

# **'Like a prison without bars': Dementia and experiences of dignity**

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## **Abstract**

The aim of this article is to investigate how life in Norwegian nursing homes may affect experiences of dignity among persons with dementia. The study had a qualitative design and used a phenomenological and hermeneutic approach. Participant observation in two nursing homes units was combined with qualitative interviews with five residents living in these units. The study took place between March and December 2010. The residents feel that their freedom is restricted, and they describe feelings of homesickness. They also experience that they are not being seen and heard as individual autonomous persons. This lack of freedom, experiences of homesickness and feelings of not being confirmed and respected as individual autonomous persons, may be a threat to their personal dignity. In order to protect and enforce the dignity of persons with dementia living in nursing home, we should confirm them as whole and individual persons, and we should try to make the nursing homes less institutional and more home-like.

## **Keywords:**

Belonging, confirmation, dementia, dignity, freedom, nursing home .

## **Background**

Overall, 80% of residents living in Norwegian nursing homes suffer from dementia<sup>1</sup>. Patients suffering from dementia are particularly vulnerable due to cognitive impairment, and they are often totally dependent of the persons who care for them. How they are cared for in this vulnerable situation is crucial for their experiences of well-being. Even though some have argued that dignity is a useless concept<sup>2,3</sup> it is a concept that is frequently in use and plays an important role in medical ethics<sup>4-7</sup>. We also think that it is a fruitful concept to use when the goal is to illuminate patients' experiences of wellbeing and the quality of the care they receive.

The study is a part of a larger Scandinavian project called 'A life in dignity', the focus of which was residents and their relatives' experiences of dignity in Scandinavian nursing homes. In the study, which this article builds on, the focus was on patients with dementia and their family care givers experiences of dignity in Norwegian nursing homes. In this article we will focus on the residents' experiences while the relatives' experiences will be presented in a later article.

Persons with dementia are rarely consulted regarding their lived experiences,<sup>8</sup> and it is of great importance to give them a voice in research to explore what they experience as important in order to live a life in dignity. The aim of this article is therefore to present and discuss what persons with dementia themselves experience as a threat to their dignity, and what they experience as important to maintain their dignity when living in a nursing home.

## *Theories of dignity*

Dignity has been emphasized as an intrinsic and absolute value related to human worth and 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.<sup>9-13</sup> Dignity as an absolute value relates to the classical Kantian dignity. Kantian human dignity or *menschenwürde* is a value that cannot be replaced, measured or traded.<sup>14</sup>

Nordenfelt presents four notions of dignity; dignity linked to 'menschenwürde', dignity of identity, dignity of moral stature and dignity of merit<sup>11</sup>. Dignity as 'menschenwürde' is related to human worth in its Kantian version, and is an intrinsic value which cannot be lost as long as the person exists. Dignity of identity is linked to a person's integrity, autonomy, self-respect and social relationships. This kind of dignity may vary, and is not an absolute dignity. Dignity of moral stature may also vary, and depends upon an individual's moral value, and may be understood as a kind of virtue. Dignity of merit is a kind of dignity that depends on social rank or formal positions which is also contingent.

Kass distinguishes between what he calls 'The dignity of being human' and 'The dignity of human being'. The first is associated with dignity related to 'living well' and to everyday life in its concreteness, and dignity related to human activity and intimate human relations. The second is a basic human dignity that all human beings have, related to human worth, an intrinsic form of dignity that we have because of 'our equal membership in the human species' (p.24).<sup>12</sup>

Jonathan Mann has made a taxonomy of dignity-violations, where he shows how violation of dignity may occur in different ways<sup>15</sup>. First one may experience violation of dignity when one is not seen, respected or acknowledged. Second dignity violation may be experienced when one is seen, but only as a member of a group. Third, violation of dignity

may happen when one's personal space is being invaded by others. Finally, dignity may be violated through humiliations. This last form of violation may also be seen as a result of the three other kinds of violations.

### *Previous empirical research on dignity*

Several empirical studies on dignity in care for older people, have found that experiences of dignity are related to a person's autonomy and integrity. This means that if a person's autonomy and integrity are not taken seriously, the experience of dignity may also be threatened.<sup>16-18</sup>

Empirical research about dementia and dignity has also emphasized dignity related to autonomy.<sup>19-21</sup> The debate in these studies has to a great degree focused on surrogate decision making and on how to make the best decisions on behalf of the person with dementia, when he or she loses the capacity to make autonomous and informed choices. There has also been a discussion between those who favor the 'former self' and those who favor the 'now self' in surrogate decision making.<sup>19</sup> Koppelman<sup>19</sup> argues that we need a more balanced approach that sees the 'whole self', considering both the 'former self' and the 'now self' to maintain a patients' dignity, since it is both the past and the present that constitute the self.

The Nuffield Council work 'Dementia Ethical Issues' presents a framework on how to develop care services that enable persons with dementia to live a better life with the diagnosis.<sup>7</sup> According to the Nuffield Council, dignity is a useful concept in 'guiding attitudes and approaches to the care of people with dementia' (p33).<sup>7</sup> A dignifying care is a care that does not discriminate but rather one that empowers the patients and values the patient as a person. The report also states that dignifying services should be flexible and promote the patients' autonomy by letting them participate as much as they can in decisions regarding their everyday life.<sup>7</sup>

Some research concludes that to enhance the dignity for persons with dementia, a ‘person-centred’ approach is acquired.<sup>22-26</sup> The term ‘person-centred care’ builds on Tom Kitwood’s<sup>27</sup> theory on how to see the person as being an expert on himself or herself and seeing the person as an individual with subjective lived experiences. The term is used in many different ways and may be seen both as a care approach and a set of techniques in work with persons with dementia.<sup>28-30</sup>

Most of the previous empirical research regarding dementia and dignity builds on the nurses’ or family caregivers’ perspective and experiences, rather than the residents’ perspectives. In this article we will, by incorporating the residents’ personal perspective, try to fill a little of this gap in knowledge.

## **Design and method**

### *A phenomenological and interpretative hermeneutical approach*

The study has a phenomenological and interpretative hermeneutical approach. In phenomenology the emphasis is on the informants’ subjective experiences of a phenomenon.<sup>31</sup> The aim of this study was not to gain an objective understanding of the concept of dignity but to identify the informants’ subjective experiences of dignity.

A hermeneutic approach emphasises the researcher’s pre-understanding. In order to gain and see new knowledge it is important to be aware of one’s own preconception. New knowledge is interpreted and developed in light of old knowledge.<sup>32</sup> The preconception in this study was built on previous research on dementia, theories on dignity and the first author’s (A.K.T.H) experiences from dementia care practice.

## *Method*

The findings presented in this article are based on participant observation in two nursing home units and qualitative interviews with five residents living in these two nursing home units.

### *Inclusion, participants and research context*

The main inclusion criterion for the residents was that the informant should have a dementia diagnosis according either to the head nurse, the general practitioner (GP) or the nursing journal, and should live in the unit where the study took place. Regarding the formal interviews, the informants should have a verbal capacity to express their feelings and experiences. The participants should also give their written consent if they were judged to have the capacity to give their consent themselves. If not, consent was obtained from proxies.

The first unit was a special care unit for persons with dementia in a small town (29,000 citizens) in Norway. Eight residents aged 79–99 lived in this unit, and all were included in the field notes. They were all suffering from mild to severe dementia, and the verbal capacity of the residents varied. Two of the women living in this unit, aged 84 and 91, respectively, participated in more formal interviews.

All the residents in the first unit were assessed as not competent to give their own consent. Consent was in this case obtained from the relatives. The residents in this unit had their own private room with bath and toilet but shared the living room and kitchen with the other residents. The doors to the unit were locked. The doors to the kitchen and to the workers' office were also locked. Most of the residents had their own key to their private room so that they were able to lock their rooms and share a feeling of privacy.

The other unit was a larger general unit in a nursing home in a larger town (between 550 000 and 600 000 citizens) in Norway. Eighteen residents aged 73–92, both residents with

dementia and residents not suffering from dementia, lived in this unit. Seven of these residents were, due to their dementia diagnosis, included in the analysis of the field notes. Three of the residents living in this unit, one 86 years old man and two women aged 89 and 94, respectively, were included in the formal interviews. The residents living in this unit also had their own private rooms, and the unit was located on the second floor. The doors were not locked in this unit. The rooms in this unit were much smaller than in the first unit; the residents had their own toilet, but had to share a bathroom with the other residents in the unit.

### *Participant observation*

Participant observation was done by A.K.T.H in the two nursing home units. The observation lasted for 3 months in the special care unit, and 2 months in the general unit. In the beginning of the observation periods, the participant observations were 'open' and explorative, to ensure that A.K.T.H was not too influenced of her own preconception. After some weeks though, the participant observations were more focused, and an observation guide was then used during the observations. The themes in the observation guide built on previous research on dignity and on new themes that had emerged through preliminary analysis of the first observations and conversations and interviews with the participants. Example on a theme that was based on previous research was 'the patients' abilities to make decisions in their everyday life'. One of the themes that emerged through preliminary analysis of the first observations was 'expressions of homesickness'. A.K.T.H observed during the daily meals, during toileting and in bathing situations. Much time was used just sitting down with the residents in their living room, listening to them and having informal conversations with both the residents and the staff. Observations and the informal conversations were written down in field notes. The researcher was in the unit between 07.30 a.m. and 10.00 p.m. 3-4 days a week. In the first nursing home, the observation time was estimated to 88.25 h; in the second nursing home the observation time was 96.25 h.

With participant observation, one is able to validate if and what the informants say in the interviews correlates with what happens in the real world. The material will also be richer when combining different methods. Themes that were seen as important from the observation study could be followed up in interviews and vice versa. The advantage of participant observation is also that one gets access to what people feel, do and say from a variety of perspectives. And one gets access to nonverbal as well as the verbal statements.<sup>33,34</sup>

Participant observation also gave rich information about the research context and made it possible to have many informal conversations with all of the residents.

### *Qualitative interviews*

The interviews were conducted by A.K.T.H when she had been in the units for 6-10 weeks. She had to wait that long for the interviews in order to develop a trustful relationship with the residents, as well as to learn who among the residents were able to participate in a more formal interview.

Some previous research has emphasised that persons with dementia may be able to express both feelings and experiences properly.<sup>35-38</sup> What is important when including persons with dementia in interviews is to ask questions that appeal to their feelings and experiences rather than to their intellectual capacities. It is also important to create a trustful and safe atmosphere in the interview situation, since an unsafe atmosphere may influence the person with dementia's ability to articulate feelings and preferences<sup>39</sup>. Thus, all the interviews with the residents were conducted in their private rooms.

The interviews started with an open ended question on how the resident experienced it living in the nursing home. An interview guide, which built on themes from previous research on dignity and dementia and on preliminary analysis of the field notes, was also used. Examples on themes which built on previous research were 'experience of the caring

relations' and 'experiences due to decision making in the day to day care'. One of the themes that emerged through preliminary analysis of the field notes and the first interviews was 'experiences of homesickness'. The interviews lasted from 30 minutes to 1 hour. Four of the interviews were audio-taped and transcribed verbatim by A.K.T.H. One of the respondents did not want that the interview should be audio-taped, so A.K.T.H. had to take notes from this interview.

### *Analysis*

When employing a phenomenological-hermeneutic approach, one moves back and forth between induction and abduction. In the beginning the material was analysed inductively; but when abstracting the themes we were more 'abductive', and our preconceptions were important in order to understand the emerging themes. The progress of the analysis may also be understood as Kvale and Brinkmann's three analytical steps, which starts with self-understanding, continues with a common sense and ends at a theoretical level.<sup>40</sup>

Examples of the self-understanding-themes that the informants mentioned during the interviews or in more informal conversations during the participant observation, were: 'The most important is that they listen to what I have to say', 'It's like being in a prison without bars' and 'This is not a home'. These could be abstracted to more common-sense themes, or subthemes, such as *to be seen and heard*, *captivity and homesickness*. The subthemes were coded into matrixes, and all parts of the material which could be categorized under the subthemes were collected.

The subthemes were then condensed to theoretical themes. We found that some of the theoretical themes could be *dignity related to confirmation*, *dignity related to freedom and dignity related to belonging*, as shown in Table 1.

The primary analysis was done by A.K.T.H, but the material was read by the co-authors so that all three authors could discuss the findings.

### *Ethical considerations*

Written consent was obtained from all the participants or from relatives if the residents did not have the capacity to give their own consent. From these residents assent was obtained prior to the interviews and the observation. The health care workers were informed about the project and could abstain from participating. Consent from the health care personnel was obtained in situations where the researcher participated in more concrete care situations with the worker, for example in bathing situations.

The participants were informed that they could withdraw from the study at any time, and that withdrawal would not have any consequences for them.

The study was accepted by the Regional Committee for Medical Research Ethics (REK Sør-Øst 2009/2222).

Names used in the article are fictitious.

## **Findings**

### *To be seen and heard*

Even though the capacity to make autonomous decisions may vary when one gets a dementia diagnosis, our findings show that residents with dementia were able to express their wishes, and that they wanted to make their own decisions in their everyday lives. They could, however, feel that their opportunity to make their own decisions was restricted, and that others made decisions for them, as Anna, who lived in the general unit, told me in the interview:

Interviewer: So you think they [the health care personnel; our comment] decide too much for you?

Anna: Yes, they do. (...), I am a grown up, and I can think; I know what I am saying, and ... even though I fumble sometimes.

When Berit describes what she thinks a good carer is like she says:

Berit: She [the carer; our comment] should listen, have her own opinions, and listen to the patients.

Grete says the same (from the field note):

When I ask her what she thinks is important in good care, she (Grete) answers: 'that they [the carers; our comment] are not fussing, that they listen to what I have to say.'

Eli described how she experienced it when the carers did not have time to listen to the residents' needs:

Eli: What's worst is ... and I understand that they are busy, but if they the care workers; our comment] just run through the corridor, and maybe someone will say 'can I have that?' – it could be pills or something – and they cannot, because they don't have time to answer, you know. And those kinds of things, it makes you feel a bit 'down'.

Interviewer: I understand ...

Eli: And one gets a bit sad.

A situation from the field notes also shows that persons with severe dementia may be able to express their own meanings and wishes. Asta was one of the patients with severe dementia. It was not possible to have long conversations with her, and it was often difficult to understand what she was trying to express. Sometimes, though, she could be very clear in her statements.

As the situation below shows (from the field notes):

In the unit where Asta lived, all the residents, except her, had their own key to their private room. One day when the head nurse came in to the living room, Asta walked straight ahead to her and asked her loud and clear: 'Can anyone tell me why I can't have my own key to my room?' The head nurse seemed to be surprised by this question from Asta, and it seemed as she did not expect her to express her wishes so clear.

The above quote and the situation with Asta show the importance of being seen and heard, and the importance of being taken seriously as an individual person. The residents are totally dependent on the carers and that the carers listen to their needs and wishes. If they do not feel that they have the opportunity to make decisions in their everyday lives, and if the carers do

not listen to them, they feel that they are not confirmed, and experience this as a threat to their dignity.

### *Captivity*

Several of the patients told about a feeling of captivity when living in the nursing home. As Grete, an 86-year-old lady suffering from dementia who had been living in the special care unit for 1.5 years, explained:

Grete: Materially, it is good to live here. We get everything we need. We get food, clean clothing and so on, but ... (...)

Interviewer: You say that it is good materially, but ... how do you enjoy living here?

Grete: You know it is like a prison without bars (...). I feel like a prisoner. I have no freedom.

One of the reasons Grete felt like being in a prison, she said, was that the doors in the unit were locked. In this unit the doors to the kitchen and to the workers' office also used to be locked, so if the residents wanted a cup of coffee or a glass of milk they were not free to walk into the kitchen and get it. Eli, an 82-year-old lady who had lived in the unit for two years, also expressed a sense of captivity related to the lack of opportunities to get out. As Eli explained when A.K.T.H sat down and talked with her (from the field notes):

Eli: 'Here we don't even have the opportunity to go out. I love to go digging in my garden.' I ask her what could be better here. She answers: 'We should have the opportunity to get out more, but I don't think they [the carers; our comment] have time for that. You know, I'm just sitting here; that's a little bit boring.'

One of the men suffering from dementia in the general unit also talked about a feeling of captivity. The doors were not locked in this unit, and there were no restrictions on walking outside. The reason he felt captive was that he was dependent on help from the personnel if he wanted to take a walk outside the unit, and he felt that they did not have time to follow him out.

Other residents also related their experiences of captivity to the fact that they were dependent on the health care personnel to get out of the unit and do what they wanted to do in

the unit, such as making a cup of coffee or a piece of bread when they were hungry. The dependency became more obvious when there were few care workers to meet the residents' need.

### *Homesickness*

Several of the informants talked about their previous homes and experiences of homesickness.

Grete, who first used the prison metaphor, also associated this metaphor with institutionalisation and homesickness: 'You feel that you are in an institution; you cannot forget that. I cannot experience this as my home.'

Eli did not experience the nursing home as her home either, as she expressed in the interview: 'This is not a home, you know.' When she was further asked about what a home was like for her, she said:

'It's a place where you may walk around and do what you like. If I want to walk in the garden, I can do so, and if I just want to sit down and read a book, I can do so. And I don't have to be afraid of what others think about what I am doing (...) When you're at home you can talk and walk around just as you want. If you want a piece of bread or a glass of milk, you go ... that's how I do it when I am at home.'

The fact that the residents experienced that they lived among strangers in the nursing home could also increase their feelings of homesickness. As Dagny, one of the residents, said one day as the researcher sat down and talked with her, (from the fieldnotes): 'I can't stand it any longer. I'm only among strangers, and I don't see my family. I don't understand where I am'.

Berit also expressed how she related her home to her family and where she belonged:

Berit: Everybody wants to stay in his or her home. I'm a grownup; I'm 93 years old.  
Interviewer: What is it that makes you wish to stay at home?  
Berit: Home is where the family is, your things. Everything happens at home; that's where you're known. But it is very nice to be here too.

What Berit thought was nice about living in the nursing home was that her physical needs were met, such as bathing, eating and having clean clothes. However, even though she thought it was nice to be at the nursing home, she could not feel that it was her home.

## *Summary of findings*

The findings show that to maintain a person's dignity it is important that the patients are confirmed as individual persons. Our findings also show that persons with dementia in nursing homes experience feelings of captivity and homesickness.

## **Discussion**

Our findings reveals two essential challenges in dementia care, which may harm the patients' dignity. The first is that we as health care personnel have scarce knowledge about the subjective experiences of patients with dementia and mainly focus on their cognitive impairment and lack of capacity for decision making. This means that we do not respect them as whole, individual persons. Secondly, institutionalisation and the institutional frames the patient are living under tend to increase the patients' experiences of being overheard and disrespected as individual, autonomous persons.

## *Dignity related to confirmation*

To maintain what we will call dignity related to confirmation it is of great importance that someone listens to our will and wishes, and that someone takes us seriously as persons. While previous research has focused on the lack of competence to make autonomous choices by persons with dementia and how to make the best decisions on behalf of the person with dementia, little research has focused on the persons' need to be seen and heard despite of his or her dementia. Our findings show that the residents to a certain degree experience that their opinions are not taken seriously. This is also supported by some previous research.<sup>8</sup>

The reason why we often think that persons with dementia lack the ability to make autonomous choices in their daily life may be that we often see the diagnosis with all the problems that follow. The diagnosis of dementia becomes the 'master status' of the person.<sup>41</sup>

We see them as ‘the demented’, who cannot manage their lives any longer. To be seen and treated as a diagnosis is the same as objectifying the person and is a threat to a person’s dignity. Koppelman states that ‘In situations in which we are treated as mere objects, or as being incapable or not worthy of being subjects or agents, we are humiliated (p.68).<sup>19</sup>. This is also supported by Mann’s taxonomy of dignity violation.<sup>15</sup> Not being seen as a person or only being seen as a member of a group, for instance, as a member of a patient group may be experienced as violation of a person’s dignity. To avoid this threat to the dignity, we should to a greater extent ask the persons with dementia what they think is important in order to live a good life, and see them as experts on their own lives. The Nuffield Council also underscores the importance of respecting the patient as a person.<sup>7</sup> We should confirm the person and his or her individual identity, which exists behind the disease. Or we should emphasize what Kitwood calls a ‘person centred care’<sup>27</sup>. A person-centered care requires that the persons around the residents know who they *are* and what they *have been*. Koppelman states that we need to see the patient with his or her ‘then self’ and ‘now self, to see the patient as a ‘whole self’. A ‘whole self’ involves both the past and the present self. If we manage to confirm the residents by seeing them as whole and unique persons, we will also protect and preserve their identity, and hence their dignity to a larger extent.

### *Dignity related to freedom and belonging*

The findings show that the feeling of lack of freedom and belonging may be related to institutional frames, like routines and locked doors, and to the fact that the residents have to live together with strangers.

Dignity of freedom and belonging may be seen in light of what Nordenfelt calls ‘dignity of identity’. According to Nordenfelt, this kind of dignity includes a person’s social relations, autonomy and life story.<sup>11</sup> Your home says something about your social relations

and your life story, and a home is a place where you feel free and autonomous. De Jonge et al.<sup>42</sup> found that history and emotional connection with the house seemed to be important for older people's experiences of home, and a nursing home does not represent a history for the residents in the same way as their previous home does. A home is in many ways the opposite of an institution or a prison. A home represents the private sphere while an institution represents the public sphere. A home is something you chose to live in by yourself, and it is something you belong to. The patients are forced to move to the nursing home because they cannot manage to live in their home any longer, and they do not experience the same belonging to the nursing home as to their home. The Norwegian architect and researcher Norberg-Schulz<sup>43</sup> states that a home should confirm our identity. The meaning of a thing or a house is of great significance, and the meaning may be more important than the function of a house. A kitchen, for example, does not only have practical functions; a kitchen also has a meaning for those who use it. The kitchen and the living room may lose some of its meanings and fail to confirm the residents' identities if routines and restrictions become more important than the meaning the rooms should have. When the doors to the kitchen are locked, or if only the workers are allowed to make food in the kitchen, the residents will not feel that they are free to use the kitchen, they may not feel that they belong to the kitchen, and they will come to feel that they are merely visitors. The question, then, may be for whom the kitchen in the nursing home is made. Maybe the kitchen could be more home-like and give the residents a greater feeling of belonging and freedom, if we let the doors be open and let the residents have the opportunity to make a cup of coffee when they wanted to. And maybe the residents could fill the roles they had before they moved into the nursing home if they got the opportunity to participate more with the workers, in planning and making the meals? The nursing home may also be less institutional and more home-like if the units were smaller and if the doors were not locked. In a home you may walk around as you like, and you may also

walk out without asking for permission to do so. To avoid locked doors and hence enable the patients to live more freely, the Nuffield Council suggests that welfare technology, such as monitoring and tracking devices, may be a solution in the care for persons with dementia.<sup>7</sup> Then there is a chance that their dignity of freedom would also be maintained to a greater degree.

Residents with dementia who long for their home may not only long for a physical place they belong to,<sup>44</sup> such as their own kitchen, they also long for *someone* they belong to, and someone who may confirm them as persons. When the residents cannot identify with the other residents in the nursing home the need for social belonging to others is not met, and it is also a challenge when those who care for them are professionals rather than their families. Then the dignity related to belonging, and hence what Nordenfelt calls “dignity of identity” may be threatened. This leads to a discussion concerning the family’s role versus the carer’s role. The relatives usually know the residents better than the care workers. Therefore, maybe the family should be able to play a larger role in the residents’ life in a nursing home; they should not only be seen as visitors when they come to the nursing home but as collaborators and as important in the residents’ life. In that case, the residents would also experience a greater feeling of belonging and their dignity would be maintained to a greater degree.

### **Limitations and transferability**

The study took place in two Norwegian nursing homes. Nursing homes in other countries may differ from the nursing homes in Norway. Findings from other cultures may be different from the findings in this study.

Only five participants were included in the formal interviews, and the findings from these interviews may not be generalised. We nonetheless think they may be transferable to similar settings. Combining participant observation with the interviews also made it possible

to have several informal conversations with participants who were not included in the interviews, and gave important information about the context and of how life in nursing home for persons with dementia may be. This also gave us a more complete and richer material.

Choosing two different nursing homes, including both a special care unit and a general unit, should secure more variations and diversity in the findings. It is a fact, though, that most of the residents in Norwegian nursing homes are women, so diversity between how men and women may experience the life in a nursing home are limited.

## **Conclusion**

Our findings and the discussion indicate that the need of confirmation, freedom and belonging are intertwined and, in our view, are linked to a person's experience of dignity. We should, to a larger extent, see persons behind the diagnosis and also focus more on the person's abilities than limitations and who her or she has been, if we want to confirm them and hence maintain their dignity. As long as the residents are in need of professional care there will be a conflict between the public and the private, between home and institution. This is a challenge, and more research is needed to find out how to meet these challenges so that the requirements for the patients to maintain their dignity could be met to a larger extent. And to get more knowledge on the persons with dementia's experiences, we should continue including them to research. More research in other countries is also needed, so that it may be able to correlate findings from different cultures.

## **Conflicting of interests**

The authors declare that there is no conflict of interest.

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## References

1. Selbaek G, Kirkevold Ø, Engedal K. The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *Int J Geriatr Psychiatry*. 2007;22(9):843-849.
2. Macklin R. Dignity is a useless concept. *BMJ*. Dec 20 2003;327(7429):1419-1420.
3. Pinker S. The Stupidity of Dignity. *New Republic*. 2008;238(9):28-31.
4. Milton CL. The ethics of human dignity: a nursing theoretical perspective. *Nursing Science Quarterly*. Jul 2008;21(3):207-210.
5. Andorno R. Human Dignity and Human Rights as a Common Ground for a Global Bioethics. *Journal of Medicine & Philosophy*. 2009;34(3):223-240.
6. Van Der Graaf R, Van Delden JJM. Claryfying appeals to dignity in medical ethics from an historical perspective. *Bioethics*. 2009;23(3):151-160.
7. Nuffield Council on Bioethics. *Dementia: Ethical Issues*. Cambridge: Nuffield Council on Bioethics, 2009.
8. Tyrrell J, Genin N, Myslinski M. Freedom of choice and decision-making in health and social care: views of older patients with early-stage dementia and their carers. *Dementia (14713012)*. 2006;5(4):479-502.
9. Badcott D. The basis and relevance of emotional dignity. *Medicine, Health Care & Philosophy*. 2003;6(2):123-131.
10. Anderberg P, Lepp M, Berglund A-L, Segesten K. Preserving dignity in caring for older adults: a concept analysis. *J Adv Nurs*. Sep 2007;59(6):635-643.
11. Nordenfelt L. The varieties of dignity. *Health Care Analysis*. Jun 2004;12(2):69-81.
12. Kass LR. Defending Human Dignity. *Commentary*. 2007;124(5):53-61.
13. Edlund M. *Människans värdighet : ett grundbegrepp inom vårdvetenskapen (Human dignity - a basic caring science concept)*. Åbo, Åbo Akademis förlag; 2002.
14. Kant I, Zweig A, Hill TE. *Groundwork for the metaphysics of morals*. Oxford: Oxford University Press; 2002.
15. Mann J. Dignity and Health: The UDHR's Revolutionary First Article. *Health & Human Rights*. 1998;3(2):30-38.
16. Franklin L-L, Ternestedt B-M, Nordenfelt L. Views on dignity of elderly nursing home residents. *Nursing Ethics*. Mar 2006;13(2):130-146.
17. Randers I, Mattiasson A-C. Autonomy and integrity: upholding older adult patients' dignity. *Journal of Advanced Nursing*. Jan 2004;45(1):63-71.
18. Jacelon CS. Managing personal integrity: the process of hospitalization for elders. *Journal of Advanced Nursing*. Jun 2004;46(5):549-557.
19. Koppelman ER. Dementia and dignity: towards a new method of surrogate decision making. *Journal of Medicine & Philosophy*. Feb 2002;27(1):65-85.
20. Jaworska A. Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value. *Philosophy and Public Affairs*. 1999;28(2):105-138.
21. Livingston G, Leavey G, Manela M, et al. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ (Clinical Research Ed.)*. 2010;341:4184-4184.
22. Buron B. Levels of personhood: a model for dementia care. *Geriatric Nursing*. 2008;29(5):324-332.
23. Wellin C, Jaffe DJ. In search for "personal care": Challenges to identity support in residential care for elders with cognitive illness. *Journal of Aging studies*. 2004(18):275-295.
24. McIntyre M. Dignity in Dementia: Person-centred care in community. *Journal of Aging studies*. 2003(17):473-484.

25. Lorentzon M, Bryan K. Respect for the person with dementia: fostering greater user involvement in service planning. *Quality in ageing*. 2007;8(1):23-29.
26. Woolley RJ, Young JB, Green JR, Brooker DJ. The feasibility of care mapping to improve care for physically ill older people in hospital. *Age & Ageing*. 2008;37(4):390-395.
27. Kitwood T. *Dementia reconsidered : the person comes first*. Buckingham: Open University Press; 1997.
28. Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurology*. Apr 2008;7(4):362-367.
29. Brooker D. What is person-centred care in dementia? *Reviews in Clinical Gerontology*. 2004(13):215-222.
30. Brooker D. A note on person-centered care and use of the term BPSD. *Journal of Dementia Care*. 2011;19(5):37-37.
31. Zahavi D. *Fænomenologi. (Phenomenology)*. Fredriksberg: Roskilde Universitetsforlag; 2003.
32. Alvesson M, Skoldberg K. *Reflexive methodology : new vistas for qualitative research*. 2nd ed. Los Angeles ; London: SAGE; 2009.
33. Graneheim UH, Norberg A, Jansson L. Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and "behavioural disturbances", and on her care providers. *Journal of Advanced Nursing*. Oct 2001;36(2):256-265.
34. Nielsen KT, Hansen HP, Huniche L, Swane CE, Johannesen H. Når sundhed, sygdom og helbredelse er mere end ord - om bruk af deltagerobservation i sundhedsvidenskabelige undersøkelser. *Månedsskrift for Praktisk Lægegering*. 2007(84):1129-1141.
35. Moore TF, Hollett J. Giving voice to persons living with dementia: the researcher's opportunities and challenges. *Nursing Science Quarterly*. Apr 2003;16(2):163-167.
36. Wilkinson H. Including people with dementia in research - methods and motivations. In: Wilkinson H, ed. *The perspectives of people with dementia : research methods and motivations*. First ed. London: Jessica Kingsley; 2002:9-24.
37. Nygard L. How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*. June 2006;13(2):101-112.
38. Sabat SR. Capacity for decision-making in Alzheimer's disease: selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*. Nov-Dec 2005;39(11-12):1030-1035.
39. Clarke CL, Keady J. Getting down to brass tacks: a discussion of data collection with people with dementia. In: Wilkinson H, ed. *The perspectives of people with dementia : research methods and motivations*. 1st ed. London: Jessica Kingsley; 2002:25-46.
40. Kvale S, Brinkmann S. *Interviews: learning the craft of qualitative research interviewing*. Los Angeles, Calif.: Sage; 2009.
41. Milne A. The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*. Jun 2010;19(3):227-233.
42. de Jonge DM, Jones A, Phillips R, Chung M. Understanding the essence of home: Older people's experience of home in Australia. *Occupational Therapy International*. 2011;18(1):39-47.
43. Norberg-Schulz C. *Mellom jord og himmel - en bok om steder og hus (Between earth and heaven - a book about places and houses)*. Oslo: Pax Forlag A/S; 1992.
44. Zingmark K, Norberg A, Sandman P-O. Experience of at-homeness and homesickness in patients with Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*. 1993;8(10):10-16.

