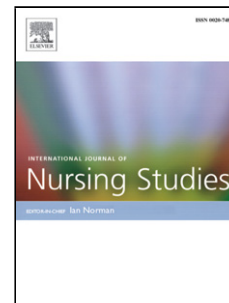


Accepted Manuscript

Title: Maintaining dignity in vulnerability: A qualitative study of the residents' perspective on dignity in nursing homes

Author: Bente Høy Britt Lillestø Åshild Slettebø Berit Sæteren Anne Kari Tolo Heggestad Synnøve Caspari Trygve Aasgaard Vibeke Lohne Arne Rehnsfeldt Maj-Britt Råholm Lillemor Lindwall Dagfinn Nåden



PII: S0020-7489(16)30003-7
DOI: <http://dx.doi.org/doi:10.1016/j.ijnurstu.2016.03.011>
Reference: NS 2721

To appear in:

Received date: 20-9-2015
Revised date: 8-1-2016
Accepted date: 12-3-2016

Please cite this article as: Hoy, B., Lillestø, B., Slettebo, Å., Saeteren, B., Heggestad, A.K.T., Caspari, S., Aasgaard, T., Lohne, V., Rehnsfeldt, A., Råholm, M.-B., Lindwall, L., Nåden, D., Maintaining dignity in vulnerability: A qualitative study of the residents' perspective on dignity in nursing homes, *International Journal of Nursing Studies* (2016), <http://dx.doi.org/10.1016/j.ijnurstu.2016.03.011>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Maintaining dignity in vulnerability: A qualitative study of the residents' perspective on dignity in nursing homes

Corresponding author

Bente Høy¹
VIA University College,
Hedeager 2
8240 Aarhus N, Denmark
e-mail: beho@viauc.dk
phone: +4587551863

Britt Lillestø² Åshild Slettebø³, Berit Sæteren⁴, Anne Kari Tolo Heggstad⁴ Synnøve Caspari⁴, Trygve Aasgaard⁴, Vibeke Lohne⁴ Arne Rehnsfeldt⁵, Maj-Britt Råholm⁶, Lillemor Lindwall⁷, Dagfinn Nåden⁴

1. VIA University College, Aarhus, Denmark
2. University of Nordland, Bodø, Norway
3. University of Agder, Grimstad, Norway
4. Oslo and Akershus University College of Applied Sciences, Oslo, Norway
5. Karolinska Institutet, Stockholm, Sweden
6. Sogn and Fjordane University College, Førde, Norway
7. University of Karlstad, Karlstad, Sweden

Maintaining dignity in vulnerability: A qualitative study of the residents' perspective on dignity in nursing homes

Background. Older people, living in nursing homes, are exposed to diverse situations, which may be associated with loss of dignity. To help them maintain their dignity, it is important to explore, how dignity is preserved in such context. Views of dignity and factors influencing dignity have been studied from both the residents' and the care providers' perspective. However, most of these studies pertain to experiences in the dying or the illness context. Knowledge is scarce about how older people experience their dignity within their everyday lives in nursing homes.

Aim To illuminate the meaning of maintaining dignity from the perspective of older people living in nursing homes

Method. This qualitative study is based on individual interviews. Twenty-eight nursing home residents were included from six nursing homes in Scandinavia. A phenomenological-hermeneutic approach, inspired by Ricoeur was used to understand the meaning of the narrated text.

Results. The meaning of maintaining dignity was constituted in a sense of vulnerability to the self, and elucidated in three major interrelated themes: *Being involved as a human being, being involved as the person one is and strives to become, and being involved as an integrated member of the society.*

Conclusion. The results reveal that maintaining dignity in nursing homes from the perspective of the residents can be explained as a kind of ongoing identity process based on opportunities to be involved, and-confirmed in interaction with significant others.

Keywords Dignity, nursing home, older people, vulnerability, phenomenological hermeneutic

1. Introduction

Dignity is a central concept in nursing (Jacobs 2001, ICN 2001, Edlund 2002) and the maintenance of dignity has become an important goal in nursing care of older people (Jacelon *et al.* 2004, Anderberg *et al.* 2007, Gallagher *et al.* 2008). However, dignity is also a vague and contested concept. Most often, it is interpreted in a liberal way, with a focus on personal autonomy (Macklin 2003, Delmar *et al.* 2011), which might be a too narrow understanding in the context of care of older people in nursing homes. In contrast to this, we think dignity viewed as autonomy excludes the voices of older people themselves. Residents are often exposed to diverse situations and are dependent on care that meets their needs, and because of this, they might experience dignity within a context of nursing homes differently.

1.1 The meaning of dignity

The term dignity comes from the Latin *dignitas*, and it seems generally accepted that the concept is related to an individual's characteristics, an intrinsic value, and an inter-subjective value associated with being human (Gallagher *et al.* 2008). Theoretical dignity has two distinct kinds of meaning: human dignity (*Menschenwürde*) and social dignity (Jacobson 2007, Nordenfelt and Edgar 2005). Human dignity is the value that belongs to every human being simply by virtue of being human. This meaning is also termed the absolute aspect of dignity (Edlund 2002), as it refers to an inner freedom for the human being to relate to himself and to his situation. As such, dignity cannot be measured or weighed or destroyed; nor is it comparative (Nordenfelt and Edgar 2005, Jacobson 2007). Conversely, social dignity, also called personal dignity, refers to the subjective or relative aspect of dignity (Edlund 2002, Nordenfelt and Edgar 2005, Jacobson 2007). Personal dignity is something that is experienced and sensed, and in contrast to human dignity, personal dignity is contingent, comparative and contextual. Jacobson describes two intertwined aspects of dignity: dignity-of-self and dignity-in-relation (Jacobson 2007). Dignity-of-self is a kind of self-respect that is held by a person and reflects an individual's identity as a person. Nordenfelt (2004) calls it 'dignity of identity' and describes it as the dignity we attach to ourselves as integrated and autonomous persons with a history and a future and with all our relationships to other human beings. Dignity-in-relation refers both to a process of reflecting worth and value back to the individual through word or deed and to the way dignity is embedded in a time and a place (Jacobson 2007). The personal

dignity can be lost or gained, threatened, violated, or promoted in some settings, but not in others. Nordenfelt and Edgar (2005) acknowledge that this notion of dignity probably is the most important in the context of illness and ageing, since it is this type of dignity that can be easily altered (undermined or enhanced) in the context of care giving, and we therefore used that frame in this study.

1.2 Dignity of older people in nursing homes

In recent publications, issues on maintaining dignity of older people in nursing homes have been raised with reference to palliative care and dying (Pleschberger 2007, Franklin *et al.* 2006, Hall *et al.* 2009a, Hall *et al.* 2009b), to illness (Oosterveld-Vlug *et al.* 2013a, Oosterveld-Vlug *et al.* 2013b) and to care (Tadd W. 2004, Bayer *et al.* 2005).

Illuminating different views and factors associated with dignity. Hall and colleagues found support for the three broad themes in Chochinov's dignity model for palliative care: illness-related concerns (level of independence and symptom distress); dignity conserving repertoire (perspectives and practices); and social aspects of the illness experience (social concerns or relationship dynamics which can erode or bolster a person's sense of dignity). In the context of illness, it was shown, that dignity was protected by: good professional care (e.g., being treated with respect), a supportive social network and adequate coping capacities. Further, it was shown that two mechanisms were especially important to maintain or regain dignity: the feeling that one is in control of one's life and the feeling that one is regarded as a worthwhile person. In the context of care, three themes were identified: respect and recognition, participation, and dignity in care.

In an early study, Stabell and Lindström (2003) showed that dignity of self is a struggle between dependency and independence and a balance influenced by factors such as: sense of control, respect, accept and the ability to change life. Although these studies give some insight into maintaining dignity from the perspective of the older people, most of the studies pertain to experiences of the dying or the ill, and surprisingly little is known about the meaning and experience of maintaining dignity in older people's everyday lives in nursing homes.

1.3 Purpose

The purpose of this study was to illuminate the meaning of maintaining dignity as narrated by residents. The following research questions were investigated: How do nursing home residents experience dignity in their day-to-day lives and, what do they

experience as important efforts from themselves and from the nurses in order to maintain dignity?

2. Methodology

This qualitative study is based on individual interviews and a phenomenological-hermeneutic approach, inspired by Ricoeur (Ricoeur 1979, Lindseth and Norberg 2004). This approach provides a suitable framework for an interpretation of intersubjective knowledge embedded in the lived experiences as it focuses on the meaning of people's experiences of being in the world, and as such illuminates both the individuality and communality of the specific context. According to Ricoeur (1979) people's experience, as lived, remains private, but its meaning becomes available to others through interpretation.

2.1 Participants and context

A purposive sample was recruited, comprising a total of 28 participants, 21 women and 7 men from six different nursing homes, three in Norway, two in Sweden, and one in Denmark. The Inclusion criteria were: (a) able to communicate and give informed consent, (b) reside permanently in a nursing home for at least two months, (c) considered able to complete an interview and (d) be interested in and willing to speak about their situation. The Participants were recruited through the head nurse of the wards, who verified that the selected participants met the inclusion criteria and were physically and mentally fit to participate in the study. Participants who were very ill, demented or confused were excluded on ethical grounds. The included participants varied in age from 62 to 103 years. All were able to share their experiences, although some of them had difficulties providing detailed narrative accounts of their experiences. The participants had lived in residential care from a few months to 22 years, and their care needs varied from being totally dependent on care for basic needs to supportive care for personal hygiene or dressing.

2.2 Data collection

The interviews took place in the residents' rooms. They were asked to narrate their experience of daily life and dignity by narrating situations where they had experienced dignity and the efforts made by themselves and by the nurses to maintain dignity. The researchers encouraged the interviewees to narrate as freely as possible with a minimum of interruption to gather as rich answers as possible. Follow-up questions were asked, inviting them to deepen their experiences about their encounters with the nursing home and the

nurses and what they considered important about life in nursing home and dignity. The interviewer could ask a participant: “Can you tell me about your experiences from events/situations in your life in the nursing home which you find significant for your experience of self-esteem? And a follow-up question: “You mentioned dancing, tell me more about that”. The interviewees narrated their life stories in a humble and honest way, despite being tired, needing a drink or having a break during the interviews. Some narrated more particular situations while others talked about their experiences in more general terms. The interviews lasted from 40 to 70 minutes. The researchers from Norway, Sweden and Denmark respectively undertook the interviews, focusing on what moves the residents. In most instances, the researcher conducted one interview with each resident. All interviews were tape-recorded, transcribed verbatim, and transformed into text.

2.3 Data analysis and interpretation

A phenomenological-hermeneutic analysis (Lindseth and Norberg 2004) was performed inductively by the researchers, including reading the text to gain a sense of the whole. This was followed by the identification of meaningful parts as well as interpretations of meaning in the text as a whole. The textual analysis was carried out in a spiral-like hermeneutic process of interpretation through three phases: a naïve reading, a structural analysis, and a comprehensive understanding including the discussion. The *naïve* reading consisted of a superficial reading of the text getting an overall impression of the stories that were told and to obtain an initial holistic understanding of the older people’s experiences as well as obtaining clues for the subsequent structural analysis. The *structural analysis* was intended to clarify the dialectic between the holistic understanding of the naïve reading, and an explanation of what the text is about. The guiding principle in this process was to trace the thematic structure of the text and to find the threads of meaning woven into the different parts of the text (Lindseth and Norberg 2004).

The text was divided into meaning units according to the concerns raised. These units were condensed and discussed among the authors, and themes and sub-themes were identified. This process included examination of parts of the text in order to validate or refute the initial understanding obtained. The *comprehensive understanding* produced an in-depth interpretation of what the text was about, based on the naïve reading, the structural analysis, and the authors’ pre-understanding. The meanings in the text evolved in a critical dialectic between the reader’s pre-understanding of parts and the whole of the text, and

relevant theoretical literature is used to deepen and widen the understanding of the text (Ricoeur 1979, Lindseth and Norberg 2004).

2.4 Ethical consideration

This study has been evaluated and approved by the Ethical Committee and Data Protection Agency within the respective countries in Scandinavia. Informed consent was obtained from all participants and they were told of their right to withdraw at any time, without giving reasons and without it affecting their right to treatment or care. All participants were given assurance that their confidentiality and anonymity would be protected. This was explained to ensure that they had a clear understanding that in the transcription of the interviews, no identifying information associated with their responses would be revealed about them. In particular, they were assured that their comments would not be disclosed to the nursing homes (Nordich Nurses Federation 2003).

3. Results

The naive interpretation revealed that the dignity experiences were associated with the residents' experiences of self, and constituted in a sense of vulnerability caused by increased susceptibility to threats or losses to the self as an integrated and autonomous person. In order to maintain a sense of dignity, they described the kind of person they strive to be and the efforts made by themselves and the nurses in trying to obtain protection and promotion of the body self, the personal self and the social self. The structural analysis resulted in three interrelated themes reflecting the meaning of maintaining dignity: *Being involved as a human being, being involved as the person one is and strives to become, and being involved as an integrated member of the society.*

3.1 Being involved as a human being

The first theme refers to the residents' dignity experiences associated with losses or threats to the bodily self. These experiences were narrated in scenarios with physical changes, such as loss of a part of the body or of sight, hearing, speech and mobility. These losses were a threat to their self-image and self-respect and meant an almost inevitable vulnerability with respect to a normal life. Generally, it seemed as if, maintaining dignity was not an issue of bodily losses per se, but was a matter of being involved and protected as a human being.

Being seen and protected as a human being was significant for the experience of a dignified life. Moving into a nursing home in order to get help for basic needs is a way for the older people to deal with the risks of indignity caused by the bodily vulnerability and desire for a normal life. While living in their former homes, many residents experienced difficulties in controlling bodily functions, associated with basic needs such as nutrition, elimination and personal hygiene, and they felt insecure. Residential care made them feel safe, a place where they could rely on support and protection. However, when their needs were not met, they felt threatened. A participant described a situation like this: *When I think back, it was depressing living at home. I have a colostomy, and I started to leak at night and couldn't manage by myself. It was pathetic, so I had to ask for help. So I think that being in the nursing home helps me to maintain my dignity, but it's awful when the nurses don't help me.* Being seen and cared for when the residents did not have the necessary resources to protect themselves was essential, and if the nurses were too busy to attend to these needs, they felt overlooked and devalued as a human being. A participant expressed a situation: *"A new resident arrived yesterday. Well, honestly, it shouldn't be like this in here. So, suddenly, I hear her shouting in the corridor. She couldn't understand why there was no one helping her. She was very frightened. But I've seen it before, when there was no staff there to help. And I must admit that I don't understand it, and find it very very wrong. We are old and helpless"*.

Preserving the body-image. Another way to deal with the risk of indignity due to the experience of bodily vulnerability while still experiencing dignity in daily life is to continue to present themselves in a way that preserves their body-image; e.g. hair styling, shaving and make-up. Appearances mattered because it was a visible impression of wellbeing or normality and symbolized the usual self. One participant expressed a situation like this: *I still try to look nice every day"*. The resident was a very pretty lady, who looked at least 10 years younger than her age. Her hair was perfect and she was wearing earrings, a wedding ring and a gold bracelet on each wrists. She was dressed very neatly. The resident was almost blind, but wore glasses in order to look good. She said: *"How I look means everything. So I am very pleased that the nurses are interested in my appearance and help me"*. The residents experience respect and involvement, when the nurses support their efforts to look good. On the other hand, maintaining dignity also meant avoiding a negative exposure of a vulnerable body in the public domain. A participant said: *They want me to sign up for gymnastics. But I will not sit on a chair and jerk my arms and legs. I feel*

ridiculous. I did a lot of gymnastics, when I was young. I know—it is important to keep training, and I can do it. But I don't like jerking my arms and legs around with other people. Another participant expressed a vulnerable situation. *"They are nice here. I have never had problems contacting the staff. I just say "I peed all over the floor." And they say, "We'll take care of it, don't worry. We are here to help you. Just call when you need us".* Lack of body control was seen as an embarrassing situation that affected the residents' dignity. However, the participant valued the nurse's ability to be discreet and not draw attention to the resident's predicament. They spoke of the way in which nurses made them feel at ease by their use of humor and their ability to treat the extraordinary as ordinary.

3.2 Being involved as the person one is and strives to become

The second theme refers to the residents' dignity experiences associated with loss or threats to the personal self. These experiences were narrated in scenarios with declining capacities and dependency in daily activity. Generally, it seemed as if maintaining dignity was not an issue of being active without help, but was more a matter of being involved as the person one is and strives to become.

Being seen as the person one is strengthens the experiences of value and a dignified life. To the participants it was important to stand up as themselves and tell the nurses what they wanted or did not want to do in daily life. Boundaries were stressed by stating desires and needs, being difficult, and when possible to negotiate their needs and desires. However, when they were not seen and recognized as the persons they were or wished to become, they did not feel respected. A participant told. *"Yes, I have tried to say what I don't want. They have sometimes asked me into the kitchen, if I would like to make biscuits, but then I say no. I don't want to sit and knead dough, and I don't like baking any more. I don't want to be involved in that kind of activities anymore, and I want my retirement to be obligation-free. I have worked so many years for my family, and now I don't want to do it any more".* Although the residents can cook, they may not necessarily want to preserve that image any longer, and attention to individual preferences and the day-to-day choices by which the participants create who they are and who they will become are significant for experiences of dignity and self-respect.

Being in the hands of others and preserving control of life. Most residents regarded asking for help as a potential threat, and increased dependency was one of the harder adjustments

they faced. The residents described these experiences in different ways. Some felt that they had been robbed of their freedom, whereas others felt valued as a person and found that the help, they received improved their quality of life. In order to retain their dignity it seemed significant to be able to make sense of one's unavoidable life-conditions and remained positive. Mary and Gerda's stories are examples of this. Mary tells: *"I'll need help for showering. But it is okay to be helped by others. Once a young man had to assist me. I was a little concerned about that, but when he helped me, I thought it was fine and the other ladies also liked to be assisted by him. Gerda tells: I love being helped. It is not degrading. No, I am not ashamed of it. It's okay. So I feel almost like a baby (laughs).* However, a participant who could not accept the current situation experienced that his dignity was threatened: *"I need help with almost everything in daily life. My dignity is not really prepared for that. I think it's hard to be dependent on others when it comes to the bathroom, and when you go to bed. Now I also get lifted into bed in a sling. I think it's degrading, not being able to go to bed or to the bathroom by myself.* When vulnerable positions are met without any opportunity to influence their situations, the residents felt devalued. One participant said: *"Sometimes the nurses move us around in the dining room. They shouldn't do that without asking us. I don't have a say. I am the last arrival. None of the residents complained - why do the nurses do that?"* Though preserving dignity could entail acceptance of help or changes of value, it was essential to be in control of their life-situations.

3.3 Being involved as an integrated member of the society

The third theme refers to the residents' dignity experiences associated with loss or threats to the social self. These experiences were narrated in scenarios where the social life context was threatened or lost. By moving to a nursing home, the older people left behind most of their belongings, their homes, their families and neighborhoods, and this constitutes a challenge to dignity. However, it seems as if maintaining dignity was not an issue of social loss per se, but was matter of being involved in the life of their families and that of the nursing homes.

Being a significant part of someone's life and doing meaningful activities was important for experiencing of a dignified life. It was vital that the participants were seen as an important part of their family and were able to visit them and have visits from them. It was also significant that they could share experiences and events with other residents at the

nursing home. A participant explains the worth of sharing an activity such as watching television with someone: *“I think it’s good that we have some men in the nursing home. I cannot talk to my neighbour, and many of the others sit in wheelchairs and things like that ... My neighbour on the other side comes and visits me and we watch television together in the evenings. I like that very much”*. Another participant explains the meaning of still being able to participate in an activity she had been part of earlier in her life: *“I like to dance. I have danced for 20 years. I dance once a week, and the bus comes and picks me up. I am the only one from the nursing home. However, the nursing home organises dancing in the afternoon for everyone. I think it’s great that they arrange that, because I like it so much”*. The residents feel respected and valued; when the nursing home made it possible for her to participate in an activity, which had been a part of her former life and which attracted attention from others in her current life.

Making sense of one’s life, one’s actions, and the events with which one is involved, were apparent in some of the residents’ experiences and contributed to a sense of dignity and involvement. One participant said: *“I try to manage by myself and make the best of it. If something is going on at the nursing home, then I go for it (going for a walk, playing bingo, etc.)*. Most participants emphasize the importance of food and mealtimes, which were seen as the highlights of the day and significant events in which they could be involved.” *I do not eat rather much but to be together with the other [residents], that means a lot to me.*

However, most of the narratives were expressed negatively and indicated lack of involvement in social life. Many of the residents’ stories were based on experiences where they felt excluded from various aspects of society and social life, and although they appreciated the activities the nursing homes organized, these activities could not always compensate for the feelings of meaninglessness and isolation. The participants felt that they were not able to talk to or carry out activities with their co-residents, and it was difficult to make new friendships or maintain the relationships they already had. A participant said: *“I don’t think it’s possible to have a meaningful life when you grow older. Firstly, it is very difficult to make new friends. I think that most people who move to a nursing home hope that they will meet someone that they can relate to and socialise with, but it doesn’t happen because we are so different, and most of the residents cannot speak at all”*. The challenges of involvement in nursing homes are also significant in the

following story:”*When I came here I went for walks with another woman, but she can’t walk anymore. Then I went for walks with the man who lives next door to me, but then he couldn’t manage it either. I walk alone now. The days are very long, if I don’t get out for my walk. Before I came here, I had a little dog, I took for walks. I miss that dog very much, but it wasn’t possible to have a dog here, so I had to leave it”.*

4. Comprehensive understanding and discussion

The findings indicate that the meaning of maintaining dignity in daily life in nursing homes from the perspective of the residents is constituted in the very existence of a sense of vulnerability to the self, caused by threats or losses. However, the study shows that the maintenance of dignity was not an issue of threats or losses per se, but can be interpreted as the residents’ ability to withstand, integrate or handle threats to the self and to be involved with one’s life as an integrated person with a history and a future. In the residents’ experience, dignity is not only an issue of autonomy, but more a concern for involvement. Dignity is maintained by being involved in a world that appears meaningful to the residents, not as an objective world “out there”, but as a humanly relational world, full of meanings. The result illuminated three forms of involvement fostering dignity: as a human being, as the person one is and strives to become and as an integrated part of the society. The importance of involvement in decision-making and involvement in social life was also emphasized in the study of (Tadd W. 2004, Bayer *et al.* 2005). They showed too, that many older people felt excluded from this. However, this study indicates not only the importance of involvement, but also how dignity in vulnerability might be maintained.

Figure 1. to be inserted

Vulnerability is part of all human conditions and is closely connected to our lived experiences as human beings. However, a deeper sense of vulnerability can be seen as an existential aspect of being old and frail. An experience based on a particularly susceptibility of threats to the self is a result of a higher than normal exposure to risk, and a reduced capacity for self protection (Kottow 2003, Sarvimäki and Stenbock-Hult 2014). The findings showed that the experiences depend on how the older people view their situation and the degree of harm perceived as inherent to the situation. The harm could occur from within the residents’ body or psyche as intrinsic threats to the self, or it could come from unfavourable contextual conditions, such as lack of attention for basic needs, values and preferences, or lack of environmental resources and opportunities for

relationships and activities. From a professional perspective, a common understanding of vulnerability holds that people who are sick or disabled, are de facto vulnerable, because their bodies and minds do not function normally (Fried *et al.* 2001). This understanding reduces vulnerability to the functioning body regardless of the psycho-socio-cultural context the residents are in, and it ignores the role of the nursing home environment. From a family carers' perspective of dignity, vulnerability was experienced as a feeling of being abandoned (Nåden *et al.* 2013). In an illness context of dignity, it was shown that vulnerability is an issue of functional incapacity (Oosterveld-Vlug *et al.* 2013a). What this study shows is that the residents feel vulnerable because of bodily, personal and social loss, but this vulnerability does not necessarily lead to a violation of their dignity. Dignity could be lost in complex interactions, e.g., when the residents were exposed to a threat and lacked the defenses or resources to deal with that threat. In the notion of vulnerability, this understanding has a parallel to a study with a life-world perspective of older people in health care. In that study, it was shown that vulnerability is increasingly understood in physical terms, such as frailty, and this understanding reduces vulnerability to the functioning body regardless of the existential experiences and the socio-cultural context or environment the older people are in. From a life-world perspective, vulnerability is seen as an inevitable part of life because of our interdependency, but also as something that can be created and perpetuated by certain situations, especially when these situations involve power differences (van der Meide *et al.* 2014). The understanding of dignity and vulnerability has also a parallel in that of Shotton and Seedhouse (1998) who stated that we lack dignity, when we find ourselves in inappropriate circumstances, and when we are in situations where we feel foolish, incompetent, inadequate or unusually vulnerable. However, as stated by Galvin and Todres (2014), this theory emphasizes agency and competence (becoming), and de-emphasizes the kinds of dignity that are associated with belonging, and connection (being). The theory overlooked the fact that dignity does not depend on the eradication of human vulnerability, but occurs within its very context, and although older people might experience vulnerability, being treated with dignity by others enhanced their dignity, especially in situations that can be experienced as threatening (Haddock 1996).

Though maintaining dignity was associated with vulnerability, the meaning was not experienced as an issue of vulnerability or losses per se, but as the ability to withstand, integrate, or handle threats. Maintaining dignity meant a struggle for self-respect,

recognition and protection, and it was a struggle for being in control and valued as a worthwhile person, both by themselves and by others. Furthermore, it meant a struggle for belonging and meaning in daily life. As such, maintaining dignity might be seen as an affirmation of something valuable in oneself as an “inheritor of being”, an affirmation that can be ruptured, or restored in the interaction with others (Galvin and Todres (2014). To Nordenfelt and Edgar (2005), changes associated with ageing and illness might lead to loss of dignity. This study confirms that a weakened body is a potential threat to dignity. However, this study also shows that the maintenance of dignity was associated with being responsive to vulnerability and with mutual efforts from both the residents and the nurses to get involved in their lives. With regard to bodily vulnerability, available resources adequate to meet essential needs in daily life were significant for experiencing dignity and involvement. In personal vulnerability, it was essential that the residents were in control of their life situations rather than being controlled by others. According to social vulnerability, it seems as if maintaining dignity was not an issue of social loss per se, but of having the ability to make sense of one’s life and to participate in meaningful activities. Generally, the residents’ perceptions of self, challenges to the self, and the available resources to manage such challenges, may define the meaning of maintaining dignity. When the residents in their interactions with the care provider and other residents comprehend a situation in a new way, such as the showering assisted by a man, dignity is maintained. Correspondingly, opportunities for dancing are significant in promoting dignity when it is a part of past and current desires. As in the study of Franklin et al (2006), an inner strength seems important for the maintenance of dignity because power may constrain a person’s ability to express vulnerability and give a positive adaption to the life. This study also showed the importance of a sense of place and the ways that the places support the residents’ sense of coherence. As in Stabells & Lindströms study (2003), maintaining dignity can be seen as a struggle for wholeness and balance in life, depending on perceptions of power and vulnerability. The findings have also parallels in Matiti & Trorey’s study of the patients’ perceptions of dignity in hospital (2004). There, maintaining dignity was explained as adjustment, and as the fulfilment of value expectations within an actual environment. Our study shows that the maintenance of dignity might be understood in more ways than the ability to adjust. It might be seen as a kind of an ongoing identity process based on opportunities to be involved and to be confirmed by significant others.

4.1 Methodological considerations

The phenomenological-hermeneutic approach, inspired by Ricoeur was very useful. It gave voice to the lived experiences of older people and enabled us to illuminate the more tacit and private aspects of dignity, pointing to both parts and the whole of dignity in nursing homes. It discloses a possible world in which dignity has a central position and is an important reason for being. The perspective opens up a lived perception of a deep common humanity in which people are involved in dignity and vulnerability.

Our study was limited to the experiences of older people living in nursing homes who were able to share their experiences. Although we cannot be sure that the people in our study did not suffer from early stages of dementia, we do not know whether our results are transferable to residents with more severe dementia. As stressed by Lindseth and Norberg (2004), a text may be understood and interpreted in various ways, because it has multiple meanings. Thus, the present interpretation is only one of many possibilities, and should be viewed as a contribution to the existing knowledge of older people's lived experiences. Intersubjective validity was sought throughout the analytic process. The interview-transcripts, case summaries, and evolving themes were discussed by the research team. The findings provided rich descriptions about the phenomenon of maintaining dignity in older people's everyday lives in nursing homes. Being frail is one of the criteria for entering a nursing home, which may be one explanation for the experiences of vulnerability in the narratives. On the other hand, maintaining dignity was not an issue of vulnerability per se, but the core of the residents' concern for dignity, which seemed to be significant for this study. Furthermore, we checked to ensure that the themes were representative of the data and captured the main topics brought forward in the interviews. Finally, we verified the developed understanding as a reflection of the themes and pertinent literature.

5. Implications for care in nursing homes

The study emphasizes the need for a caring approach, sensitive to older persons' experiences of vulnerability caused by increased susceptibility to threats or losses to the self-esteem. Dignified care might alleviate the vulnerability of the residents and enable them to get involved and be in control of their daily life situations, for example, by being there for the residents and caring for their needs. Furthermore, care must focus on the residents' values, strengths, and how they see themselves in the specific context. This means meeting the resident on his/her own terms, and seeing the resident as he or she really is in the interplay with the context (Nåden and Eriksson 2004, Anderberg *et al.* 2007, Heggestad *et al.* 2013). The nurse should invite and encourage the older persons to make

decisions regarding their own situations and to participate in meaningful activities (Gastmans 2013). Caring might focus not only on the relationship between the nurse and the resident, but also on a network of relationships and a shared understanding of the daily life in the nursing home. Finally, it is important that care focuses on environmental and contextual values and conditions where the older persons' interests and capabilities can flourish (Gallagher *et al.* 2008, Rehnsfeldt *et al.* 2014).

6. Conclusion

Our study demonstrated a comprehensive understanding of maintaining dignity in daily life from the perspective of older people living in nursing homes. The meaning is constituted in the residents' very existence; a sense of vulnerability to the self, caused by threats and losses. However, the maintenance of dignity was not an issue of losses per se, but can be seen as the residents' ability to withstand, integrate or handle threats to the self and be involved with one's world. Maintaining dignity can be explained as as a kind of ongoing identity process based on the ability to be involved and to be confirmed by significant others. This knowledge emphasizes the potential of a dignity-oriented approach to the care of older people and may assist nurses and other health care providers to understand the maintenance of dignity from the residents' perspective.

Summary statement

What is already known about the topic?

- Dignity is an important goal in nursing care of older people
- Dignity is a vague and contested concept often interpreted in a liberal way, with a focus on personal autonomy
- Most studies on dignity of older people in nursing homes pertain to the experiences of the dying or the ill.

What this paper adds

- The meaning of maintaining dignity in daily life in nursing homes is constituted in the residents' very existence, a sense of vulnerability to the self, caused by threats or losses.
- The maintenance of dignity is not an issue of threats or losses per se, but can be seen as the residents' ability to be involved with one's world as a human being, as the person one is and strives to become and as an integrated member of the society.
- Maintaining dignity can be explained as as a kind of ongoing identity process based on ability to handle threats and being involved and being confirmed by significant interaction with others.

References

Anderberg P, Lepp M, Berglund A & Segesten K (2007) Preserving dignity in caring for older adults: a concept analysis. *Journal of Advanced Nursing* 59, 635-643.

Bayer T, Tadd W & Krajcik S (2005) Dignity: the voice of older people. *Quality in Ageing* 6, 22-29.

Burack OR, Weiner AS, Reinhardt JP & Annunziato RA (2012) What matters most to nursing home elders: quality of life in the nursing home. *Journal of the American Medical Directors Association* 13, 48-53.

Delmar C, Alenius-Karlsson N & Mikkelsen AH (2011) The implications of autonomy: Viewed in the light of efforts to uphold patients dignity and integrity. *International Journal of Qualitative Studies on Health and Well-being* 6.

Edlund M (2002) *Mäniskans värdighet: et grundbegepp inom vårdvetenskapen (Human dignity - a basic caring science concept)*, A Doctoral Thesis edn Vasa.

Franklin L, Ternstedt B & Nordenfelt L (2006) Views on dignity of elderly nursing home residents. *Nursing Ethics* 13, 130-146.

Fried LP, Tangen CM, Walston J, Newman AB, Hirsch C, Gottdiener J, Seeman T, Tracy R, Kop WJ, Burke G & McBurnie MA (2001) Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology: Series A* 56, M146-M156.

Gallagher A, Li S, Wainwright P, Jones IR & Lee D (2008) Dignity in the care of older people - a review of the theoretical and empirical literature. *BMC.Nursing* 7, 11.

Galvin K & Todres L (2015) Dignity as honour-wound: an experiential and relational view. *J Eval.Clin Pract* 21, 410-418.

Haddock J (1996) Towards further clarification of the concept 'dignity'. *Journal of Advanced Nursing* 24, 924-931.

Hall S, Longhurst S & Higginson I (2009a) Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age & Ageing* 38, 411-416.

Hall S, Longhurst S & Higginson IJ (2009b) Maintaining Dignity at the End of Life: The Views of Older People in Care Homes. *Psycho-Oncology* 18, 327.

Heggestad AK, Nortvedt P & Slettebo A (2013) Dignity and care for people with dementia living in nursing homes. *Dementia (London)* 1-17.

Heidegger M & Schmidt DJ (2010) *Being and time*. State University of New York Press, Albany, N.Y.

ICN (2001) The ICN code of ethics for nurses. *Nurs Ethics* 8, 375-379.

- Jacelon CS, Connelly TW, Brown R, Proulx K & Vo T (2004) A concept analysis of dignity for older adults. *Journal of Advanced Nursing* 48, 76-83.
- Jacobson N (2007) Dignity and health: a review. *Social Science & Medicine* 64, 292-302.
- Kottow MH (2003) The vulnerable and the susceptible. *Bioethics* 17, 460-471.
- Kvale S (1996) *Interviews: an introduction to qualitative research interviewing*, 3. printing edn. Sage Publications, Thousand Oaks.
- Lindseth A & Norberg A (2004) A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences* 18, 145-153.
- Matiti MR & Trorey G (2004) Perceptual adjustment levels: patients' perception of their dignity in the hospital setting. *International Journal of Nursing Studies* 41, 735-744.
- Nåden D & Eriksson K (2004) Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nursing Science Quarterly* 17, 86-91.
- Nåden D, Rehnsfeldt A, Rahlm MB, Lindwall L, Caspari S, Aasgaard T, Slettebo A, Saeteren B, Høy B, Lillestø B, Heggstad AK & Lohne V (2013) Aspects of indignity in nursing home residences as experienced by family caregivers. *Nursing Ethics* 1-14.
- Nordenfelt L (2004) The varieties of dignity. *Health Care Anal.* 12, 69-81.
- Nordenfelt L & Edgar A (2005) The four notions of dignity. *Quality in Ageing* 6, 17-21.
- Nordenfelt L (2009) *Dignity in care for older people*. Wiley-Blackwell, Chichester, West Sussex.
- Nordich Nurses Federation (2003) *Ethical Guidelines for Nursing Research in the Nordic Countries. Etiske retningslinier for sygeplejeforskning i Norden.*, Revideret udgave edn, Sygepleiernes Samarbeid i Norden, Oslo.
- Oosterveld-Vlug MG, Pasman HR, van Gennip IE, Muller MT, Willems DL & Onwuteaka-Philipsen BD (2013a) Dignity and the factors that influence it according to nursing home residents: a qualitative interview study. *Journal of Advanced Nursing*.
- Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Willems DL & Onwuteaka-Philipsen BD (2013b) Changes in the Personal Dignity of Nursing Home Residents: A Longitudinal Qualitative Interview Study. *PLoS One* 8.
- Pleschberger S (2007) Dignity and the challenge of dying in nursing homes: the residents' view. *Age and Ageing* 36, 197-202.
- Rehnsfeldt A, Lindwall L, Lohne V, Lillestø B, Slettebo A, Heggstad AK, Aasgaard T, Rahlm MB, Caspari S, Høy B, Saeteren B & Nåden D (2014) The meaning of dignity in nursing home care as seen by relatives. *Nursing Ethics* 21, 507-517.
- Ricoeur P (1979) *Fortolkningsteori (Interpretation theory: discourse and the surplus of meaning)*. Vinten, Kbh.
- Sarvimäki A & Stenbock-Hult B (2014) The meaning of vulnerability to older persons. *Nursing Ethics*.

Sellman D (2005) Towards an understanding of nursing as a response to human vulnerability. *Nursing Philosophy* 6, 2-10.

Shotton L & Seedhouse D (1998) Practical dignity in caring. *Nursing Ethics* 5, 246-255.

Stabell A & Lindström UÅ (2003) The nursing home residents pursuit towards integrity and dignity [Norwegian]. *Nordic Journal of Nursing Research & Clinical Studies / Vård i Norden* 23, 29-34.

Tadd W. (2004) Comparative analysis of data from older people's focus groups from all centres focus groups from all centres., Deliverable 9 edn, Dignity and Older Europeans Consortium.

Tadd W, Bayer T & Dieppe P (2002) Dignity in health care: reality or rhetoric. *Reviews in Clinical Gerontology* 12, 1-4.

van der Meide H, Olthuis G & Leget C (2014) Why frailty needs vulnerability: A care ethical perspective on hospital care for older patients. *Nurs Ethics*.

Walsh K & Kowanko I (2002) Nurses' and patients' perceptions of dignity. *Int J Nurs Pract* 8, 143-151.

Woolhead G, Calnan M, Dieppe P & Tadd W (2004) Dignity in older age: what do older people in the United Kingdom think? *Age and Ageing* 33, 165-170.



Figure 1. Core themes of residents perspectives of maintaining dignity

Summary statement

What is already known about the topic?

- Dignity is an important goal in nursing care of older people
- Dignity is a vague and contested concept often interpreted in a liberal way, with a focus on personal autonomy
- Most studies on dignity of older people in nursing homes pertain to the experiences of the dying or the ill.

What this paper adds

- The meaning of maintaining dignity in daily life in nursing homes is constituted in the residents' very existence, a sense of vulnerability to the self, caused by threats or losses.
- The maintenance of dignity is not an issue of threats or losses per se, but can be seen as the residents' ability to be involved with one's world as a human being, as the person one is and strives to become and as an integrated member of the society.
- Maintaining dignity can be explained as as a kind of ongoing identity process based on ability to handle threats and being involved and being confirmed by significant interaction with others.