and relational care for people with dementia. Here again, Dagny experienced someone taking the time to listen to her and taking her seriously.

Task-centred care – the opposite of confirming and relational care

Relatives also described situations that they saw as violations of dignity. The common factor in several instances was the carer's being busy getting their job done, and not communicating with the residents when helping them. In some situations, carers

communicated with other carers when helping a resident, 'talking over the residents' heads'.

One of the relatives described in an interview:

G (relative nursing home 1): I have seen some examples where ... they are sitting and feeding a person, and while they are feeding him or her, they have been talking to someone else. And I have seen situations where one of the carers just mechanically put something into the resident's mouth. It's terrible! I've also seen other examples where they talk to a relative over the resident's head.

The first author also observed examples of carers' seeming more occupied with getting the job done, and where delivering basic physical care became task-centred. As the two situations below illustrate (from the field notes, from nursing home 2):

Situation 1:

When I arrive at the unit today, Sigrid, one of the residents, is sitting at the same place she sat yesterday, in a wheelchair, and one of the nurses is feeding her. The nurse has cut the bread into small pieces and is feeding Sigrid with a fork. There is no verbal communication between Sigrid and the nurse; it is more like a mechanical feeding without any conversation around the meal.

Situation 2:

Most of the residents have finished their dinner when I come to the unit. Only Emma and Sigrid are left. A nursing assistant sits down with Emma and Sigrid, feeding both of them at the same time. There is no conversation between the nursing assistant and the patients she is feeding.

A theme seen in both the quote and the field notes, is that the resident is not given the opportunity to interact with the carer. The carers do not seem to recognize the resident as a relational human being. Both Sigrid and Emma were suffering from severe dementia. Sigrid had some verbal capacity left, but it was often difficult to understand what she was saying. Emma did not have any verbal capacity at all. This suggests that it may be more challenging to see and recognize individuals with dementia as relational human beings when they cannot respond verbally. It shows the importance of knowledge about how to communicate with individuals who no longer have any verbal capacity so that they can experience being seen as equal human beings.

Discussion

Our findings show that dignity-promoting care for people with dementia is care that confirms the residents' personhood and that confirms them as relational human beings. To maintain a person's dignity we should treat him or her as more than an object or a task. To treat a person with dignity, we argue, is the same as respecting the person and taking this person seriously as a relational and equal human being.

Dignity related to confirming person-centred care

Treating a person merely as an object or a task, may be seen as objectifying the person, and posing the most serious threats to dignity, as it affects human worth, dignity of *menschenwürde*, and social dignity or dignity of identity (Jacobson 2009a, Moody 1998, Nordenfelt 2004).

In order to treat a person with dignity, and not as an object, it is important to confirm 'a whole self' (Koppelman 2002). 'Confirmation of the patient', or confirming care, means seeing and understanding the whole person, meeting the patient on his/her own terms, and seeing the patient as the one he or she really is (Nåden & Sæteren 2006, Rundqvist & Severinsson 1999). This is also in line with what Kitwood described as 'person-centred' care (Kitwood 1997). Confirming, person-centred care is care that sees the person behind the diagnosis and behind the patient role: care that takes the patient's dignity of identity and social dignity seriously (Jacobson 2009b, Nordenfelt 2004). Earlier research shows that confirming care may be of particular importance for people with dementia (Rundqvist & Severinsson 1999). For individuals with dementia, confirming care involves someone seeing them and listening to their life stories. Telling one's life-story may be seen as a way of trying to draw attention to who a person is. By telling their life stories, as Dagny got the opportunity to do, patients are seen as more than a number or a task or a patient in the nursing home unit.

Earlier research has also shown that telling one's life story may help promote the identity and self-esteem of individuals who suffer from dementia (McKeown *et al.* 2010, McKeown *et al.* 2006, Ryan *et al.* 2009). We argue that promoting identity and self-esteem is the same as promoting the person's dignity of identity or personal and social dignity, and is therefore of great importance when it comes to promoting the residents' dignity.

According to our findings, though, staff need time and resources to promote the residents' social dignity. Earlier research shows that when resources are scarce, health care personnel seem to prioritize physiological or biomedical needs, and that psychosocial needs are left unattended to (Pedersen *et al.* 2008, Slettebø *et al.* 2010). Research also shows that lack of resources can be a threat to dignity-promoting care (Egede-Nissen *et al.* 2013, Jakobsen & Sorlie 2010). Pullman claims that how resources are allocated and the low priority given to long-term care, reflects how we, as a society, value the needs of dependent older people (Pullman 1999). We argue that undervaluing a whole group is a threat both to basic dignity and social dignity. To show that we as a society value the needs of people with dementia living in nursing homes, and want to protect their basic and social dignity we should give more resources to long-term care.

Dignity related to relationship-centred care

To avoid a mere individualistic focus in the care of people with dementia, we need to see dignity within a wider relational frame. Human beings are relational, and dignity is a relational concept, ie, we experience dignity in relation to others (Frank 2004). Dignity is a matter of how we treat and are treated by others (Badcott 2003, Jacobson 2009b). Our findings emphasize the importance of the residents' relational needs. This is supported by previous studies (Sellevold *et al.* 2013, Sherwin & Winsby 2011, Wilson & Davies 2009).

A dignifying caring relationship is a relationship in which both the patient and the care worker interact and participate in a meaningful way. This was illustrated in the situation where Dagny got the opportunity to tell her story. The Norwegian philosopher Hans Skjervheim states that if one does not let the other person participate, the relationship becomes a subject-object or instrumental relationship. He calls this “the instrumental mistake” (Skjervheim 1996). Care becomes instrumental rather than an interaction between the carer and the resident. Wilson and Davies (2009) claim that to develop personal and responsible relationships in care, and move the focus from an instrumental notion of care, carers need to find out what matters to each resident (Wilson & Davies 2009). To avoid task-centred care and to maintain both dignity related to human worth and social dignity, we should not only see the person as a passive receiver of care, but as a relational subject with agency.

A relational perspective may, furthermore, provide an alternative understanding to the focus on individual-based autonomy related to dignity in earlier research. According to Nordenfelt’s notion of dignity of identity, autonomy is a fundamental element of a person’s dignity (Nordenfelt 2009). Pullman, though, claims that autonomy may be crucial to certain aspects of dignity, but should not be ‘confused with the whole of it’ (Pullman 1999, p 26). Moreover, if autonomy is to be a guiding principle in care for older people, Pullman suggests that we need to redefine the concept. Some have argued for a relational perspective on autonomy (Mackenzie & Stoljar 2000, Sherwin & Winsby 2011). Sherwin and Winsby claim that the traditional concept of autonomy, where the focus is on individuality and rationality, may lead to the discrimination of and undervaluing of older people who may lack the capacity to reason or be totally dependent of others (Sherwin & Winsby 2011). Discrimination and undervaluing people may be understood as violations of dignity, as people who are undervalued are not treated as equal human beings. Relational autonomy is concerned with promoting the autonomy of undervalued and oppressed people, and takes the interdependence and the social

circumstances in the situation seriously (Sherwin, et al. 2011). Moreover, relational autonomy makes it possible to confirm individuals with dementia as equal human beings, despite their cognitive impairments.

Limitations and transferability

A limitation of this study is that it took place in two Norwegian nursing homes. Dementia care settings may be different in other cultures. We also know that nursing homes differ from place to place in Norway, and that some nursing homes have more resources than others.

Nonetheless, we think that the findings may be transferable to similar settings.

This article only presents findings from interviews with the relatives and from participant observations, and does not incorporate the residents' experiences. This may be seen as a limit in this article. However, we have already published an article that focuses on the residents experiences (authors anonymised, 2013b).

Conclusion

Dignity is not purely a theoretical concept. It is important to both the residents and their relatives and to the health care personnel. Analysing the various connotations of dignity as a concept can give us a broader understanding of person-centered and relational care based on how residents and, in this case, relatives experience the personal and subjective wellbeing of their spouse, family member or friend.

However, dignity is also a practical matter, and is almost always related to personal experiences, emotions and intuitions. Relatives of people with dementia may "feel" that the patients' dignity is threatened. They feel that the care or the situation is not dignified. As a phenomenon experienced in particular situations, dignity is very often associated with feelings of respect being shown, of how the person's integrity prevails and of caring being

done with compassion and empathy. Our findings confirm these experiential and practical dimensions of dignity.

Declaration on conflict of interests

The authors declare that there is no conflict of interest.

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