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'Like a prison without bars' : dementia and experiences of dignity

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‘Like a prison without bars’ – Experiences of dignity among persons with dementia when living in a nursing home

Abstract

The aim of this article is to present some main findings on how life in a nursing home may affect experiences of dignity among persons with dementia. The study had a qualitative design and used a phenomenological and hermeneutic approach. Participant observation was combined with qualitative interviews with five residents in two different nursing home units. The study took place between March and December 2010. The residents feel that their freedom is restricted, and they describe feelings of homesickness. The feelings of lack of freedom and of homesickness may be related to a more fundamental need for freedom, belonging and identity. The findings are analysed and discussed in light of Nordenfelt’s theory of dignity, in light of Goffman’s theory of the total institution and stigma, as well as theories concerning home and identity.

Background and aim of the study

80% of residents living in Norwegian nursing homes suffer from dementia (1). As health workers we have an obligation to maintain the dignity of these vulnerable people. To do so, we need more knowledge on how these residents experience life in the nursing home, and what they experience as maintaining or as threatening to their dignity. The aim of this article is to describe and discuss how persons with dementia experience their identity- or autonomy-related dignity as being maintained or harmed. The findings in this article will be discussed in light of previous research on dementia, freedom and at-homeness, and in light of Nordenfelt’s theory of dignity.

In this article, we will answer the following research question:

- How may life in the nursing home affect the residents' experience of dignity related to identity?

Theoretical framework

Nordenfelt's theory of dignity

Nordenfelt (2004) presents four concepts of dignity; dignity linked to 'menschwürde', , dignity of moral stature, dignity of merit and dignity of identity. Dignity as 'menschwürde' is, according to Nordenfelt, universal and related to human worth. This kind of dignity cannot be lost as long as the person exists. Dignity of moral stature depends on 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. Dignity of identity is linked to a person's integrity, autonomy, self-respect and social relations. This kind of dignity may vary, and is not an absolute dignity. It represents a person's subjective experiences of dignity. It may be taken away or (be) threatened by external events, by the acts of other people, as well as by injury, illness and old age.

Both dignity of menschwürde and dignity of identity relate to the classical Kantian understanding of dignity. According to Kant, every human being has a dignity that is related to the human worth and autonomy (2).

In this article, the findings will mainly be discussed in light of dignity of identity, as we find this to be the form of dignity in Nordenfelt's theory that is most relevant to our research questions.

Previous research on dementia and dignity

Dignity, dementia and autonomy

Much of the research on dementia and dignity has emphasised dignity related to autonomy, and hence the challenges in decision-making for persons with dementia (3-8). The debate in these studies has to a great extent concerned surrogate decision-making and how to make the best decisions on behalf of the person with dementia when they lose this capacity to make autonomous choices.

Tyrrell et al. states that how persons with dementia themselves experience the decision-making in the day-to-day care, and what the persons with dementia themselves experience as important, has rarely been emphasised or discussed in previous research (9).

Remarks on previous research on dementia and dignity

Most of the previous research builds on the nurses' perspective and experiences, or the families' perspective, rather than the residents' perspectives. In this study we will, by incorporating the residents' 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 (10). In this study it was important to identify the informants' subjective experiences of the life in the nursing home related to dignity.

A hermeneutic approach emphasises the researcher's preconception. 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 (11, 12). The preconception in this study was built on previous research on dementia, theories on dignity and the first author's experiences from dementia care practice.

Method

The overall study was based on participant observation in two nursing home units and qualitative interviews with five residents and seven relatives. This article is based on findings from the participant observation in the two nursing home units, and the interviews with the residents. Findings from interviews with the relatives will be presented and discussed in another article.

Inclusion, participants and research context

The main inclusion criterion for the residents to the formal interviews was that the informant should have a dementia diagnosis according to the head nurse, the General Practitioner (GP) or the nursing journal, and live in the unit where the study took place. In addition, the informants should have a verbal capacity to express their feelings and experiences. Qualitative interviews were conducted with five residents. The participants should also give their written consent if they were judged to have the capacity to give their consent themselves. If they did not have the capacity to consent, consent was obtained from proxies. Assessing capacity to give consent and giving consent on behalf of a person is a big research ethical issue, which we have discussed in a previous article on research ethics (13). The procedure for how the participants were assessed and the research ethical implication for this will not be described further here.

The first unit was a special care unit for persons with dementia in a nursing home 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 with a code lock. The doors to the kitchen and to the workers' office also used to be locked. Most of the residents had their own key to their private room so that they were able to lock their rooms and have 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. 7 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 placed 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 the first author in the two nursing home units. The observation lasted for three months in the special care unit, and for two months in the general unit. The researcher was in the unit between 07.30 a.m. and 10.00 p.m. three to four days a week. In the first nursing home, the observation time was estimated to 88.25 hours; in the second nursing home the observation time was 96.25 hours.

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. If different sources confirm each other, this may strengthen the findings. 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 (14, 15).

Participant observation also made it possible to have informal conversations with all of the residents, and not only with the residents who were included in the formal interviews.

Qualitative interviews

The interviews were conducted by the first author when the first author had been in the units for six to ten weeks. The researcher waited that long with the interviews in order to get to know the residents and develop a trustful relationship with them, as well as to learn whom among the residents were able to talk and participate in interviews.

Some previous research has emphasised that persons with dementia may be able to express both feelings and experiences properly (16-19). What is important when including persons with dementia in qualitative interviews is to ask questions that appeal to their feelings and experiences rather than to their intellect. 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 (20). Thus, all the interviews with the residents were conducted in their private rooms.

The interviews lasted from 30 minutes to 1 hour. Four of the interviews were audio-taped and transcribed verbatim by the first author. One of the respondents did not want that the interview should be audio-taped, so the first author had to take notes from the interview instead.

Analysis

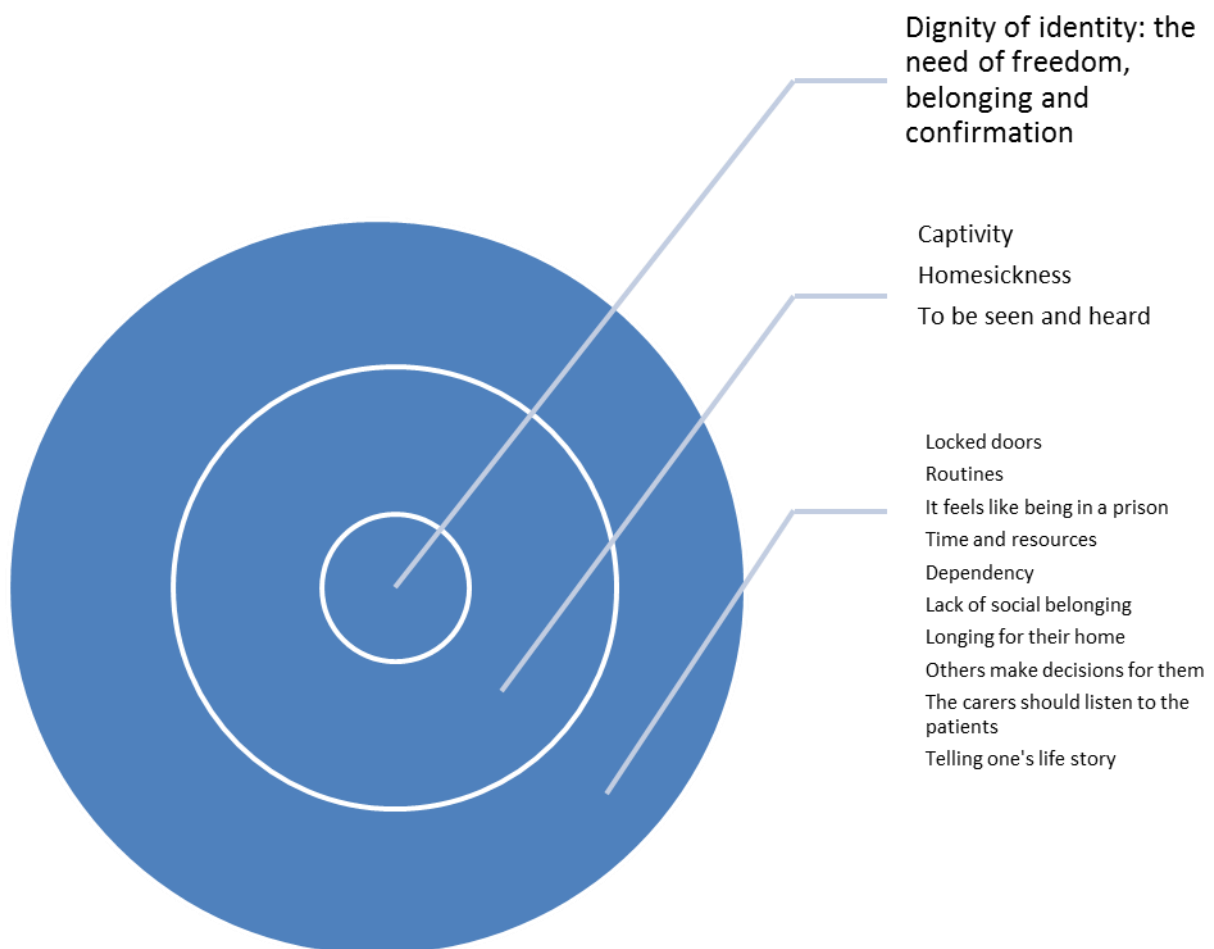
Analysis in qualitative research is both a systematic and a creative process. The aim is to look for themes and patterns in the material. In this study bricolage was used as a means for analysis. With bricolage one combines different methods and techniques in the analysis and move back and forth in the material, for example coding categories into matrices, combined with more creative approaches such as looking after metaphors, writing summaries and drawing illustrating models. It is an eclectic way of creating meaning in the material(21) .

When employing a phenomenological-hermeneutic approach, one moves back and forth between induction and abduction. In the beginning of the analysis the data were analysed inductively; but when abstracting the themes we were more ‘abductive’, and used our preconception and the theoretical frame to try to understand the emerging themes.

First the interviews and field notes were read thoroughly several times, and summaries were written down in order to try to grasp an overall meaning of the text and to search for topics, themes or metaphors that the informants talked about or used, or which emerged in the field notes. An example of a metaphor that was presented by one of the informants was the ‘prison’ metaphor. Some of the themes or categories that the informants mentioned, or which emerged from the field notes, were *locked doors, dependency, routines, lack of time and resources, decision-making, homesickness* and *lack of social belonging*. These themes could be abstracted to more common-sense themes, or subthemes, such as *to be seen and heard, captivity* and *homesickness*. These subthemes were then abstracted to the theoretical theme. We found that the overall themes in the findings could be *the need of freedom, belonging* and *confirmation*, which may be related to Nordenfelt’s ‘dignity of identity’.

The progress of the analysis may also be understood in terms of Kvale’s three analytical steps, which start with self-understanding, continue with a common sense level and ends up with a theoretical level (21). These steps are illustrated by the model below. The outer circle

shows the topics the informants talked about, or themes that emerged during the first readings of the field notes, and what Kvale talks about as ‘self-understanding’. These topics were gathered in the second step, the ‘common sense level’, which is shown as subthemes in the middle circle. The last level may be understood as the core or essence of the findings presented in this article, and represents the third level in Kvale’s analysis, the theoretical level.



The main analysis was done by the first author, 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 when the researcher assisted in bathing situations.

The participants – residents, relatives and health care workers – 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

The findings in this article build to a large extent on two metaphors, the prison metaphor and the home metaphor, which were used by some of the informants. Themes that emerged in the field notes could also be related to these metaphors.

The prison metaphor related to dependency and autonomy

The prison metaphor was first used by Grete, an 86-year-old lady suffering from dementia who had been living in the special care unit for 1.5 years:

I: How do you experience living in a nursing home?

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

I: 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.

As the material was read further, this metaphor, 'being in a prison' or 'being captive', seemed so important that we had to go further with it. We also saw that it could be seen as a contrast to the home metaphor.

The prison metaphor related to environmental barriers, dependency and lack of resources

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 of the unit. As Eli explained when the first author 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.

The prison of powerlessness – when not being seen and heard as an autonomous person

Even though the capacity to make autonomous decisions may vary when one gets a dementia diagnosis, our findings also 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 when I talk with her (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 patients' 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'.

I: I understand ...

Eli: And one gets a bit sad.

These quotations show the importance of being seen and heard as individual autonomous persons. The patients 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, it may be interpreted as a feeling of powerlessness. And if we see the feeling of powerlessness in light of the prison metaphor, it could be interpreted as a prison of powerlessness.

The prison metaphor related to homesickness

Several of the informants talked about their homes and experiences of homesickness. They related *homesickness* to *institutionalisation* and *lack of social belonging* or *social captivity*, while they related *home* to *freedom* and *belonging to others*.

Homesickness, institutionalisation and lack of social belonging

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.’ What she experienced as being ‘at home’ was to be free, to do what she wanted to do.

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 did not know the people they lived with in the nursing home could also increase their feelings of homesickness. And as Dagny said one day as the researcher sat down with her: ‘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

Our findings show that persons with dementia in nursing homes experience that their physical needs, such as bathing and having food and clean clothes, are met, but they also experience feelings of captivity and homesickness. The findings also show the importance of being confirmed as an individual, autonomous person.

Discussion

The categories and metaphors may be related to *autonomy*, *home* and *identity*, and what Nordenfelt describes as 'dignity of identity'. A person's identity may be understood as the person's 'self', with a life story, his or her values and view of life, and his or her roles in life (22, 23).

Taken seriously

To maintain the dignity of identity it is of great importance that someone listens to our will and wishes, and that someone takes us seriously. While previous research has focused on persons with dementia's lack of competence to make autonomous choices, 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 they are not seen or heard. This is also supported by some previous research (9).

The reason why we often think that persons with dementia lack the ability to make autonomous choices 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 (24); or, if we use the prison metaphor, we may say that we impound the residents in the diagnosis and all the shortcomings that we may associate with the disease. 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. This may not only be seen as a threat to the person's subjective experience of dignity of identity, but also as a threat to what Nordenfelt calls 'dignity of *menschwürde*'. This shows how these two kinds of dignity may be closely related to each other.

When persons with dementia experience that they are not taken seriously as autonomous persons, this may also be interpreted as what Goffman describes as *stigma* (25). Goffman describes stigma as the discrepancy between how the person experiences his or her identity, and how the society around the person sees the identity of the person (25). If we see Goffman's theory of stigma and social identity in light of Nordenfelt's theory of dignity of identity, stigma might be seen as a threat to the person's dignity. This is also supported by Mann's taxonomy of dignity violation (26). Mann claims that not to be seen as a person or only be seen as a member of a group, for instance as a member of a patient group, may be experienced as a threat to a person's dignity. To avoid this stigma and threat to the dignity of identity, we should to a greater extent ask the patients what they think is important in order to live a good life, and see them as experts on their own lives. We should try to see the person and his or her individual identity, which exists behind the disease. But this means that the persons around the residents should also know something about who they are and what they

have been, and be willing to listen to the residents' telling of his or her life story. This may lead to a greater feeling of being seen and heard.

If we manage to confirm the residents by seeing them as unique persons we will also protect and preserve their identities to a larger extent, and hence protect and preserve their dignity of identity.

Conflict between home and institution

The findings show that the feeling of lack of freedom, belonging, and at home-ness may be related to institutional rules and routines, and to the fact that the residents had to live together with strangers. Goffman talks about 'the total institution' and how these 'total institutions' may offend the identity of a person (Goffman, 2007). A nursing home may be experienced as a 'total institution'. 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 (27). 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 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 (28). 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 owners of 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. May be the kitchen could be more home-like and give the residents a greater feeling of at home-ness 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 could also be less institutional if the units were smaller, and the residents did not have to share the living room and the kitchen with so many different people.

De Jonge et.al. found that history and emotional connection with the house seemed to be important for older people's experiences of home (29), and a nursing home does not represent a history for the residents in the same way as their previous home does. A home is more than a house, and residents with dementia who long for their home may not only long for a physical place they belong to (30, 31), such as their own kitchen, they also long for *someone* they belong to, and someone who may confirm their identities. Nordenfelt states that social relations are important for the persons' identity, and hence to the dignity of identity. This implies that dignity of identity must be understood as a relational concept. 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 may be a threat to the dignity of identity. This is supported by Hauge (27). Hauge also states that rooms that the residents share in a nursing home, like a living room and a kitchen, cannot represent the private-sphere as long as there are so many different individuals living together. It is also a challenge when the residents do not know each other, and when those who care for them are professionals rather than their families. This leads to a discussion concerning the family's role versus the carers role. A home represents a history with the family. The relatives know the residents' histories better than the care workers. So

maybe the family should be able to play a larger role in the residents' life in 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 could also have their identities confirmed by their relatives, and the dignity of identity would be maintained to a greater degree.

Limitations and transferability

This was a small study with few participants included in the interviews, and the findings 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 get information from the participants who were not included in the interviews. This secures a 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 show that the need for freedom, at-homeness and confirmation are intertwined and linked to dignity of identity. This means that we should to a larger extent try to see identity behind the diagnosis, and also try to focus more on the person's abilities than limitations and who they have been, if we want to confirm their identity. As long as the patients 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 of identity could be met to a larger extent.

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