

(Engelsk) Research involving older persons with dementia; ethical considerations

(Norsk) Forskning som involverer eldre personer med demenssykdom; etisk ettertanke

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1) Abstract

In a research project where ten persons with dementia and their close families participated, the researcher explored how older people suffering from dementia could live meaningful lives.

The aim of this article is to discuss some ethical considerations when persons with dementia are included in research, and to emphasize how to ensure their integrity and dignity. The qualitative research project involved fieldwork and interviews. Martinsen's ontological situational ethics gave the basis for the discussion of the results. Affected memory and language contributed to vulnerability. Relatives contributed to trust and made it possible for persons to convey narratives about what had been meaningful to them throughout their lives. Individual considerations promoted dignity and integrity. It was necessary to apply discretion

and have knowledge about dementia and communication to make the best of the ethical challenges that continuously arose.

Keywords: dementia, dignity, discretion, integrity, research ethics.

1) Introduction

Nearly 80 000 people suffer from dementia in Norway today, and approximately 10 000 new cases are discovered annually (1). According to World Health Organization (WHO) (2) around 50 million people have dementia worldwide, and there are nearly 10 million new cases annually. In order to provide optimal care and nursing, we need the voices of the affected persons to understand their experiences and what is essential to them. Traditionally persons with dementia has been excluded from research, mainly due to underestimation of their capability to participate (3).

In a recent study the overall focus was to explore how older persons suffering from the middle to late stage of dementia can experience a meaningful life when living in a nursing home (4). The experience was that it was ethically challenging to safeguard dignity and integrity for the persons during research. The researcher felt continuous unrest during the research process. Unrest might be a trigger to increase awareness in different situations during a research project and makes the researcher perform the best judgement to safeguard the participants (5).

2) Previous research

Previous research including persons with dementia has addressed consent and moral sensitivity through the entire research process (6-11). A review study (12) on ethical challenges in dementia research where 29 papers were included, concluded that there seems to be a lack of agreement on ethical standards concerning recruitment and the issues of risk in research. Another study (13) has analysed research ethics in 66 empirical studies involving older people in nursing homes. They conclude that fragility and vulnerability as challenges to

ethical research need more discussion. Researchers (14) have critically assessed different approaches to promoting safe participation of persons with dementia in qualitative research in a literature review. Evidence suggests that participation can contribute to well-being and social inclusion, as further research (15) also has highlighted.

2) Theoretical perspectives

Persons with dementia are considered a particularly vulnerable group (16, 17). Wogn-Henriksen (6) has studied how persons suffering from Alzheimer's disease experienced living with the early stage of this condition. They expressed uncertainty, discomfort, anxiety and concern. Wogn-Henriksen (6) interpreted this as an experienced vulnerability which she discusses as an experience of nakedness and lack of ability of self-protection; a fragile way of living, exposed to a wealth of unmanageable threats. The person feels small, fragile and powerless. Each individual who participated in the research project on which this article is based, might also have felt vulnerable. Vulnerability can be attributed to symptoms related to dementia. It affects memory, thinking, orientation, comprehension, learning capacity, language and judgement (2).

Ethical considerations are associated with ethical challenges and assessment of how the researcher can safeguard ethical responsibility and support wellbeing for the participant during research (16). It might be an ethical challenge if the research considerations do not correspond with the ethical obligations the researcher has towards each participant (18). Focus was on a meaningful life in the nursing home (4), and the researcher noticed that it was through the social interactions with the participants that their vulnerability and the ethical challenges became visible. Martinsen (19-21) emphasizes that ethics – arguments of right and

wrong, shameful or good – lives in the human interactions themselves. According to Martinsen the basis of ethics is to dare to approach each other, based on confidence that the other wants to do you well. In confidence, we are placed at the hands of each other in a vulnerable, mutual exposure. The individual showing me confidence, urges me to take care of him, and not exploit his exposure, and thereby inflict dishonour upon him. Martinsen (20, 21) links ethics to an ontological situational ethics. As embodied subjects, we are in the situations we are immersed and incorporated into, in a world of basic conditions. It is an ontological, fundamental life-condition that we as vulnerable and dependent human beings, need each other. Trust, open speech, compassion, mercy and hope – are fundamental to our existence (20, 21). The relationships we enter into, always have some typical features. At the same time, the situation is also singular, unique (20).

According to Martinsen, phenomenology can be understood as work where one continuously has to contemplate one's value-based and theoretical conditions, at the same time as one describes and interprets a field (20). Phenomenology interprets basic ethics – the ethics the person him or herself is involved in (20). To interpret life in human relations is at the same time to show life's positive opportunities, often in conflict with what breaks it down (20). In every research project careful assessment of risks and burden in comparison with benefits to the subject or others should be carried out (16). Contemplation, description and interpretation can help to assess risks, burden and benefits in research.

Vulnerability and dependency are described as fundamental to our entire being (21).

Vulnerability opens life to us and is a precondition for our ability to experience other person's suffering, and encourages us to take care of each other's integrity (21). Martinsen (22)

interprets integrity as an experienced vulnerable life context which implies limits for interventions. It appeals to the other for attentiveness, as a will to protect what is vulnerable, if needed, but it is a protection meant to maintain the other as whole and undamaged. Dignity is related to promoting respect for all human beings and to protect their health and rights (16).

Based on experiences from the research project (4), research and theoretical considerations regarding ethics, the aim of this article is to consider some ethical challenges to safeguarding the dignity and integrity of persons with dementia when doing research on them. The research question is: How can the researcher safeguard dignity and integrity during a research project where persons with dementia are participating?

1) Research methods and participants

2) Research methods

The research was based on a qualitative design, where data were gathered through fieldwork and interviews in nursing homes in a rural and an urban community. Ten persons in their 80s and 90s, and their next of kin took part. The fieldwork lasted for seven months and provided opportunity to become acquainted with the daily routines, and to develop confidence with the participants through encounters. Conversations with the participants about daily life and their activities, interests and habits throughout life were carried out. The researcher was an experienced nurse with relevant education beyond qualification. This implied having knowledge about dementia, how to communicate with a person with language problems and answer simple questions about health. After some time, a certain level of confidence was established, and the interviews were carried out in the nursing homes. The relatives of each

person were invited to participate in the interview. Close relatives participated in four of eight interviews. The interviews were transcribed verbatim.

2) Participants

A head nurse recruited the participants. The inclusion criterion was that the persons should suffer from dementia; they should be able to participate in a conversation, and to talk about what had been important to them during their lifespan. Furthermore, the participants should have close relatives who could provide an informed consent on their behalf, and who were willing to take part in the research. All the relatives signed the consent document. Two of ten participants signed the consent document themselves. Eight patients gave their assent to either their relatives or the recruiting person before the project started. All participants expressed an assent at each encounter with the researcher after being informed about the research project. The patients had complex clinical pictures, and extensive nursing care needs. Based on a total evaluation of the person's health conditions, two interviews were cancelled. The relatives participated in interviews about the participant's previous life early in the research period. This provided some familiarity between the researcher and the participants, which was helpful in the conversations. The interviews were conducted as a two-way conversation, as this made the participants most comfortable.

2) Data analysis

The analysis of the data was inspired by qualitative content analysis (QCA) (23) (Table 1). It was particularly focused on the ethical considerations through the whole text. QCA can help reveal the latent meaning in the chosen text (23). Meaning units – constellations of statements relating to the same meaning – were identified across the text, condensed, and coded with

terms close to the text. The themes and the sub-themes that constituted the findings, were formulated through re-discussing the extracts of the data material against the researcher's experiences through the research process, the phenomenological approach and the research question.

Table 1 Examples from the content analysis of the interviews with persons with dementia in nursing homes in northern Norway. Ethical considerations concerning protection of dignity and integrity constitutes the main theme.

Meaning unit	Condensed meaning unit	Code	Main theme	Sub-Theme
«This was not exactly the right time of the day, as.... It takes some time before I wake up...»	This was not the right time of the day.	The right time of the day	Protecting dignity and integrity when one is living with serious disease	Feeling inadequate
«The first thing I will do when I come home is to make thin pastry served with butter, cinnamon and sugar, because I have such an urge for it»	I will make thin pastry when I come home because I like it so much.	Joy of life related to values	Protecting dignity and integrity when one is living with serious disease	Radiate hope and joy
“I have become so ill that I cannot pay attention anymore. I can fade away any moment. I am already half dead. I don't know where I am, if I am on earth or in heaven. It is a difficult situation.”	It is a difficult situation that I have become so ill that I am already half dead.	Being seriously ill	Protecting dignity and integrity when one is living with serious disease	Being concerned about the future

1) Ethical considerations

The project was approved by the Regional Committees for Medical and Health Research Ethics (REC) and Norwegian Social Sciences Data Service (NSD) before onset. In the information and consent document the participants were informed that the data would be retained beyond the project period as it was assumed that it could provide basis for further

publication within the same framework as in the main project. Focusing on ethical considerations is considered as publishing within the same framework, as this is of utter significance in every research project.

1) Results – situations that were ethically challenging

Experiences of consent, involving of close relations, finding the right room, time of day and the best way of introducing the recorder, will be presented. Also, some aspects of the encounters and considerations related to the participants were particularly vulnerable.

2) Making an effort to secure consent – involving close relations

At each meeting the researcher gave an overview introduction of the research project and told the participants that they were part of the presented project. During the dialogue, the researcher expressed herself as simply as possible, and underlined that whatever they wanted to say, was valuable and important. Generally, the researcher got limited direct feedback on her information about the research, except that they willingly told her about their lives. It was therefore sometimes complicated to assess whether the research considerations corresponded with the ethical obligations towards each participant.

To become acquainted with and develop trust from the persons with dementia, it was essential to acquire confidence from the relatives. They should feel confident that the researcher could protect their spouse, father or mother's self-confidence. The balance between inclusion of relatives and relating to the participant as a unique individual was ethically challenging. The relatives that participated in the interviews added details from the person's life, whenever

these had been forgotten, or when he or she was too tired to find the words. In doing this, they contributed to a more complete recollection of the past. The interview with Marie shows an example of this:

Marie: I had cows. Was it two cows we had at home? Relative: We had both two and three.... Marie: I think it was that, yes. I don't remember. Relative: And hens and a pig. Marie: The hens. My husband used to say that I shouldn't let the hens out, because he was afraid of being hit in the head by them. Oh, you know, I laughed many times, but I didn't dare to laugh while he was watching.

2) Finding the right room, time of day and the best way of introducing the recorder

Challenges involved choosing a suitable room, time of the day to perform the interview, as well as how to introduce the tape-recorder. Three of eight interviews were carried out in the evening because it was suitable for the relatives to participate then. The person with dementia appeared to be more tired in the evening than during the daytime. Both the relative and the person her or himself assured the researcher that it was okay to perform the interview. The participants were experienced as more talkative in the daytime. The five other interviews were completed in daytime. The researcher attempted to choose a time of day when the participant felt in the best shape.

Kristian, with whom the researcher talked a lot, stated his insecurity at the start of the interview. He said: "This was not exactly the right time of the day, as... It takes some time before I wake up...". When he was assured that he was perceived as an articulate and aware person both in the morning and the afternoon, he replied: "Well, well just barely...". The interview lasted for about two hours. He repeated himself on some occasions, but it seemed like he told from his life with pleasure.

Seven of eight interviews were performed in the person's personal room, and one in the corner of the living room. During the interview in the living room some persons passed through several times, without staying there. One of the interviews in the participant's bedroom lasted approximately 20 minutes. It was terminated by the person getting up and leaving the room. He said: "I liked to talk to people. Now I will go to bed. I will go out now." It turned out that this person had been socially extrovert and talkative when meeting other people in his local community. The dialogue with him went much more smoothly when held in the common sitting room of the nursing home, with more people present.

The use of a tape-recorder was specified in the information and consent document and accepted by the relatives. None of the participants had ever seen such a small tape-recorder, and some of them looked at it with scepticism. It was explained as well as possible, that the recording was essential in remembering the important points brought forward in the interview. However, it didn't seem that this clarification was entirely satisfactory for the older persons, mainly because of the uncertainty about how much they were able to understand.

2) Making the encounters beneficial to the participants

The researcher met with one or more persons simultaneously. They were singing, reading the newspaper or discussing daily subjects of general interest. To become acquainted with each person, the researcher kept a polite and open-minded attitude, small talking about the weather and whatever was on their minds. The meetings were deliberately kept informal and relaxed, putting as little pressure on the persons as possible. Marie said, "The first thing I will do when I come home is to make thin pastry served with butter, cinnamon and sugar, because I have such an urge for it." The researcher asked: "Would you have liked to have a place here in the

nursing home where you could make this pastry?” She smiled and replied; “Yes of course...” Because of her current condition, Marie would have needed assistance if she had made pastry in the nursing home. Talking about these values has no limitation.

2) Considerations when the participant is particularly vulnerable

It was ethically challenging to promote hope and wellbeing during the encounters, while keeping an open communication around that their participation in the research project was related to the fact that they had dementia. The relatives of Kristian had underlined how participating in the research project was beneficial to his wellbeing: “The fact that he is given the opportunity to tell you about his life, not necessarily correct to the smallest detail, I think contributes to his self-confidence. That is far more important than providing him with a reality check.”

During the interviews several of the participants tried to hide their loss of memory and their difficulties in expressing themselves orally. When they no longer managed to take part in the conversation, compensation by using humour or expressions like “That was then, but not now” were often applied. Some of the relatives expressed that the family had not experienced humour applied this way by the person before.

It was challenging to decide how to talk about the consequences of dementia that the person experienced. The researcher decided not to bring the subject up during the encounters, unless the persons did so themselves, although the disease was an inclusion criterion. An example was that if the person was asked to go for a walk outside their residential department of the nursing home, most of them would turn the invitation down referring to inability to find the

way back. When the researcher conveyed her understanding of their challenges and told that she was responsible for bringing them back safely, several of the persons accepted a walk outside their familiar area.

During another interview that took place in the person's room, the participant was nearly completely silent. It was uncertain whether he wanted to perform the interview. There was doubt as to whether the interview should continue, however at the same time it was important that he did not feel rejected. It turned out that he was seriously ill. Anton talked about his illness and the fact that he would soon die: "I have become so ill that I cannot pay attention anymore. I can fade away any moment. I am already half dead. I don't know where I am, if I am on earth or in heaven. It is a difficult situation." He spoke about what was closest to his mind here and now. It was the thought of the approaching death and not so much his former life that gave meaning to him.

1) Discussion – promoting dignity and integrity during research

The results emphasize that the persons with dementia are vulnerable and that being participants in research projects might be a risk to their integrity. The limits of intervention could be challenging to determine when the participant was polite and verbally expressed that it was okay to speak to the researcher. It was important to be attentive in order to protect the participant as whole and undamaged.

Persons with dementia remember to varying degrees what they have done earlier in their lives (1, 2). Conversation about previous activities, interests, habits and values may remind them of

what has been lost. This can be exhausting. The person often moves between remembering and lacking memory. The researcher must use discretion (19) to distinguish between what the patient is capable of, what gives an experience of loss, and what the patient can achieve with help. Martinsen (19) states that performing ethical discretion requires awareness, attention, insight, imagination and involvement to optimise assessment and interactions for and with the persons. Expedient use of discretion might provide an opportunity for ethical considerations (21).

It was important to find the right time of the day, understanding when the participant was too tired to conduct a conversation and how long the different encounters should last. The room where we met, was also of significance. Cooperation with family members was important. If the researcher succeeds in the use of discretion, the participants can experience benefits by participating in research. If not, the experience might be a burden for the person, and that might be a risk to their dignity.

2) Vulnerable persons as participants in research – benefits and risks

WHO contemplates dementia as a deeply stigmatising condition (2). It has been described how persons suffering from the disease feel they are frequently underestimated by their surroundings, and that this limits their ability to apply unaffected skills (6, 19, 24). Martinsen (21) maintains that shame can occur based on insults, one has to have a feeling of shame not to offend and shame is connected to reservation. The researcher had to act with support and acceptance and ensured that the encounters became as undemanding as possible. This is in line with a study that reported episodes of lucidity in persons suffering from advanced dementia, when they were met with support and acceptance in undemanding situations (25).

That was particularly evident in situations involving close relatives and familiar conversation partners, and when the participants were allowed to choose the conversation subject.

The opportunity for the participants of getting to know the researcher, might have provided a feeling of personal acceptance. Hellström, et al. (10) discusses personal acceptance as an advantage of participating in research projects. The researcher was challenged to safeguard the cautious trust the persons showed by allowing an unfamiliar person to sit down by their side. This cautious trust can be understood as some kind of reservation, we do not let ourselves go in total trust (26). Løgstrup (26) also discusses how the conventions in social life has a protective purpose: Common courtesy contributed to the encounters with the persons becoming as smooth and easy as possible, revealing no obvious uncomfortable mental exposures.

To varying degrees the persons repeated, forgot and spoke incoherently because of their language problems. At their best performance, they told about what they felt was relevant and meaningful from their lifespan. There is always a limited access to parts of the lifespan that the researcher is allowed in on, regardless of dementia or not. According to Martinsen (20) a narrative puts the history of one's life in the centre, it will never be told in a neutral way, and it holds a moral which we must relate to. The storyteller passes on something which has made an impression on him or her, and the listener must learn from what is told. As long as the researcher managed to make the situation as undemanding as possible, meet the participants with respect and support, they managed to tell stories from their life. The participants were allowed to talk without interruptions and the researcher had to answer different questions, also of private character, for instance about her own family. The participants seemed to feel

comfortable when the names of their close relatives and values that their relatives or themselves had told about, were mentioned and acknowledged.

It is considered that the conversation about local food tradition was an expression of Marie allowing herself to maintain hope, related to a future that reflected her values. However, she was also aware of her limitations. It seemed as a sense of hope, fundamental to her existence (20, 21), but at the same time realisation of limitations and personal fragility became evident when discussing wishes for the future. Rustøen et al. (27) illuminate hope as an important strategy to maintain quality of life through serious illness. The ethical responsibility of the researcher was to be attentive to the importance of hope for the person. Through communicated confirmation and acknowledgement, the participant could experience acceptance and benefit.

Sometimes it was difficult for the participants to understand what was going on during the research project. Dooley et al. (28) shows that persons suffering from dementia often try to disguise their lack of understanding of the ongoing conversation by applying humour. It was important to support the participant's attempts to manage the situation, for instance by a simple acknowledging sentence such as: "Yes, you are right". The cognitive deficiency may also have limited their ability to put the information about the project together in an understandable whole. Probably most of the participants understood that the researcher was interested in them as individual persons, but their understanding of the implications of the research might have been more limited.

It is difficult to assess whether all the participants were fully aware of the consequences of their disease. Likely they were aware of their fragility, but they did not particularly communicate it verbally. General phrases and humour had a protective effect. It was the researcher's responsibility to strengthen this protection by acknowledging their way of handling their personal insufficiency. In cases when the conversation died out, asking further questions was avoided. The researcher would keep talking, allowing the participant to catch up with the conversation when he or she chose to.

2) The future, to a lesser extent the past, is of significance

In previous conversations Anton had told the researcher about his values through his life. In the interview he focused mostly on his future concern. This was at first thought of as a breach of the foundation for the research. Martinsen relates participating attention to see with "the eye of the heart" which makes the other person appear important (19). It was by participating attentively that it was possible to understand what was at stake for Anton. He spoke of what was meaningful to him here and now as he had a critical heart condition that gave him serious symptoms night and day. His speech about his coming death could also be a signal that he needed to leave the project. It could be an expression of frustration, discomfort or taking a non-responsive and passive attitude, which are indicators of stress (17). As the researcher was only superficially acquainted with the participants, these observations were found somewhat challenging. The participants might have experienced discomfort without expressing it directly. It might also have been a benefit for Anton to be allowed to tell someone about his thoughts regarding his serious disease and imminent death.

2) Being connected to close relations

The participation of the family strengthened the person's self-confidence and ability to tell about his or her lifespan. It seemed that the existence of the participants was enhanced by the relationship with their close family. Trust, open speech, compassion, mercy and hope as described by Martinsen (20, 21) emerged through their narratives. Family members have an important role as spokespersons and assistants to help improve memory when persons with dementia participate in research (8).

The researcher also had to be aware of the possibility that the presence of the family members may have led to the participant being insufficiently heard. When a participant spoke less, this might have been because they were used to the relatives speaking on their behalf, it could be a result of exhaustion or that they were unable to find the proper words. The risk was losing track of what had been and still was important to the persons themselves. It was important to discreetly encourage the person to speak for himself. Ways to accomplish this involved turning directly to the participant with clarifications, questions and comments during the interview.

During the interviews the relatives contributed to dignity and respect, by helping the persons with dementia to recollect different memories from their past. Hydén (29) describes the case when a close relative or a care person speaks on behalf of a person during a conversation as "vicarious voices". When persons with dementia are given the opportunity to bring forth narratives from their own lives with the help of relatives, this could contribute to maintain identity and a sense of self (29). Participation in research can be beneficial when family involvement is appreciated and exploited by letting the family member enter the necessary keywords so that the participant can present their narratives. The researcher had been

introduced to each person's lifespan by their relatives in advance and was therefore able to contribute as a "vicarious voice" similar to the relatives. The researcher could have instructed the relatives to make use of the principle of "vicarious voice" before the interview started.

2) Suitable rooms, time of the day and technical equipment

Suitable rooms in the nursing home for interviews were not always available, or the chosen room was inconvenient for the person. It is important to do the interview in surroundings familiar to and comfortable for the participant (30). The physical interview locations obviously had different meaning to us, and it took the researcher some time to realise the meaning of the room for each of the participants. According to Martinsen (21) the person will be embodied in the room with all his senses where something is recognizable and linked to his life experiences. The room is significant and affects us both with joy, sorrow, hopes and lacks. Optimal choice of location of each interview requires knowledge of the person. However, the choice of room was mainly dictated by the available infrastructure of the nursing home.

The researcher had to be attentive and show the persons that she had sufficient time during each encounter. It is important to find the person where he is in his experience of time, and let his appeal to be taken care of, determine the bustle (21). Disease, life experience and daily condition influenced the person's mood and their ability to communicate which meeting time was best for them. Being present in time may create space for mutual sharing of experiences (21, 22). There were many conditions that had to be taken into consideration. Some of the relatives only had occasion to participate in the interviews in the evening when the person with dementia was apparently more tired than in the daytime.

The statement of Kristian about his inability in the morning was considered being presented with a joyful undertone, but with a lot of intrinsic seriousness and uncertainty. According to Martinsen (21), the person needs to be met in a way so that he is able to be present in the moment. To do that, the sensation of the person must guide the researcher and her knowledge. Initially Kristian was uncertain of the interview situation, and he had an expressed limited self-esteem due to his condition. He showed good ability to express his feelings when he was shown compassion and understanding of his challenges related to the dementia. It was also important to show similar interest when he repeated himself. The researcher experienced that Kristian's self-confidence improved as a result of the interview that was undertaken as a two-way conversation.

Somehow the interview became more formal and tense than the conversations, because of the relatives being there and the use of the tape-recorder. That was challenging, as the research depended on good interviews on tape. McKillop and Wilkinson (30) underlines the use of a tape-recorder as an ethical challenge; the researcher must obtain permission from the participant to record a conversation, at the same time, recording is essential in securing a correct presentation of the communication. It was a balance between the risk of offending the person's dignity and integrity, and a wish to offer them a voice through interviewing them.

1) Conclusions

This article has discussed how the researcher must safeguard dignity and integrity during a research project where persons with dementia, living in nursing homes are participating. The

uncertainty and unrest experienced during the entire research project can be considered a strength, as it kept the researcher alert and attentive to protecting the participant's dignity and integrity. It was difficult to be completely certain about how the persons actually experienced their participation in the research. The ethical considerations concerning research on vulnerable persons, participation of the relatives, in which room and at what time the interview should be carried out, are key elements. The interpretation process triggered a search for sense in the multitude of understandings of vulnerability, life-experience, hope and approaching death. It was individual what promoted dignity and integrity for each person. It was necessary to apply discretion to make the best of the ethical challenges that continuously arose. To apply the best discretion, it was appropriate that the researcher also had education as a nurse, and therefore had relevant knowledge. Optimized communication, cooperation with close relations, finding the right room and moment for the encounters, gave the participants the possibility to express themselves as well as possible so that their dignity and integrity could be safeguarded.

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