



Regular Article

“Take me to the back, or they’ll think I am not normal” - Ethical reflections on narrative research with people with dementia living in long-term care institutions

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ABSTRACT

Background: Over 80% of older adults in long-term care institutions live with cognitive impairment/dementia. They represent a particularly vulnerable group, yet the perspective of people with advanced dementia has still not been sufficiently explored. These people are often excluded from research, also because of ethical and methodical issues and legal barriers.

Design: In this paper we discuss ethical considerations and challenges which arise in qualitative research with people living with advanced dementia. We present ethical issues in research using a design inspired by ethnography with the aim to encourage future research in this field. Methods applied were observations, interviews and informal talks with people diagnosed with moderate and severe dementia. Two different long-term care institutions were researched: a specialized dementia-care unit and an institution based on a community-oriented household-model. Participants were older adults with dementia, and data were collected within a period of two years. Staff and next of kin were included in data collection. A thematic and narrative analysis was performed.

Challenges linked to ethical and methodological issues were experienced throughout the whole research process. These included getting approval from a local ethical committee, gaining access to the field, dealing with process consent and complex qualitative analysis, representing the participant's stories in a respectful way, enabling reciprocity as well as dealing with difficult situations in long-term care and questions of the vulnerability of both the participants and the researcher.

Conclusion: It is possible to include vulnerable adults living with advanced dementia in qualitative research. This should be done more extensively in order to make the experience of a group that is growing in numbers visible. Strategies of reflexivity have to be carefully planned and organized in advance because methodological and ethical aspects are strongly intertwined. In contemporary qualitative narrative research, it is recommended to not only present the participant's stories, but also the researcher's own story that exerts influence on the research process. Approaches derived from care- and process ethics as well as appreciative inquiry can provide valuable support throughout the research process.

1. Introduction and background

Adults living with dementia in institutions are vulnerable. They are often neglected in research also because ethical concerns and barriers have to be dealt with. There is a growing body of research in nursing homes and other long-term care institutions, but older adults living with more advanced dementia are still underrepresented. In this paper we want to focus on ethical concerns and challenges that arose in the

research process with people with advanced dementia and present some useful applications. Our aim is to reflect upon and discuss ethical aspects to support future research in the field of qualitative research with people with advanced dementia. Ethical issues concerning research with people with beginning dementia and dementia in general have been widely discussed (Reitingner et al., 2018; Thoft et al., 2021) but few have involved experiences of people with advanced dementia. This article draws on research and experiences from a doctoral thesis project

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exploring activity and participation of people living with advanced dementia (Tatzer, 2017). The research aim of the empirical study was to explore the experience of activity and participation of people with moderate to severe dementia living in long-term care. Moreover, it aimed at better understanding the function of activities and occupations in constructing one's identity and gaining meaning. If personhood and identity are important concepts that contribute to the wellbeing of people with dementia as described by Kitwood and others (Kitwood & Bredin, 1992), occupation could be a means to experience personhood and identity. The original study was inspired by ethnography (Hamersley & Atkinson, 2007) as an attempt to grasp the situatedness and transactional nature of activities and occupations and the relationship to identity and meaning-making.

1.1. Dementia – variation of age, disease or cognitive disability?

How researchers frame and conceptualize dementia or neurocognitive disorders can strongly influence the qualitative research process. Therefore we include a discourse around dementia and our understanding of it as well as the political and legal context in Austria in order to clarify how we dealt with ethical challenges.

Dementia is seen as a condition that changes many essential aspects in a person's and their family's life. It is known to affect social participation and relationships, an area where more research is needed (Harmer & Orrell, 2008). People with dementia can have a high quality of life despite their limitations and it was argued that the extent to which a person is "disabled by intellectual or cognitive disabilities depends upon the level and quality of support that is provided to live with those disabilities" (Perrin et al., 2008, p. 7). One of the challenges is linked to the difficulty to discriminate if changes in the brain are linked to normal ageing or seen as a pathophysiology (Snowdon, 2001).

Research about epigenetics and criticism on the medical view on dementia as an illness (Lock, 2013) was strengthened by the fact that there is still no medical cure for dementia (Alzheimer's Association, 2014). Some even say, there will never be a medical way of "curing" this complex condition, and social and societal aspects should be stressed. Seen from a historical perspective, the framing of dementia as an illness started in the 1970s with the disadvantage that other non-biological factors such as environmental, even political factors including poverty, injustice and racism have not been researched in relation to dementia (Lock, 2013). In recent discussions, the environmental and social influences on the individual risk of developing a neurocognitive disorder have received more attention. Recently, modifiable risk-factors for the development of dementia or neurocognitive disorders have been identified that include social and political aspects such as social isolation, education and even air pollution next to medical risk factors such as diabetes or high blood pressure (Livingston et al., 2020).

Following a relational anthropology, human beings are understood as social beings who are embedded in their (social) environment. People with dementia remain interconnected even if communication may be challenging (Schockenhoff & Wetzstein, 2005, p. 264) and there is a call for solidarity and change towards a more "dementia-friendly society" (Wissmann et al., 2008). Kitwood (1997) introduced two principles in good dementia care: first, focusing on remaining abilities and not only deficits and second, a re-defining memory as interactive and not only individual. According to Leibing (2006), the consequent application of these principles would lead to a revolution:

„To follow Kitwood's instructions through completely would bring about a major revolution, not only because it would mean a large investment of time and staff during a period of ever tightening health budgets, but also because redefining 'memory as interactive' would only be possible after a major shift from what is deeply rooted in our thinking and practice: that memory is the carrier of individual identity and personhood.“ (Leibing, 2006, p. 255/256)

One essential question here is how people with dementia see

themselves. Thus representatives of "Promenz", an Austrian self-help-group, reject the label "dementia" ("without mind") and call themselves "people with forgetfulness" (PROMENZ, 2023). Keeping this aspect in mind, we see people with dementia as active agents in their lives and dementia as a disability according to the UN-Convention of human rights for people with disabilities. Yet recognizing dementia as a disability cannot only be seen as a matter of claiming rights, autonomy and independence. It should also address care and support needs, and focus more on a positive conceptualization of interdependency, as stated in a discussion paper by Alzheimer Europe (Alzheimer Europe, 2017).

1.2. Dementia and long-term care (LTC) in Austria

In 2022, more than 19,5% of the Austrian population were over 65 years old (Statistik Austria, 2022) and the risk of developing a neurocognitive disorder increases with age (Livingston et al., 2020). It is acknowledged that many older adults with more advanced dementia and other comorbidities need long-term-care. In a representative study in long-term care institutions in Austria, it was found that 82,3% of the residents showed signs of cognitive impairment whereas only 58,5 had a formal diagnosis (Auer et al., 2018). It was claimed that people with dementia are in need of palliative care (Kojer & Heimerl, 2009) because it is a chronic, life-shortening condition. It is not yet clear which kind of care organization is best for people with dementia in need of long-term care since outcomes of studies differed (Weyerer et al., 2005). Thus it was shown that special dementia-care units that are "homelike" are not by themselves sufficient to maximize the quality of life of people with dementia (Wood, 2005).

1.3. The political and legal regulations and frameworks in Austria

In 2008, Austria ratified the UN-convention for people with disabilities (UN, 2006). Adults living with dementia are protected by the declaration of the human rights convention for people living with disabilities (Müller & Walter, 2013). Müller & Walter describe that some practices in nursing homes are contradictory to the UN-convention (p. 84). Article 19 of the convention demands interventions to prevent isolation from the community or segregation. Yet, some long-term-care institutions provide a segregated model of living due to the behavioral and psychological problems often associated with people with advanced dementia.

Two housing models have been set up for these people: the specialized dementia ward (special care units – in German "Demenzstation"), often a more medicalized approach including a geriatric and multi-professional health care team, and a community housing model including public spaces for participation for the inhabitants ("Hausgemeinschaftsmodell"). Müller and Walter (2013) are sceptic, if a segregating model that often includes closed wards can be compatible with the UN-Convention at all. Older adults living with advanced dementia are particularly vulnerable to structural violence and coercion so that the health and social care systems have to be sensitive in dealing with these issues.

A segregation of public support service in two parallel systems that offer services for older adults on the one hand, and for people living with disabilities on the other hand, should be challenged (Müller & Walter, 2013). For nearly 10 years, the national dementia strategy plan as well as the establishment of dementia-friendly communities and districts have contributed to create a broader public awareness. This has resulted in the growth of supportive initiatives and projects in the care for people with dementia (Juraszovich, Sax, Rappold, Pfabigan, & Stewig, 2015).

1.4. Design and methods of the original study

Methodology and ethical aspects are intertwined; thus, we present the design and methodology of the original study in order to better understand the ethical aspects. A design in the qualitative tradition

inspired by ethnography was used (Hammersley & Atkinson, 2007). Observations (Nygard, 2006), informal talks and interviews were used in a specialized care unit and a home-like unit for a longer period of time, the data collection was done over a period of two years. The settings were established through the activity profile of the participants and ranged from walks in the park with relatives to observations in the institutions at different times and seasons. Activities that were observed ranged from routine activities in the organization (e.g. meal-times) to care activities (e.g. assisting with eating; dressing) therapies offered (e.g. music therapy, occupational therapy, validation therapy); activity-programs (by non-specialized staff), visits with relatives and holidays with staff. Data comprised field notes from observations, transcripts from observations and interviews and informal talks with people with dementia, staff and relatives. Three family members were part of the observations and contributed elements of life-stories to the data collection. One family member was interviewed by telephone. The periods of observation per participant lasted from 5 months to 12 months. Many observations were recorded and transcribed, in order to capture verbal expressions as an attempt to gain access to their perspectives. Many people with moderate and severe dementia are not able to tell continuous stories – the participants used gestures, sounds, behaviors and other ways to compensate for their problems in verbal communication.

An interesting narrative approach has been developed by Alsaker et al. (2009) that is called “narrative-in-action” or “enacted narratives” and combines narrative theory with an ethnographic approach. Based on the work of Mattingly (1998) and Ricœur (Ricœur et al., 2008), it claims that narratives are embedded in actions and everyday occupations that take place transitionally. It was used in addition to a thematic analysis in order to reach a deeper level of interpretation. The detailed process of the analysis and methodological aspects are described elsewhere (Tatzert, 2019; Tatzert et al., in press-a).

2. Ethical considerations in the research process

In the following part, we describe some of the challenges, but also advantages of our approach regarding the ethical considerations throughout the research process, from ethical approval to deciding about the final stories of the participants in the thesis.

2.1. General ethical aspects

People with moderate and severe dementia living in nursing homes have the right to participate in research, but are often excluded and this enforces a process of marginalization (Röse, 2016). Research in the life-world of people with dementia demands a reflexive and conscious way of dealing with ethical challenges throughout the whole research process. The Scottish Dementia working group has published some guidelines for research involving people with dementia that was helpful in the preparation (Scottish Dementia Working Group Research Sub-Group U. K., 2014). Alzheimer Europe published guidance for research with people with dementia (Alzheimer Europe, 2011), especially when adults cannot give their written consent anymore:

- The potential benefit of the research projects should be higher than possible risks
- The risk to induce stress or malaise should be kept minimal for participants
- The involvement of a formal ethical committee is recommended
- The legal advisor of the person with dementia has been authorized to give written consent.

All these recommendations were followed and we applied for approval at the local ethical committee.

2.2. Influencing choices to the research process

The ethical approval of a local ethical committee was required at that time in Austria, also because the participants were living in institutions and therefore deemed to be particularly vulnerable. However, the more formal processes of ethical approval can lead to restrictions in creativity that may be necessary to include persons with severe cognitive impairment.

After the first meeting with the ethical committee, several amendments were requested. They included: 1. Not to ask the person with dementia for written consent to minimize stress. 2. The person had to have a legal advisor or next of kin who could give written consent. 3. Both institutions had to be chosen in advance. These requests led to changes in the research process that were quite fundamental, because it led to the choice of institutions before starting data collection and excluded people with advanced dementia without next of kin. The original plan was to choose the second institution after having preliminary results from the analysis in the first institution, as is common in qualitative research, and also to ensure a wide range of experiences. The benefit of obtaining ethical approval was that access to the institutions was easier. 4. The phase and severity of dementia had to be made explicit through a formal assessment. 5. Another amendment was the change of the title to “pilot-study” – this was possibly because of the small number of participants in the qualitative research.

The benefit that was also acknowledged by the ethical committee was the potential benefit for the participants in having more social contacts. The directors of the institutions were supportive because they wanted their work to be more visible and feedback derived from the research was seen as beneficial. Both organizations received feedback and results were discussed with both the managers and the staff. Finally, after getting approval and having chosen the two institutions, the recruitment of possible participants and the data collection started with an adapted plan for getting access to participants. Data collection took place in two LTC institutions in Austria. One of them was a public institution with a special care unit for people with dementia. The other one was a private home using a house community model.

2.3. Choosing and gaining access to participants

Most people with dementia in long-term care live with moderate and severe cognitive impairments. The requirement of the local ethics committee demanded an assessment of the medical range of the phase and severity of dementia. In Austria, a commonly used cognitive screening tool is the Mini Mental State Examination (MMSE) (Folstein et al., 1975), which is mandatory for obtaining medication prescribed for dementia. The actual scores of the MMSE are not very sensitive, especially with people with sensory impairments in hearing or sight. The use of cognitive screening tools like the MMSE is criticized because they do not give information about a person's ability to express feelings or experiences (Heggestad et al., 2013, p. 33). One pragmatic decision was to put the focus on excluding people with mild dementia. For that reason, it was deemed sufficient that the participants were rated below 20 points for inclusion. The assessment was done by staff so as not to put more pressure on possible participants. However, some of the assessments scores were some weeks or months old at the starting point of the research. Thus, the inclusion criteria were a formal dementia diagnosis and Mini Mental Status (MMSE) of under 20 points to exclude people in the so called “early” stages.

The final Inclusion criteria of the participants were:

- A medical diagnosis of moderate to severe dementia (MMSE below 20 Points)
- Living in a long-term care institution for more than a month
- Voluntariness and giving verbal and or/behavioral „assent” (see later)

- „Informed Consent “: The legal representation had to give written consent
- Age: 60+

Participants were sampled using a maximal variation strategy considering age, mobility, gender and social factors to gain a deeper understanding within a small sample of participants. To get a better impression about possible skills and competences of the participants, another scoring instrument was used stemming from occupational therapy, the Pool Activity Level Instrument (PAL). It is a more resource-orientated scale to describe the competencies of a person with cognitive impairment. It was developed by Jackie Pool (2008) and validated in its English version for people with dementia (Wenborn et al., 2008). It comprises 4 skill levels: planned, exploratory, sensory and reflex activity. There was no validated version in German available, so it was translated and retranslated and discussed with experts from the field to ensure the accuracy of the translation. This additional information was helpful to identify the level of skills the participants had to engage in activities.

2.4. Exclusion criteria

Because the leading research question of the original study was about the experiences of activity and participation, people with dementia who were in terminal care and in the process of dying were not included. Also, people who had no explicit next of kin or legal advisor had to be excluded due to the stipulations of the ethical committee. Finally, four older adults living with dementia (74; 79; 81 and 93 years old) in the “moderate to severe” phases were recruited in two different long-term-care organizations.

2.5. Organizational choices

As a result of a literature review, two different organizational forms were chosen: a more home-like unit (“housing-model”) and a specialized dementia care unit. The institutions were explicitly recommended by two experts in the field as “good” institutions. At the time of the data collection, there was no uniform quality assurance system for long-term-care institutions in Austria.

2.6. Access to the institutions and participants

The staff leaders were informed and gave written consent for the research before starting data collection. They were especially important in their role as gatekeepers. All staff and next of kin were informed and gave their consent.

All names used were pseudonyms, in total, 121 pseudonyms were given in the fieldnotes resulting from the observations of four participants with their surrounding social environment. Staff gave verbal consent to being part of the research. In the second institution, the first author gave a short introduction for staff members to inform them about the aims and methods of the research but also to build a relationship.

Working with staff members as door openers is a common way of gaining contact to possible participants. It has to be considered that power relations have an impact on research relationships.

2.7. Assent, consent and dissent

Consent is a much-discussed concept in the field of dementia. Traditional understandings of informed written consent would exclude people with moderate dementia and adds to the problem that this group’s perspective is not well researched (Dewing, 2009, p. 236). It can be time-consuming to recruit participants and the whole process is dependent on gatekeeper’s attitude to research.

It was particularly difficult to include men and individuals who were socialized as males with moderate and severe dementia. This may be

because the world of long-term care is strongly gendered (Reitingner & Heimerl, 2014) and there are less older men living with moderate dementia in long-term-care due to the difference in life-expectancy in Austria. Three men and their next-of-kin who were asked declined to participate.

Dewing (2008, p. 61) proposes a process model for the inclusion of people with dementia. Dewing stresses the positive effects of research, to do something meaningful from the point of the persons living with dementia and even sees “therapeutic potential”. At the beginning of the research, 3 questions should be asked by the researcher: 1. How do I know this person is consenting? 2. What type of appreciation does this person have of their consent? 3. How would this person demonstrate reluctance and/or objection? She describes a five step model: (Dewing, 2008, p. 62 ff.):

1. Background and preparation
2. Establishing the basis for consent
3. Initial consent
4. On-going consent monitoring
5. Feedback and support

The first phase consisted of getting approval to contact the persons from next of kin or the legal advisor and getting some information about their life-stories. The second phase consisted of establishing the basic information about the person’s capabilities to give consent. In this stage, assessment instruments are often used to judge the person’s ability to give consent. Alternatively, the judgement of staff such as nurses or medical doctors who know the person well is used, also because it can be an unpleasant experience to “get tested”. Furthermore, cognitive screenings are not useful to decide whether the person would like to express feelings and their point of view (Heggstad et al., 2013). To sum up, we used the existing measures of the MMSE, interviewed next of kin and staff and additionally applied the PAL Instrument.

Close contact with staff who knew the persons well was crucial. Activities that were deemed too private were discussed beforehand with staff (such as dressing and washing in the housing community model). What was deemed appropriate differed: thus it was possible to observe a male participant while he was getting dressed and shaved and who enjoyed social contact, while it was seen inappropriate with another female participant.

An exclusion criterion was, if neither the person nor next of kin could give consent. A principle that was helpful was obtaining either “assent” or “dissent”. “Assent” means the approval of a person who is not able to give full informed consent but can express their opinion by a relevant behavior, like for example cooperation (Black et al., 2010, p. 82). “Dissent “, means the clear refusal to participate. Heggstad et al. (2013) stress the importance of assent, contrary to consent.

2.8. Giving information about the research process

Heggstad et al. (2013) state that it can be harmful to give the „full information“ about the research, especially when explicitly stating the diagnosis of dementia. This was discussed with staff. We asked how the persons speak about themselves and whether they knew about their diagnosis or not. It is recommended to use the language the persons use themselves and not “label” them (Ericsson et al., 2011). The process of consent is ongoing and behavioral cues are important indicators in the actual situation of the observations. Another recommendation we applied was to use an ethical logbook and get informed about communication techniques and about dementia and its consequences.

2.9. Application in the research process

The lifeworld of long-term-care is complex and including people with more advanced dementia living in long-term-care in research can be challenging, also in terms of interactions. Heggstad et al. (2013)

recommend to have some professional knowledge and skill in communicating with people with cognitive impairment in nursing homes. Heggstad et al. (2013) stress that professional expertise is necessary to participate in a setting of daily care routines as a researcher. They reason that it is easier to prospectively judge problematic situations and that even staff in the institutions cannot preview how a person will react to a stranger in a research situation. They recommend to stay vigilant and rather exit a situation, when it is not clear, whether the person participating in research experiences stress or not.

The background of the first author as an occupational therapist was useful in this regard, but made it necessary to reflect and organize reflexivity and also to clarify her role in the research process. The principle values and image of people with dementia were resource-orientated, also due to her professional experiences with people with cognitive impairment. Consequently, we assumed that people with cognitive impairment were able to make decisions if they got supported and that they were aware of their situation, if not proven otherwise, as recommended by Ericsson et al. (2011).

The proposed decision tree of dissent and assent by Black et al. (2010) was followed. This was useful but created other challenges: it is time-consuming and requires stable relationships with staff. Since it can take a long time to recruit and process consent with people with advanced dementia, another problem can arise: the health status can change rapidly because of the vulnerability in terms of health and co-morbidity. One example of ethical reasoning in the recruitment was whether to include a participant despite his changed health and mobility status. The second participant suffered a fall shortly before starting the data collection after giving assent and consent by his next of kin. After a discussion with staff and the next of kin, he was not excluded from the project, because the additional social contact was deemed beneficial. He was using a wheelchair for transport in the home-like institution and experienced decreased mobility. Using the theoretical sampling, the first author was looking for other participants in the second institution who were able to walk without assisting aids to get a more differentiated perspective. Another person could express his dissent clearly. When the first author asked him, whether he wanted to participate and would like to receive visits, he replied: *"I don't want anything"* (Tatzert, 2017), so we did not include him in the study. Another person was not included because his next of kin did not consent.

With Mrs. Bacher, one of the participants who was 93 years old at the start of the data collection, the initial contact is presented in the following excerpt from the fieldnotes, it is written from the perspective of the first author:

I make eye-contact and greet her "Hi". She replies: "Well, come here to me", I nod, „yes, I will sit with you". She is searching for eye contact and starts a conversation with me. After 5 minutes, I ask her if she enjoys conversations. She replies, yes. I ask whether I can come and visit her again. She says yes. I am not sure, if she understood what I meant. She starts talking about her daughter. I ask her if it is ok to talk with her daughter, too. She says, yes, sure. I am not sure whether she understands, but she seems ok. (Tatzert, 2017, p. 120)

To inform the participant that the researcher was in contact with her next of kin, signaled safety. When the observations took place, the first author was in continuous contact to make sure that the participants were not uneasy. *"Mrs. Bacher, I am visiting you from time to time and I also sometimes record what we talk about. "She replies: "Yes, yes, that makes me happy". I am laughing and reply, that I am also happy, and thank her for her friendliness. (Tatzert, p. 121).*

Mr. Franz, another participant, could express himself verbally, when the first author (I=Interviewer) first met him.

I: *"Mr. Franz, do you enjoy getting visits?"*

F: *"With me at home?"*

I: *"I mean, here, in this place."*

F: *"Does not bother me."* (Tatzert, 2017, p. 121).

In his case, the next of kin were happy that he participated in the research because they felt that the social benefit would be important for his well-being.

In Mr. Peters case, another participant, his personality and communication style were important to know before starting the data collection. Mr. Peters was described by his daughter Simone as *"being too polite"* to say, if something was bothering him. Simone described some behavioral cues that indicated, when he was uneasy:

Simone explains to me that Mr. Peters, her father, is too polite to say something, if he is bothered. She describes that he gets fidgety, stops talking, looks at his watch and says goodbye, if he wants to end the conversation. (Tatzert, 2017, p. 12)

If a situation was unclear, asking and including the participants themselves was helpful. For example, Hella, the daughter of Mrs. Mischke, told the first author a lot about Mrs. Mischke's life and her biography while she was present. In this situation, it was not clear, whether it was acceptable for Mrs. Mischke that her daughter shared many details of her biography in her presence with me, as shown in the field notes excerpt:

I am a bit overwhelmed in the situation, because Hella starts to tell me the whole life-story of her mother, Mrs. Mischke. A dialogue unfolds, that makes me feel a little better, but I ask: „Mrs. Mischke, are you ok with this, when Hella tells me this about your life? Mrs. Mischke replies: Yes, yes, that is no problem at all. And I believe it in this situation.

2.10. Maintaining dignity

All participants who could express themselves verbally (even if not easy to understand without context) had so-called lucid moments, in which they could provide insight to their experiences in the long-term-care institution. Those lucid moments alternated with expressions of disorientation and temporal discontinuities. Sometimes we had the impression that the participants were ashamed of their situation and the fact that they lived in a nursing home. If this was really the case, was hard to differentiate.

Three of the four participants delivered meaningful explanations of their situation, often in contact with their next of kin. Some of these explanations were present in *"shared stories"*, an element we found in the narrative analysis meaning that stories that were in some way told by staff, next of kin but also by the participants themselves. The alternative explanatory models of why the participants were living in this institution could fulfil an important function in maintaining an acceptable identity and dignity and to avoid indignity.

One participant did not have this alternative explanation, which may be due to the fact that she had been living in institutions for several years in contrast to the other participants.

Mrs. Mischke for example, was explaining to the first author that she was in a health regimen because of her lung disease that needed special medical treatment. This was also true because the high-end treatment needed was certainly also justifying her living in a nursing home. The lung-disease was deemed more acceptable than her cognitive impairment. It was important to know this fact, to not shame Mrs. Mischke unintentionally. Nevertheless, it appeared that Mrs. Mischke was well aware that she was living in the nursing home and not going to go home, once, she said: *"I am here every day, just from time to time I go home, to see, if everything is in order"*. That was a statement that her daughter confirmed, she was taking her mother to her home every now and then to spend time with her (Tatzert, 2017, p. 220).

Mr. Peters described the dementia-ward where he was living quite differently. Once he described it as a day care center, where he came to eat, sometimes he described it as a school. Biographically this made sense because the town where the dementia-ward was located was the

same where he completed his apprenticeship as a young man. He was still clear about the fact that he had been living on the ward for more than a year. He gave the death of his wife and social aspects as reasons:

Mr. Peters: Yes, I go everywhere with the people, to the farming, and everywhere, but I don't work as much as I used to, don't I? Because I too, had a farm. But my wife died, the children moved out and, what should I do? Just be at home and stare at the cattle? This is stupid.

Me: So, that, is how you got here?

Mr. Peters: Yes, and then I came here and now I am already here for a year'' (Tatzert, 2017, p. 220).

Farming is an expression from his past, in his current situation, Mr. Peters refers to the occupational therapy group in the garden as his work and that was meaningful for him.

2.11. Ethical issues related to narrative data analysis

During the research process it became clear that the individual stories of the participants were so rich and the context so important to understand their experiences that the original plan to only do a thematic analysis was dropped. In addition, a narrative analysis was done to preserve the individual and contextual aspects. Gubrium and Holstein (2008) stress a form of analysis that captures social dimensions of narratives and call this a „narrative ethnography“. It became clear that the participants would be recognizable by staff and other persons who knew them, so this was discussed with the next of kin and the second author. It was deemed more important that the stories as results were preserved and also seen as a form of appreciative inquiry to present the persons more holistically. Including next of kin was crucial to understand symbolic meanings of actions and verbal and physical expressions, but also lead to challenges of untangling whose perspective is really captured in the situation. Other methodological aspects of the narrative analysis are published in detail elsewhere (Tatzert, 2019).

2.12. Reflexivity and vulnerability

Next to considering the challenges related to data collection and building relationships with participants, it is important to plan strategies of reflexivity and deal with vulnerability not only of the participants but also of the researcher. Using a research diary, a consistent peer group as well as close supervision by an experienced researcher with vulnerable groups (the second author) was helpful. To make the active role of the researcher transparent during the research process in data collection, analyzing and interpreting is important in qualitative research (Bailey & Jackson, 2003; Finlay, 2002). The abductive parts of the analysis and possible intertwining with their own biography and story should be made explicit. It was necessary to sharpen my awareness of projection and assumptions about ageing and disability, as already stated by Dewing (2009).

Spending time with the participants and establishing relationships with them and their families led to asking many questions for the first author, a white, able-bodied person in her thirties at that time: What would it be like to live with an advanced cognitive impairment in such an environment as a nursing home? What would be important, what would I be proud or ashamed of? In general, the first author experienced that the older adults with dementia that were observed had many resources and were often underestimated. The first author had to change her perspective to better understand the lifeworld in the nursing homes. Some of the next examples are written from the perspective of the first author.

In one situation, I was observing a person who could not walk anymore and was occasionally sitting on a chair with a physical restraint. The fieldnotes from that situation show that I had to change my perspective to get to a plausible interpretation.

To the right, Mrs. Quirmnach sits on a chair with a table that is fixated and restrains her from standing up. Next to her, Mrs. Staller is sitting. Her table is made from a transparent material and I am watching her, how she is moving her hands on the table, like she would wipe something or grasp something from the air, objects that I cannot see. I am asking myself, if she has visual hallucinations, if her cognitive status has worsened? Later, when I am changing position, to better be able to observe Mr. Peters, I become aware of the fact that there are reflecting lights on the transparent surface of the table, the light behind her chair is reflected and I understand now the wiping movements. These reflections are only visible from her perspective, or behind her.

In this situation, I wrote in the research diary that the interpretation of the behavior of Mrs. Quirmnach occurred mainly in the frame of her cognitive impairment. It was a seemingly meaningless behavior by a person with a disability. After changing the position and perspective, it was clear, that it was a rather meaningful behavior, the intention to clean the table.

2.13. Organizing reflexivity

It was important to organize different possibilities for reflexivity in advance. Communicative spaces for reflection can be seen as essential component in doing appreciative inquiry and are part of process ethics (Heintel, 2006). Some of the most useful measures taken were:

- Supervision by an experienced researcher in the field of long-term care and also with vulnerable groups (the second author)
- Having a peer-group with regular intervention for methodical and ethical questions as they are often intertwined in ethnographic-inspired research.
- Using interpretation-groups with researchers stemming from other disciplines for example taking part in an ethnopschoanalytic group interpretation
- Exchange with advocates living with dementia themselves at conferences and meetings

2.14. Dealing with changing skills and loss

As a researcher I was a witness in unpleasant, embarrassing and sometimes shameful situations. It was challenging to deal with changing health status, loss of skills and competences and the death of participants. Another participant's health decreased during the research process that stretched for over a year, so the first author checked with the staff and asked, whether it was deemed too stressful for him. Consequently, the visits and observations were adapted to shorter periods of time, but it was not deemed necessary to stop them. During moments of more lucidity, I told him about my role and that he helped with a study project and I used the language that he offered. Mr. Peters recognized me during the first period of the observations later, after six months, I realized that he misconceived me as one of his family members. In this case, I did not correct him nor lied to him, as proposed in communication techniques such as validation (Feil & de Klerk-Rubin, 2010).

Three of the participants died after the data collection, so while writing up the final results and checking in with the next of kin meant to be confronted with grief. Moreover, my own feelings of sadness as first researcher needed reflection and an organized room for exchange, because I had built relationships with all of them. To be part of the doctoral college of palliative care and organizational ethics was helpful in this regard, because the field offered a community of experts dealing with sensitive research, but also the experience of how to deal with grief and loss.

Biographical events also influence the research process. The fact that my grandmother developed a severe cognitive impairment during my research process and was moved to a nursing home brought some challenges. Being next of kin of a person who was part of the same group

that I researched required special attention. The experience in another institution as a next of kin myself was sometimes disturbing and lead to questioning the accuracy of my research. Thus, it was important to also face difficult situations and keep a research role without neither embellishing nor demonizing the field of long-term-care.

2.15. Acknowledging reciprocity

Vernooij-Dassen et al. (2011) stress the need for reciprocity of human beings and also adults living with dementia and the importance of creating opportunities for reciprocity as human-beings in a care-situation. Therefore, acknowledging reciprocity is an important issue in an observation situation – being aware of the fact that the participants are helping the researcher without putting stress on them.

Opportunities of reciprocity, of „giving “something back” and thus creating meaning in a social situation were appreciated by the participants. Sharing food – and also accepting food – is an easy practice for expressing gratitude. The first author was repeatedly offered food, and also brought some, like chocolate. Many older adults living with dementia in long-term-care have no easy access to buy pastries or chocolates and offer it, as you would in the role of a host. Also, some of the residents shared their life-experiences as “older adults” with the „young “researcher, such as advising to really “*enjoy life while you can.*” Pleasant situations derived from these moments: for example, at a carnival party at the dementia ward, the first author was dressed up as a bee with dangling tentacles. One of the residents was delighted and repeatedly complimented the researcher throughout an observation period of 3 h on her sweet look. Because of the common pattern of repetition due to the cognitive impairment, the researcher was receiving compliments at least 15 times.

2.16. Dealing with emotions and consternation

As a participating observant, the first author was exposed to multiple interesting and odd experiences in the research. I was bitten by a dog, was dancing at festivities with persons living in long-term-care, took part in a catholic mass even though I am not religious. There were lots of moving situations, positive ones as well as negative ones.

All the participants generated meaning from the fact that they were helping their next of kin by living in the nursing home and not having them to care for them permanently (anymore). For this, all of them, “*pulled themselves together*” to endure their life situation. Another participant, Mrs. Mischke, explicitly stated that she “*did not want to become a burden*” or to “*not fall into the hands of anyone*”. She expresses her dilemma of dealing with her loss of autonomy for her daughter’s sake – to endure the sometimes difficult situations in the dementia-ward and “*feeling trapped*” gave meaning to her, even if it was exhausting (Tatzer, 2017, p. 232).

Losing competencies and skills was met with grief and sadness. The participants were aware of their limitations in their autonomy at the closed dementia ward and expressed their sadness and frustrations. Receiving help was sometimes also a source of shame. We want to introduce a story by Mr. Peters, who the first author observed for over a year, the last year of his life. During this time, his health and cognitive abilities declined. His daughter, Simone, wanted to fetch him to visit another family member on another ward of the institution. Mr. Peters was dizzy, had trouble walking and recognizing people. After the short visit, Mr. Peters was irritated and aware of his changing condition. He was aware about how the staff and his daughter talked about him, his changing condition and his declining health.

Simone goes to the nurses to tell them about her father’s dizziness. She asks if he’d rather be in the room or in the lounge (in the back). He says, “To the back, or they’ll think I’m not normal.” “Who’s going to believe that?”, I ask. “The ones that sit inside with me. They all think I don’t know my way around anymore. (...) but what are you supposed to do?” he

continues. I ask while walking, “And ... is that unpleasant?”, Mr. Peters looks at me and says, “Yes.”

He continues, “Then they ask how it’s going, are you still healthy anyway. I say: Well, of course, I know you all. Just because they ... Yes, now that they are so outside ... picked down. Then I say: Then take me down if it doesn’t suit you. It’s a shame.”. “A pity?”, I ask, “Today you are not satisfied, Mr. Peters?” “No, what can you do. You have to take it as it comes. Because ... what can I do.” He turns to his daughter and says, “What new pair of jeans do you have, Simone?” She tells him that the doctor will come to see him after lunch. I stay a little longer because I want to see how Mr. Peters reacts after all this contact. He says: “It’s a shame, you wouldn’t believe it, but ... I’m pulling myself together anyway, but it’s not going my way, sad”. (Tatzer, 2017, p. 231).

To understand this statement, “*to the back, or they’ll think I am not normal*” it is important to know that the dementia ward had two areas for dining and eating meals, one in the front, where mostly older adults who needed help with eating were sitting, and in the back, where the residents who were able to eat in a hygienic manner and who followed social conventions and rules were seated. The unspoken rule in the organization was that only the persons who still functioned well with activities like eating could eat in the back. Retrospectively, it becomes clear that Mr. Peters feared to be moved to the other room, therefore meaning that his status in the institution would change from a person who is still able to eat by himself to someone who cannot do that anymore. He also „others“ the persons who need more help as “*not normal*” This fortifies Ericsson et al.’s (2011) argument to assume that older adults with dementia are often aware of their situation, and we would like to add, even in the moderate and severe phases of a neuro-cognitive disorder.

3. Discussion and conclusion

In this article, we presented and discussed ethical issues in qualitative research with people with advanced dementia. Ethical concerns arise along the research process and demand multiple platforms for the researchers to reflect their own roles. Decisions are necessary in every step of doing research with people with dementia. Research is challenged by the tensions between providing transparent information, the risk to harm, and the chance to empower persons with dementia.

Using a model of process consent that already has been established in the research with people with dementia (Dewing, 2008) as well as using multiple methods to organize reflexivity, following the known principles are useful in including persons with moderate and severe dementia in a research project. Including next of kin and staff was necessary to ensure moral sensitivity and assent as well as consent. Ethnographically inspired designs combined with a complex narrative analysis were especially applicable for this purpose (Tatzer, 2019). Including next of kin in the narrative approach was a good way to “translate” the meaning of activities and links to biographical facts that would not have been understood otherwise.

Hydén (2013) stresses the function of “scaffolding” of the next of kin, who are able to fill narrative gaps in a dialogue together with a person with expressive speech disorder that is common among older adults living with advanced dementia in long-term care. Collaborative and embodied aspects of storytelling are thus a resource. Unfortunately, people living with dementia without next of kin could not be included due to stipulations by the ethical committee, yet. This particularly vulnerable group should get more attention in research.

Basically, it is necessary to build up respectful and reciprocal relationships throughout the course of the research (McKillop & Wilkinson, 2004). Acknowledging and seizing opportunities for reciprocity is another important aspect in doing qualitative research and it could be fruitful in the further development of an “anthropology of the good” as discussed by Robbins (2013) to encompass negative stereotypes of what it means to live with cognitive impairments in long-term-care as an older

adult.

Kowe et al. (2022) found out that participatory research has beneficial and critical impact on the researchers. An increased understanding of people with dementia and wider theoretical knowledge improve one's competences when working with people with dementia. Challenges and critical aspects concern the additional effort and time and the difficulty of establishing a balanced relationship with persons with dementia. These findings support the importance of informed consent as well as the careful guidance of processes and communication – verbal and non-verbal – that is needed to keep good contact with the persons with dementia. The underlying concept of a relational anthropology is sensitive to interdependencies of people, vulnerability and emotional as well as embodied aspects of decision making (Gómez-Virseda et al., 2020). Care ethics contribute fundamentally to these relational aspects of research with people with dementia (Denier & Gastmans, 2022).

One essence of the empirical experiences and theoretical reflections concerning ethical issues in the research with people with advanced dementia is: Even with severe impairments, it is possible to apply a qualitative research design and get to a deep level of interpretation.

CRedit authorship contribution statement

Verena C. Tatzer: Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft. **Elisabeth Reitingner:** Resources, Supervision, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- Alsaker, S., Bongaardt, R., & Josephsson, S. (2009). Studying narrative-in-action in women with chronic rheumatic conditions. *Qualitative Health Research*, 19(8), 1154–1161. <https://doi.org/10.1177/1049732309341478>
- Alzheimer's Association. (2014). Treatment for Alzheimer's disease. http://www.alz.org/alzheimers_disease_treatments.asp. (Accessed 17 November 2014).
- Alzheimer Europe. (2011). *The ethics of dementia research*. Alzheimer Europe.
- Alzheimer Europe. (2017). Dementia as a disability? Implications for ethics, policy and practice. https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_ethics_report_2017.pdf.
- Auer, S. R., Hofler, M., Linsmayer, E., Berankova, A., Prieschl, D., Ratajczak, P., Steffl, M., & Holmerova, I. (2018). Cross-sectional study of prevalence of dementia, behavioural symptoms, mobility, pain and other health parameters in nursing homes in Austria and the Czech republic: Results from the DEMDATA project. *BMC Geriatrics*, 18(1), 178. <https://doi.org/10.1186/s12877-018-0870-8>
- Bailey, D. M., & Jackson, J. M. (2003). Qualitative data analysis: Challenges and dilemmas related to theory and method. *American Journal of Occupational Therapy*, 57(1).
- Black, B. S., Rabins, P. V., Sugarman, J., & Karlawish, J. H. (2010). Seeking assent and respecting dissent in dementia research. *American Journal of Geriatric Psychiatry*, 18(1), 77–85.
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics*, 4(2), 59–64.
- Denier, Y., & Gastmans, Ch. (2022). Relational autonomy, vulnerability and embodied dignity as normative foundations of dignified dementia care. *Journal of Medical Ethics December 2022*, 48(12), 968–969.
- Ericsson, I., Hellström, I., & Kjellström, S. (2011). Sliding interactions: An ethnography about how persons with dementia interact in housing with care for the elderly. *Dementia*, 10(4), 523–538. <https://doi.org/10.1177/1471301211409376>
- Feil, N., & de Klerk-Rubin, V. (2010). *Validation: Ein weg zum verständnis verwirrter alter menschen*. Reinhardt.
- Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209–230.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189–198.
- Gómez-Virseda, C., de Maeseneer, Y., & Gastmans, C. (2020). Relational autonomy in end-of-life care ethics: A contextualized approach to real-life complexities. *BMC Medical Ethics*, 21(1), 50. <https://doi.org/10.1186/s12910-020-00495-1>
- Gubrium, J. F., & Holstein, J. A. (2008). Narrative ethnography. In S. N. Hesse-Biber, & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 241–263). Guilford Press.
- Hammerley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3 ed.). Routledge.
- Harmer, B. J., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health*, 12(5), 548–558.
- Heggestad, A. K., Nortvedt, P., & Slettebø, Å. (2013). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, 20(1), 30–40.
- Heintzel, P. (2006). Das klagenerfüllende prozessethische beratungsmodell. In P. Heintzel, L. Kraimer, & M. Ukowitz (Eds.), *Beratung und Ethik. Praxis, Modelle Dimensionen*. (pp. 196–243). Leutner Verlag.
- Hydén, L. C. (2013). Storytelling in dementia: Embodiment as a resource. *Dementia*, 12(3), 359–367.
- Juraszovich, B., Sax, G., Rappold, E., Pfabigan, D., & Stewig, F.. Dementiastrategie Gut Leben mit Demenz. <https://www.demenzstrategie.at/>.
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Kitwood, & Bredin, K. (1992). Towards a theory of dementia care: Personhood and Well-being. *Ageing and Society*, 12, 269–287.
- Kojer, M., & Heimerl, K. (2009). Palliative Care ist ein Zugang für hochbetagte Menschen - ein erweiterter Blick auf die WHO-Definition von Palliative Care [Palliative Care is an Approach for Aged Persons - an Enhanced View to the WHO Definition of Palliative Care]. *Palliativmedizin*, 10, 154–161. <https://doi.org/10.1055/s-0029-1220406>, 03.
- Kowe, A., Panjaitan, H., Klein, O. A., Boccardi, M., Roes, M., Teupen, S., & Teipel, S. (2022). The impact of participatory dementia research on researchers: A systematic review. *Dementia*, 21(3), 1012–1031. <https://doi.org/10.1177/14713012211067020>
- Leibing, A. (2006). Divided gazes. Alzheimer's disease, the person within, and death in live. In A. Leibing, & L. Cohen (Eds.), *Thinking about dementia. Culture, loss and the anthropology of senility*. (pp. 240–269). Rutgers University Press.
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., ... Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the lancet commission. *The Lancet*. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
- Lock, M. M. (2013). *The alzheimer conundrum: Entanglements of dementia and aging*. Princeton University Press.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge University Press.
- McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself!: Advice to researchers from someone with dementia on being interviewed. *Dementia*, 3(2), 117–125. <https://doi.org/10.1177/1471301204042332>
- Müller, A. T., & Walter, M. (2013). Die vergessene Dimension in der stationären Altenhilfe. Implikationen des Übereinkommens über die Rechte von Menschen mit Behinderungen für demenzerkrankte Personen in Alten- und Pflegeheimen. *Recht der Medizin*, 3, 84–92.
- Nygard, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections [Research Support, Non-U.S. Gov't]. *Scandinavian Journal of Occupational Therapy*, 13(2), 101–112.
- Perrin, T., May, H., & Anderson, E. (2008). *Wellbeing in dementia*. Churchill Livingstone Elsevier.
- Pool, J. (2008). *The pool activity level (PAL) instrument for occupational profiling: A practical resource for carers of people with cognitive impairment*. Jessica Kingsley Publishers.
- PROMENZ. (2023). In *Website of PROMENZ*. Self Help Group. <https://www.promenz.at/>.
- Reitingner, E., & Heimerl, K. (2014). Ethics and gender issues in palliative care in nursing homes: An Austrian participatory research project. *International Journal of Older People Nursing*, 9(2), 131–139.
- Reitingner, E., Pichler, B., Egger, B., Knoll, B., Hofleitner, B., Plunger, P., & Heimerl, K. (2018). Research with people with dementia—ethical reflections on qualitative research praxis on mobility in public space. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 19(3). <https://doi.org/10.17169/fqs-19.3.3152>
- Ricœur, P., Blamey, K., & Thompson, J. B. (2008). *From text to action essays in hermeneutics, II. Continuum*.
- Robbins, J. (2013). Beyond the suffering subject: Toward an anthropology of the good. *The Journal of the Royal Anthropological Institute*, 19(3), 447–462. <https://doi.org/10.1111/1467-9655.12044>
- Röse, K. M. (2016). Ich bin nicht entmündigt! Ethische Reflexionen in der ergotherapeutischen Forschung mit von Demenz betroffenen Personen in der Institution Pflegeheim. *Ergoscience*, 11(2), 68–76.
- Schockenhoff, E., & Wetzstein, V. (2005). Relationale Anthropologie—ethische Herausforderungen bei der Betreuung von demenzen Menschen. *Zeitschrift für Gerontologie und Geriatrie*, 38(4), 262–267. <https://doi.org/10.1007/s00391-005-0321-y>
- Scottish Dementia Working Group Research Sub-Group, U. K. (2014). Core principles for involving people with dementia in research: Innovative practice. *Dementia*, 13(5), 680–685.
- Snowdon, D. (2001). *Aging with grace: What the nun study teaches us about leading longer, healthier, and more meaningful lives*. Bantam Books.
- Statistik Austria. (2022). *Bevölkerung nach Alter/Geschlecht*. <https://www.statistik.at/statistiken/bevoelkerung-und-soziales/bevoelkerungsstand/bevoelkerung-nach-alter/geschlecht>.
- Tatzer, V. C. (2017). Das ist irgendwie mein ding: Aktivität und partizipation aus sicht von Menschen mit mittelschwerer und schwerer demenz in der Langzeitpflege: Eine narrative studie. In [This somehow my thing." Activity and Participation of People with moderate and severe Dementia living in Long-term Care - a narrative Study.] [PhD Thesis.

- Klagenfurt, Austria: Alpen Adria University Klagenfurt]. <https://permalink.obvsg.at/AC12609329>.
- Tatzert, V. C. (2019). Narratives-in-action of people with moderate to severe dementia in long-term care: Understanding the link between occupation and identity. *Journal of Occupational Science*, 26(2), 245–257. <https://doi.org/10.1080/14427591.2019.1600159>
- Tatzert, V. C., Alsaker, S., Satink, T., & Reitingert, E. (in press). Narrative Forschung mit Menschen mit fortgeschrittener Demenz in der Langzeitpflege. Methodologische und pragmatische Aspekte. In S. Teupen, J. Serbser-Koal, F. L. Uribe, C. Dinand, & M. Roes (Eds.), *Qualitative Forschung mit Menschen mit Demenz. Beiträge aus dem MethodenForum Witten 2021* Beltz Juventa.
- Thoft, D. S., Ward, A., & Youell, J. (2021). Journey of ethics - conducting collaborative research with people with dementia. *Dementia*, 20(3), 1005–1024. <https://doi.org/10.1177/1471301220919887>
- UN. (2006). *Übereinkommen über die Rechte von Menschen mit Behinderungen*. Retrieved 30 09 from http://www.parlament.gv.at/PAKT/VHG/XXIII/I/I_00564/imfname_113868.pdf.
- Vernooij-Dassen, M., Leatherman, S., & Olde Rikkert, M. G. (2011). Quality of care in frail older people: The fragile balance between receiving and giving. *BMJ Online*, 342 (14). <https://doi.org/10.1136/bmj.d403>
- Wenborn, J., Challis, D., Pool, J., Burgess, J., Elliott, N., & Orrell, M. (2008). Assessing the validity and reliability of the Pool Activity Level (PAL) Checklist for use with older people with dementia. *Aging & Mental Health*, 12(2), 202–211.
- Weyerer, S., Schäufele, M., & Hendlmeier, I. (2005). Besondere und traditionelle stationäre Betreuung demenzkranker Menschen im Vergleich. *Zeitschrift für Gerontologie und Geriatrie*, 38(2), 85–94. <https://doi.org/10.1007/s00391-005-0293-y>
- Wissmann, P., Gronemeyer, R., & Klie, T. (2008). *Demenz und Zivilgesellschaft - eine Streitschrift*. Mabuse-Verl.
- Wood, W. (2005). Activity situations on an Alzheimer's disease special care unit and resident environmental interaction, time use, and affect. *American Journal of Alzheimer's Disease and Other Dementias*, 20(2), 105–118.