

How individuals with dementia in nursing homes maintain their dignity through life-story telling – a case study

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Abstract

Aims and Objectives The aim of this article is to present and discuss findings on what individuals with dementia do themselves to maintain or promote their dignity of identity when they live in a nursing home.

Background The majority of residents living in Norwegian nursing homes suffer from dementia. Individuals who suffer from dementia are particularly vulnerable, and, their dignity of identity is at risk. It is therefore of great importance to explore how we can maintain their dignity of identity

Design The study builds on a phenomenological and hermeneutic design.

Methods The article reports three cases or life-stories based on participant observation in two different nursing homes and interviews with five residents with dementia living in these nursing homes. Fifteen residents with dementia from these nursing home wards were included in the overall study.

Findings Individuals with dementia living in nursing homes may use life-story telling or narratives to manage chaos and to find safety in their lives. Storytelling is also used as a way to present and maintain identity. We can see this as a way of maintaining dignity of identity or social dignity.

Conclusion Life-story telling can be seen as an important way of preserving dignity for people with dementia. It is of great importance that health care professionals are open to and listen to the life stories people with dementia tell.

Relevance to clinical practice As nurses we have an obligation to ensure that dignity is enhanced in care for people with dementia. Knowledge about how residents with dementia use life-story telling as a way to maintain dignity is therefore of great importance to health care workers in nursing homes.

Keywords

Dementia, dignity, identity, life-story telling, narrative, nursing home

Introduction

In 2010, it was estimated that 35 million people were suffering from dementia worldwide (Brodaty *et al.* 2011). Around 80% of residents in Norwegian nursing homes suffer from dementia (Selbæk *et al.* 2007). It is our obligation as a society to ensure that people with dementia receive care that enables them to experience a dignified life (The Nuffield Council On Bioethics 2009). According to Gastmans, maintaining dignity for patients can be seen as the essence of good nursing care (Gastmans 2013). The Norwegian government has stated the importance of focusing on dignity in care in what they call a “guarantee of dignity”, which was introduced from 1 January 2011. The government also introduced “Care Plan 2015” (Norwegian Ministry of Health and Care Services 2005-2006) and “Dementia Plan 2015” (Engedal 2010). The aim of these political initiatives has been to improve the quality of care. To do this, we need to know more about what the residents themselves perceive as most important in enabling them to live a life in dignity, and what they do themselves to enhance their dignity.

Dignity is closely related to identity. This means that maintaining dignity is also about reclaiming our identity. It is therefore important to get knowledge on how people maintain or reclaim their identity, and hence their dignity of identity.

Background

Previous theories on dignity and identity. Theories on dignity as a concept distinguish between dignity as an absolute value and relative or subjective forms of dignity. The absolute form of dignity is related to human worth, while the relative form of dignity is related to a subjective dignity or a social dignity, which depends on our experiences of how we are treated and how we present ourselves as human beings (Jacobson 2009, Leget 2013, Nordenfelt

2004, Pullman 2004). It is what Nordenfelt calls dignity *related to identity*, or what Jacobson calls *social dignity* which is the focus in this article.

According to Nordenfelt, dignity of identity is a subjective form of dignity, which can be understood as a kind of self-respect, closely related to a person's autonomy, integrity and social relationships. It may also include a person's life story. Dignity of identity can be enhanced or harmed in social relationships, and can be seen as the most important form of dignity related to ageing and illness (Nordenfelt 2009). Jacobson claims that social dignity is influenced by social interactions and can be violated through rudeness, condescension, disregard, objectification and abjection (Jacobson 2009).

Theories on life-story telling and identity. According to theories on life-story telling and identity, we construct our versions of our lives through narration. Stories tell who we are (Frank 1995, 2010, Mishler 2004). When getting ill, we tell our stories to work out our changing identity and to reconstruct our map (Frank 1995). Rosenwald and Ochberg claim that life stories "are the means by which identities may be fashioned" (Rosenwald & Ochberg 1992, p.1).

Dementia, life-story work and identity. Earlier research shows that that people with dementia can reclaim their identity through narrative writing of stories (Hydén & Örvulv 2009, Ryan *et al.* 2009). People with dementia may experience connectedness, self-reliance and personal growth when presenting their life-stories (Karlsson *et al.* 2014). Research also shows that life-story work can enhance person-centered care by enabling care workers to see the individual behind the disease and by enabling the person with dementia to be seen and heard. In addition, life-story work might help nurses to see people with dementia as individuals and as more than a homogenous group (Kellett *et al.* 2010, McKeown *et al.* 2010, Russell & Timmons 2009).

Research on dementia and life-story work has not related life-story work to dignity. With this article, we believe we are filling a knowledge gap on the relationship between dignity and life-story work, among people with dementia.

Aim

The aim of this article is to describe what individuals with dementia do themselves to maintain their dignity when living in nursing home.

Methods

Design

The study has a phenomenological and hermeneutic approach. In phenomenology, the focus is on the individual subjective experiences related to a phenomenon. However, in order to interpret and understand these subjective experiences, we are dependent on the hermeneutics (Gadamer, 2004, Polit and Beck, 2008).

The hermeneutic approach emphasizes that one always has ideas, built upon previous experiences, knowledge and research. We cannot understand another person's experiences without preconceptions (Frank 2010, Gadamer 2004). This 'old' knowledge or preconceptions will melt together with the new, when we analyze and discuss the new finding in light of previous research and theories (Gadamer, 2004).

In this article, we use a case study design, with narrative analysis. The article reports three cases or stories, from a qualitative study on dignity in dementia care. The cases build on participant observation and qualitative interviews with five residents from one special care unit and one general unit in two different nursing homes. Fifteen residents with dementia from these nursing home wards were included in the overall study.

When analyzing the stories we were inspired by Arthur Frank's method of narrative analysis (Frank 1995, 2005, 2010). Narrative analysis is in line with the phenomenological and hermeneutic approach. Phenomenology is about taking the participants' subjective first-hand lived experiences seriously. The stories represent these subjectively lived experiences (phenomenology). This approach is in line with how Frank describes 'dialogical interpretation' (Frank 2010). In dialogical research the researcher does not 'finalize' the research participant (Frank 2005). Finalizing the other is the same as trying to capture him or her in a final definition (Frank 2005). Dialogical research and dialogical interpretation, is also in line with hermeneutic thinking, where one never sees knowledge as something final. Knowledge is always an ongoing process.

Data collection

Participant observation. During the participant observation, the first author was on the nursing home wards three to four hours a day for three days a week and participated as a kind of nursing assistant in the daily life and the daily care in the nursing home. The first author participated during meals, and assisted the nurses or the nursing assistants when helping the residents with personal hygiene and toileting. In addition, the first author sat down with the residents in their living room, participating in their conversations. Participant observation in the special care unit took place from March to May 2010. In the somatic unit, participant observation took place between October and December 2010. The total time spent in these nursing home wards was 184.5 hours.

Participant observation made it possible to have what Spradley and McCurdy call "field-conversations" (Spradley & McCurdy 1972), in addition to the formal interviews. The first author wrote down these informal conversations and the observations in field notes. The first

author could also use “follow-up” questions in the interviews on themes that emerged through participant observation.

Interviews. Five of the residents were included in formal interviews, one interview with each of the informants. The formal interviews lasted approximately from half an hour to one and a half hour. In the interviews, the first author used a theme-guide, which started with open-ended questions to gather the richest answers possible. The aim of starting with an open question was to avoid prescribed themes guiding the answers. This is in line with dialogical research, as described by Frank (Frank 2005). Later in the interview, the first author asked more specific questions which built on themes from previous research on dignity. This is in line with the phenomenological and hermeneutic approach in the study.

The first author held the interviews with the participants in their private room to ensure that the atmosphere around the interview was as comfortable and safe as possible.

Research ethics

As the first step, the head nurse assessed the patients’ competence to give informed consent. The head nurse performed a holistic and comprehensive assessment of the residents, built on her particular knowledge of the patients’ abilities. If the head nurse assessed one of the participants as not competent to consent, a relative gave consent on behalf of the resident. The head nurse in the units also informed the research participants and the relatives about the study and obtained consent from the participants or from relatives before the research project started. The head nurse informed the participants that they could withdraw from the research at any time. They were also informed that a withdrawal would not have any consequences for them. The fact that the head nurse was the one who assessed the patients’ competence to consent and hence recruited the participants may have had an impact on who participated in this study. The role between the head nurse and the residents may be seen as an asymmetric

relation where the nurse is the one who has the power, and hence may influence on the residents' decision-making. The consent process, though, was an ongoing process, as argued for in previous studies (Dewing 2007, Wilson 2011). This means that we renegotiated the consent throughout the study. The first author and the head nurse had an ongoing discussion on who should participate, for example in the formal interviews.

The first author also had to be sensitive to how her presence in the unit affected the residents. If her presence in the care situation seemed to stress the resident, she withdrew from the situation. We discuss more thoroughly how the ethical challenges of the research were solved in another article we have published on the study (Heggestad *et al.* 2013a).

The names used in this article, are fictitious.

The Regional Committee for Medical Research Ethics – South-East (No 2009/2222) approved the study.

Analysis

Analysis of the field notes started in the field as a part of the fieldwork. The field notes were written down in a table with four columns, one column with descriptions of what the researcher saw and heard, one column with personal reflections on what the description could mean, one column with methodical and research ethical reflections and one column with reflections on themes that emerged. These reflections became important in the analysis process. Through these reflections, sub-themes and themes emerged, and we incorporated some of the sub-themes in the interview guide.

The analysis of the interviews started in the interview situation and continued during the transcription-process and reading of the transcribed interviews.

The cases or the stories used as examples in this article, emerged through the informal conversations between the first author and the residents, and in the formal interviews. Several of the participants told their life-stories. Frank claims that narrative analysis does not have ‘a prescribed set of steps that the analysis should follow’ (Frank 2010, p.72). Prescribed procedures are monological and represent the opposite of dialogical research (Frank 2005). Narratives in themselves help us to interpret our world, and may help us to understand the storyteller, but the capacity of the story depends on ‘its power to compel attention’ (Frank 2010,p.27). The analytical questions that were asked when reading and interpreting the stories were, ‘What does the story tell?’, ‘What do the stories and storytelling mean to the storyteller?’ and ‘Do the stories say something that represent the material as whole?’

The first author did the main analysis of the narratives, but the co-author also did an active analytical analysis, reading the material. Both of the authors met several times to discuss the meanings and findings of the material.

Results

The first author experienced several times that the residents had a need to tell their life story when she was sitting with them in the living room, visiting them in their private room as a participant observer in the nursing home wards and during the interviews. These stories could be about how they met their husband or other episodes that seemed to mean something special for them. The stories had formed their identity. We illustrate this with three life stories as examples.

The stories compelled attention – and they ‘touched’ us. This was also why we thought it was important to do further analysis of what these stories meant to the storytellers.

We interpret this life-story telling as a way of trying to make coherence in a chaotic world and a way to be seen and heard – and hence a way to maintain and promote the dignity of identity or social dignity of the teller.

Two stories about feeling of belonging and safety when living in a chaotic world

Eli's story. Eli lived in the special care unit together with seven other residents. She had been living in the nursing home for two years. Eli had good verbal capacity, and the first author had many longer conversations with her. Eli participated in an in depth interview as well. Several times when Eli talked with the first author, she told stories from her childhood or the story about how she met her husband. In this article, we present a story from her childhood. (From the field notes):

I sit down with Eli and talk as she eats her breakfast. Again, she asks me, as she did the other day, about why she has to stay in the nursing home. "What place is this?" she wonders. "Well, well," she says after a while, "the most important thing is that one can enjoy oneself". Then she starts telling me about her childhood, and about how she met her husband, and about the good life, they have had together. She also tells me about her mother, that she used to bring water from the sea and pour it over Eli and her siblings. "My mother thought it would bring us good health. We were never sick. We were six siblings, and we never got flu, so I think it helped. We had to take a spoon of fish oil every day. Mother stood there, ready with the spoon." She tells the same story several times this morning.

At the beginning of the conversation, Eli seemed to be confused. She did not know where she was, or why she had to stay in the nursing home. Eli's experiences of her life world often seemed to be chaotic and fragmented. However, when she started to tell stories about her life, she calmed down, and she seemed to be proud of the life she had lived.

Dagny's story. Dagny also lived in the special care unit. Dagny often got restless and anxious. When she got restless, she often expressed that she did not want to stay in the nursing home any longer. Dagny had one story she often repeated, and when she got confused, frustrated and longed for her home, the nurses or the nursing assistants encouraged her to tell stories from her life. Then she would calm down.

(From the field notes):

Dagny and I sit in her room. She is confused and frustrated. "You've got to get me out of this room", Dagny says. "I don't want to stay here any longer. I want to leave this place. I don't enjoy being here, but I don't know where to go." I try to calm her down and turn to another theme to talk about. I have recognized that the carers often try to let her talk about her childhood when she is in this mood. Therefore, I show her a picture hanging on her wall, of a lake. I know she loves to talk about how she swam across the lake where she lived when she was a child. She looks at the picture and we start talking about how nice it is. "You know, I used to live by a lake." She starts telling the whole story about the flood that took the house they lived in several times, and she tells about how they used to swim across the lake during the summer time. When she talks about this, I can see how she gets calmer, and she even smiles when she tells the story. It is as if she has forgotten her longing for home.

Because of their dementia, both Eli and Dagny could be confused and long for their homes and their relatives. However, they would calm down when telling their stories. They seemed to be proud of their stories. When they told the stories, they were the experts. Telling their stories was something that they managed. When they talked about their lives, nobody could correct them or reality-orientate them, and say that they were wrong. This, we think, demonstrates how life-story telling can help to give a feeling of coping, a feeling of belonging

and safety in a chaotic world. Feeling of belonging can promote dignity of identity or social dignity.

One story about previous roles and identity

Anna's story. Anna was in her mid 80's and suffered from dementia. She had a good verbal capacity and the first author had several meaningful and adequate conversations with her. She came to live in the nursing home because she could not manage to feed or take care of herself at home anymore, because of her dementia.

Anna used to sit in the same chair in the living room in the nursing home every day.

Sometimes she sat there talking with the other residents in the unit, but often she sat there alone, and if nobody sat down with her, she sat there sleeping. The unit where Anna lived was a general unit. The first author often sat down with Anna, and they had many interesting conversations. Anna talked about her life in the unit, but she also told stories from her life before she moved into the nursing home. Anna also participated in a more formal interview. The story told here is a reconstruction of her story telling from the interview and from informal conversations. The parts included in the reconstruction of Anna's story, were all stories, which Anna repeated to the first author several times, both in informal conversations and in the formal interview. Since she repeated these stories, we thought that these stories meant something special for her as parts of her whole life-story. Anna's story may be seen as one whole story, but it may also represent several stories about her earlier life and about her life in the nursing home, and it may represent stories other residents told. (From the field notes and interview):

'I think I've been here for 3-4 months now – no, I'm not quite sure, but I've been here for a while. I'll stay here forever. I'm fine with that now. I'm 89 years old, just imagine! Still, they all say I don't look that old. I did gymnastics, you know, I've been active. I won't boast, but I've been active. I used to sing a lot too. I was singing at that

outdoor restaurant. Everyone wanted to listen to me. "Come, let's listen to her," they said. I was there for a long time. Everybody was asking for me. The whole restaurant was full of people, and it was because of me. The owner of the restaurant got a lot of money when I was there, you know, and they got many guests. I also used to sing at family parties at Christmas time and on our national day, and so on. I used to play the organ too. We had a huge organ at home. "You play the organ, Anna, play for us!" they said. I sat there all day, playing the organ. They were dancing and having fun, as I played the organ. I was a little bit proud, I was popular you know. When I didn't go around singing and playing anymore, it ended. I just used to sit down at home. That's how it ended. Now I can't play the piano or the organ anymore. Now, when I've got so old, I am old you know, I've been old for many years. Now I'm nowhere, now I'm just here. I have had an entertaining life. The singing was the funniest part.'

The storytelling in itself tells us something important; that Anna had a need to tell her story to someone. It is a story of a girl who used to be acknowledged by an audience. She felt that she was important both as a gymnast and a singer, and these roles seemed to be important to her and her identity. Now she had become old and lived in a nursing home unit where it seemed that nobody knew about her career, and she could not play the piano anymore. By telling her story, she painted a picture of who she had been, so that the listener could see that she was more than just one resident among others, and more than a person who suffered from dementia. Through the storytelling, she appeared as an active participant in her own life, instead of a passive resident who sat sleeping in her chair waiting for the next meal.

Discussion

Relational dignity or what Nordenfelt calls 'dignity of identity' depends on the social relationships and how you are seen as a whole person with a life story (Nordenfelt, 2004).

What Nordenfelt does not mention is how we, ourselves, may maintain our own dignity. We argue that life-story telling is a way for people with dementia, living in nursing homes, to maintain their social dignity or dignity of identity. They maintain their dignity by telling the

story of who they are. This is also in line with Frank who writes that, 'The stories that their elders sing to the children at night are their dignity' (Frank, 2010, p.149). Frank also claims that stories 'care for us'. Therefore, by telling a story, the residents are caring for themselves.

Dignity related to feelings of belonging, confidence and safety

According to earlier research, people with dementia may have difficulties with talking about and remembering the present, while they may still remember their past (Edvardsson & Nordvall 2008, Son *et al.* 2002). People who suffer from dementia may not know where they are, or how old they are, but many may remember who they have been. When cognitive functions fail for people with dementia, their stories continue to function. This shows why people with dementia often tell their life stories.

Telling stories from the past may give feelings of belonging and safety (Edvardsson & Nordvall 2008, Karlsson *et al.* 2014). Eli and Dagny's stories demonstrate this. They could both be confused and not know where they were, but as they started to tell their stories from childhood; this appeared to give them feelings of safety in their confusion. It was as if they placed themselves in the world. By telling stories which involved family members and significant others, Eli and Dagny upheld their feelings of belonging in life, when everything else around them was confusing. People with dementia may feel lost in the present, but when talking about the past and about their life, they may feel more confident and safe (Edvardsson & Nordvall 2008). In an earlier article, we have argued that feelings of belonging may be an important part of dignity of identity (Heggstad *et al.* 2013b).

The residents have experienced big changes in their lives, both directly related to their dementia, but also indirectly related, for example, to moving from their own home to a nursing home. Telling stories, like Eli, Dagny and Anna did, may be a way of dealing with fears of what change may bring (Frank, 2010). An earlier study about dignity in palliative care

found that feelings of hopelessness were seen as serious threats to the experience of dignity (Hack et al., 2004). Telling stories may bring hope, and may help the person to feel valued (Chochinov, 2002, Frank, 2010). Bringing hope and letting people feel valued may enhance their experience of dignity (Chochinov, 2002).

Life-story telling and dignity of identity

We can also see life-story telling as a way of trying to bring attention to who a person is and a way of revising and maintaining identity (Frank 1995, 2010, Mishler 2004).

Earlier research has shown that life-story telling may promote the identity and self-esteem of people who suffer from dementia (McKeown *et al.* 2010, McKeown *et al.* 2006, Ryan *et al.* 2009). Anna related her identity to her earlier role as an artist and singer. She had meant something special for others and, through this role as a singer, she felt valuable. Haddock underscores the relation between dignity and having feelings of being essential and valuable to other people (Haddock 1996). The importance of telling others who we are and have been lies in others' acknowledging and confirming us as people and not merely as a diagnosis. This is, according to Goffman, also about seeing the person's factual identity (Goffman 1974). But in order for the identity that a person tries to construct to exist, it has to be accepted socially (Sabat & Harre 1992). This means that someone has to listen to our story of who we are, and someone has to take our story seriously. According to Frank (1995), listening to others' stories is a fundamental moral act. If care workers listen to the patients' stories, they may get to know the person behind the diagnosis, and they can adjust the care to that person. This shows how life-story telling can make a change and have a meaning for the storyteller, and promote their dignity of identity. The challenge though, is that not all people with dementia are able to tell their stories because of linguistic or cognitive deficits (Hydén & Örvulv 2009). This means that the narratives and storytelling may be of no help for people with dementia

who have problems with for example language. However, if the person suffering from dementia does have linguistic problems, we should seek to get the life-story from those who know the person.

Some claim that identity and personhood may be lost when a person gets dementia, because of their declined memory (Addis & Tippett 2004, Jetten *et al.* 2010). Some also claim that dignity may be lost when having dementia, as they relate dignity to the ability to reason (Cooley 2007). What is common for those who claim that personhood may be lost in dementia, is how they relate personhood and identity merely to cognition and the ability to reason.

We will argue though, that personhood and identity do not only depend on our brain and cognition. According to Hughes, this strong emphasize on cognition and the ability to reason may even lead to negative stereotyping attitudes and prejudices (Hughes 2001). Because of this emphasize on cognition, we often think that people with dementia cannot contribute anything. Storytelling may 'shift the cultural conception of illness away from passivity – the ill person as a victim of the disease and the recipient of care – toward activity' (Frank 1995). To be seen as a person behind the diagnosis and to be seen as a person despite of cognitive deficits is about being taken seriously as a human being. We will argue that, when we are taken seriously as human beings, our dignity is preserved. Taking the person with dementia seriously means listening to what the person mentions as being important for him or her. By sitting down and listening to the residents' life stories, carers engage in the resident's world, and let the resident be an active participant in his or her own life.

Strengths and Limitations

Some claim that it is not possible to generalize from case studies. This is common to all kinds of qualitative research. Even though it may not be generalizable, it may be recognizable for

similar practices. Furthermore, case study research is useful when studying a phenomenon in its natural context, and it enables the researcher to see how a phenomenon is influenced by the context (Baxter & Jack 2008, Houghton *et al.* 2013). This was what we did in this study. Participating in observation combined with interviews made it possible to get richer information about the context and the life world of the research participants. In line with Frank, we believe that stories may engage more than traditional presentations of quotations (Frank 2010). Moreover, we think it is important to ‘catch’ the reader and claim attention if scientific knowledge is going to reach out (Frank 2004).

Conclusion

As health care workers, we have a special obligation to maintain and promote the dignity of residents living in nursing homes. To do so, we need knowledge about what is important for the residents in their lives. Knowledge about their medical conditions is not enough. We should be open to the residents’ life stories. This article demonstrates the importance of this and shows the connection between life-story telling, identity and dignity. We often see dignity as a vague concept. This article shows that dignity is about concrete experiences and lives, respecting residents as whole human beings. Maintaining the residents’ dignity is about respecting the lives they have lived.

Relevance to practice

Nurses have an obligation to ensure that dignity is maintained in care for their patients. Knowledge about how residents with dementia may use life-story telling as a way to maintain their dignity is therefore of great importance to clinical practice in nursing homes

What does this paper contribute to the wider global clinical community?

- Knowledge on the connection between dignity and life-story telling
- Knowledge on the importance of listening to the life-stories of people with dementia living in nursing homes
- Knowledge on how nurses may promote dignity of people with dementia by valuing their life-story telling
- Knowledge on the importance of seeing and acknowledging the person behind the diagnosis

References

- Addis DR & Tippett LJ (2004): Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory* **12**, 56.
- Baxter P & Jack S (2008): Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *Qualitative Report* **13**, 544-559.
- Brodsky H, Breteler MMB, Dekosky ST, Dorenlot P, Fratiglioni L, Hock C, Kenigsberg P-A, Scheltens P & De Strooper B (2011): The world of dementia beyond 2020. *Journal of the American Geriatrics Society* **59**, 923-927.
- Dewing J (2007): Participatory research: A method for process consent with persons who have dementia. *Dementia* **6**, 11-25.
- Edvardsson D & Nordvall K (2008): Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia. *Journal of Clinical Nursing* **17**, 491-498.
- Engedal K (2010): The Norwegian dementia plan 2015—'making most of the good days'. *International Journal of Geriatric Psychiatry* **25**, 928-930.
- Frank A (2004): After Methods, the Story: From Incongruity to Truth in Qualitative Research. *Qualitative Health Research* **14**, 430-440.
- Frank AW (1995) *The wounded storyteller: body, illness, and ethics*. University of Chicago Press, Chicago.
- Frank AW (2005): What is dialogical research, and why should we do it? *Qualitative Health Research* **15**, 964-974.
- Frank AW (2010) *Letting stories breathe: a socio-narratology*. University of Chicago Press, Chicago.
- Gadamer H-G (2004) *Truth and method*. Continuum, London.
- Gastmans C (2013): Dignity-enhancing nursing care: a foundational ethical framework. *Nursing Ethics* **20**, 142-149.
- Goffman E (1974) *Stigma : notes on the management of spoiled identity*. J. Aronson, New York.

- Haddock J (1996): Towards further clarification of the concept 'dignity'. *Journal Of Advanced Nursing* **24**, 924-931.
- Heggestad AKT, Nortvedt P & Slettebø Å (2013a): The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics* **20**, 30-40.
- Heggestad AKT, Nortvedt P & Slettebø Å (2013b): 'Like a prison without bars': dementia and experiences of dignity. *Nursing Ethics* **20**, 881-892.
- Houghton C, Casey D, Shaw D & Murphy K (2013): Rigour in qualitative case-study research. *Nurse Researcher* **20**, 12-17.
- Hughes JC (2001): Views of the person with dementia. *Journal of Medical Ethics* **27**, 86-91.
- Hydén LC & Örvulv L (2009): Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies* **23**, 205-214.
- Jacobson N (2009): A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights* **9**, 1-9.
- Jetten J, Haslam C, Pugliese C, Tonks J & Haslam SA (2010): Declining autobiographical memory and the loss of identity: effects on well-being. *Journal Of Clinical And Experimental Neuropsychology* **32**, 408-416.
- Karlsson E, Sävenstedt S, Axelsson K & Zingmark K (2014): Stories about life narrated by people with Alzheimer's disease. *Journal of Advanced Nursing*.
- Kellett U, Moyle W, McAllister M, King C & Gallagher F (2010): Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing* **19**, 1707-1715.
- Leget C (2013): Analyzing dignity: a perspective from the ethics of care. *Medicine, Health Care, And Philosophy* **16**, 945-952.
- McKeown J, Clarke A, Ingleton C, Ryan T & Repper J (2010): The use of life story work with people with dementia to enhance person-centred care. *Blackwell Publishing Ltd*.
- McKeown J, Clarke A & Repper J (2006): Life story work in health and social care: systematic literature review. *Journal of Advanced Nursing* **55**, 237-247.
- Mishler EG (2004): Historian of the Self: Restorying Lives, Revising Identities. *Research in Human Development* **1**, 101-121.
- Nordenfelt L (2004): The varieties of dignity. *Health Care Analysis* **12**, 69-81.
- Nordenfelt L (2009) The Concept of Dignity. In *Dignity in care for older people*, First edition edn (Nordenfelt L ed.). Wiley-Blackwell, Chichester, pp. 26-53.
- Norwegian Ministry of Health and Care Services (2005-2006) Care plan 2015 - long term care future and challenges (services Nmohac ed.). Norwegian ministry of health and care services, p. 22.
- Pullman D (2004): Death, dignity, and moral nonsense. *Journal Of Palliative Care* **20**, 171-178.
- Rosenwald GC & Ochberg RL (1992) Introduction. In *Storied lives: the cultural politics of self-understanding* (Rosenwald GC & Ochberg RL eds.). Yale University Press, New Haven, Conn., pp. 1-18.
- Russell C & Timmons S (2009): Life story work and nursing home residents with dementia. *Nursing Older People* **21**, 28-32.
- Ryan EB, Bannister KA & Anas AP (2009): The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies* **23**, 145-157.
- Sabat S & Harre R (1992): The Construction and Deconstruction of Self in Alzheimer's Disease. *Ageing and Society* **12**, 443-461.
- Selbæk G, Kirkevold Ø & Engedal K (2007): The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *International Journal of Geriatric Psychiatry* **22**, 843-849.
- Son G-R, Therrien B & Whall A (2002): Implicit memory and familiarity among elders with dementia. *Journal Of Nursing Scholarship: An Official Publication Of Sigma Theta Tau International Honor Society Of Nursing / Sigma Theta Tau* **34**, 263-267.
- Spradley JP & McCurdy DW (1972) *The cultural experience*. Science Research Associates, Chicago.

Post print version, published in *Journal of Clinical Nursing*, 2015, 24, p2323-2330.

The Nuffield Council On Bioethics (2009) *Dementia: Ethical Issues*. In *Nuffield Council Reports*, 1st edn. Nuffield Council on Bioethics, London.

Wilson CB (2011): The value of reflexivity in resolving ethical dilemmas research in care homes. *Journal of Advanced Nursing* **67**, 2068-2077.