

The importance of moral sensitivity when including persons with dementia in qualitative research

Anne Kari T Heggstad

Oslo and Akershus University College of Applied Sciences, Norway; University of Oslo, Norway.

Per Nortvedt

University of Oslo, Norway; Oslo and Akershus University College of Applied Sciences, Norway.

Åshild Slettebø

University of Agder, Norway; Oslo and Akershus University College of Applied Sciences, Norway

Abstract

The aim of the article is to show the importance of moral sensitivity when including persons with dementia in research. The article presents and discusses ethical challenges encountered when a total of fifteen persons with dementia from two nursing homes and seven proxies were included in a qualitative study. The examples show that ethical challenges may be unpredictable. As researcher you participate with the informants in their daily life and in the interview situation, and it is not possible to plan all that may happen. A procedural proposal to an ethical committee at the beginning of a research project based on traditional research ethical principles may serve as a guideline, but it cannot solve all the ethical problems one faces during the research process. Our main argument in the article is therefore, that moral sensitivity is required in addition to the traditional research ethical principles throughout the whole process observing and interviewing the respondents.

Keywords

Moral sensitivity, qualitative research, ethical principles, dementia research, research ethics.

Introduction

In this article we will present and discuss some ethical challenges encountered during a Norwegian research project in which persons with dementia and some of their relatives were included as participants. The overall aim of this project was to find out what persons with dementia and their proxies experience as advancing their dignity and what they experience as infringements on their dignity in daily care. It was a qualitative study based on participant observation in two different care units, and on qualitative interviews.

The aim of this article is to discuss the importance of moral sensitivity when including persons with dementia in qualitative research. One may as researcher meet research ethical challenges in any study when including vulnerable informants, but in this article we choose to focus on challenges in qualitative research, since that is what our experiences build on. There have been few qualitative studies which have included people with dementia as participants (1, 2). As health researchers we have a moral obligation to ‘produce’

knowledge that may improve the quality of care and enhance the dignity for these very vulnerable patients. To acquire such knowledge and to show that we as researchers take patients suffering from dementia seriously it is important to give these patients a voice in the research (2-5). But including persons with dementia in research raises some particular ethical dilemmas (6), and to gain knowledge about how to meet these ethical challenges is also important. When including persons with dementia in qualitative research ethical challenges may be encountered from the planning to the reporting. Writing a proposal which build on some procedural principles may function as a guideline, but one cannot as a researcher foresee all the situations and research ethical challenges or how the research subjects reacts to the researcher's participation. This may be even more challenging if the research subjects do not understand your role as a researcher. Developing moral sensitivity as a part of the research process is therefore crucial. Hence, we will argue that traditional research ethics has to take more seriously the relational and contextual protection of research subjects as part of the research process.

The challenges that will be presented and discussed to show the importance of moral sensitivity are challenges related to assessing a person's capacity to give his or her own consent, challenges that may be encountered when informing about the research, challenges that arise when the researcher participates in the daily care, and challenges when reporting

findings. . The terms ‘I’/’me’/’my’ in the examples refer to the first author’s voice in the concrete situations as researcher, while the terms ‘we’/’us’ in the rest of the article refer to all three authors.

Previous research on dementia and research ethics

Previous research on persons with dementia that has focused on research ethics has mainly emphasized the process of giving consent (7-9) and how to assess the participants’ ability to give their own consent. According to Dewing, the focus has to a large extent been on consent taking place at the beginning of a project and not as a process where one may assess the participants’ ability to consent throughout the research (10) . In addition, only a few studies have focused on other ethical challenges than the procedural ones when including persons with dementia in qualitative research.

Some other studies have debated moral sensitivity related to research ethics (11, 12), but it has not been related to research where persons with dementia have been included as participants.

Method

The overall study was a qualitative study based on the first author's participant observation in two different care units where 15 patients were observed, and qualitative interviews with five persons with dementia living in these units, as well as with seven relatives.

The participant observations lasted for three months in the first nursing home. In the second nursing home the observation period lasted for two months. During these months the researcher was in the units for 3–6 hours between 07.30 am and 10 pm, three days a week. The total time spent on observations was approximately 184.5 hours.

Inclusion

The first inclusion criterion for the patients was that there was a written consent either from the patients or from their proxies in cases where the patients lacked competence to consent. In addition, the participants should have a diagnosis of dementia according to the nursing journal or the General Practitioner (GP) in the unit. They also had to be residents of the units in which the fieldwork was carried out. Informants that were included in the interviews should be able to express themselves verbally. These inclusion criteria for the interviews were considered and accepted also by the head nurse in the unit.

If the patient was judged competent to give his or her informed consent, consent was given in advance. If the patient was assessed not to have the capacity to give a written informed

consent, it was obtained from the proxies. The exclusion criterion was that if consent was not obtained from the patients or their proxies the patients were not included.

When consent has been obtained from a proxy assent from the participants themselves should be required when including participants in interviews (9, 13). Hence, when the patients were assessed not to be competent to give their written consent, they were given the opportunity to give their verbal assent to participate in interviews. 'Consent' is here understood as the written agreement based on full understanding of the research, while 'assent' is a verbal agreement to participate based on less than full understanding (8).

The workers in the units could refuse to participate in the study. If they did they would not be included in the field notes. None of the workers refused participation. When the researcher participated in caring situations such as bathing, a written consent was obtained from the carer she assisted.

The study was approved by the Regional Committee for Medical Research Ethics. Names used in this article are fictitious.

Research ethics

Traditional research ethics

In Norway all research aimed to create new knowledge about health and illness has to be approved by the Regional Committee for Medical Research Ethics (REK) (14). Guidelines for research ethics often build upon traditional normative theories and principles, such as principles of respect for autonomy, non-maleficence, beneficence, and justice (15, 16). According to Guillemin and Gillam, this kind of ethics may be seen as a ‘procedural’ ethics(12). The procedural ethics, which all researchers in Norwegian health research must follow, is important in order to protect the participants and prevent risk and harm, but moral sensitivity in the situations may be an important supplement to this kind of ethics.

Moral sensitivity as a supplement to traditional research ethics

In qualitative research ethical challenges may not always be predictable, and moral questions may arise at any time during the research process (16). Merely having a focus on procedural rights and a protocol that one writes at the beginning of the research is no guarantee for being able to solve all these important ethical problems (12). Juritzen et al. (17, p.644) argues that: ‘a rule-bound obtainment involves a risk of making the process routinized and mechanical, and remote from the ethically reflected practice which is desirable’.

Moral sensitivity can be described as attention to the moral values involved in a conflict-laden situation, acknowledging what principles are involved in the situation, as well as

awareness of one's own role in the situation (18). It may be understood as an important precondition for behaving and judging morally, as moral sensitivity is important for moral attentiveness and a full-fledged understanding of moral situations. While traditional moral principles are founded on rational reasoning, the concept of moral sensitivity takes both emotions and reasoning in the situation seriously (19-21). This means that to sense the moral significance in a situation one needs to be 'touched' both emotionally and cognitively. Our research on persons with dementia seems to underscore these theoretical insights to the full.

Discussion of the importance of moral sensitivity when including persons with dementia in research

When talking about risk and avoiding harm in clinical research, it is common to focus on the potential of doing physical harm to the participants. The risk of doing harm in this project had more to do with stressing the patients mentally and socially. It may be easier to predict physical harm, for example when trying out new medicines or surgery. To forecast mental and social harm or risk in qualitative studies may be more difficult. As researchers, you participate with the informants in their daily life and in the interviews and you cannot be sure how the research subjects may react to this. It therefore requires a high level of attentiveness in the concrete situations, as the examples and discussion below will show.

The importance of moral sensitivity when assessing a person's capacity to give consent

Even though a person suffers from dementia, this does not mean that he or she is not capable of giving his or her own consent. To claim that a person is not competent because of a diagnosis would be excluding. This means that a person with dementia deserves a fair evaluation of his or her competence to make an autonomous choice about participating. To evaluate the capacity to consent when including persons with dementia, it is common to use different kinds of neuropsychological tests, such as the Mini Mental State Examination (MMSE), which is a screening instrument for cognitive impairment. But neuropsychological tests do not say anything about the patients' abilities to express their feelings or experiences (22). Neither do neuropsychological tests capture the full picture of a person's competence with respect to giving informed consent. The fact that persons with dementia may go in and out of lucidity and confusion(23), also means that the results of such tests may vary from one day to another. In fact, and in line with our previous experience, people who go through such tests may find them humiliating and experience them as threats to their dignity (1, 24-27). Instead of letting the participants go through cognitive screening, there is a possibility to let a nurse or a doctor who knows the patient well do a more general and holistic evaluation of the person's capacity to consent. This requires more comprehensive knowledge about the person over time.

But both neuropsychological tests and more general evaluations done by health care professionals can give uncertain results. There will always be a risk that some of the participants who are competent to give a written consent, may be assessed as incompetent, and hence risk that the participants are disempowered. Disempowering a person may be understood as not respecting that person's autonomy. In order to avoid this uncertainty in the consent process and to avoid harm, and because the capacity to make decisions may vary it is important to be sensitive to what the participants understand through the research process and renegotiate the consent constantly (10, 28, 29) as the example below demonstrates.

Example 1:

After I had been in the units for some weeks, I discovered that some of the participants understood more about the research than the first assessment of their competence indicated. They gave interesting and important comments to the project, as exemplified by the case of Eli, who made some interesting reflections at the end of the interview:

I: I will also have interviews with other residents in this unit.

Eli: Yes, that's important. Then you may compare the different experiences. Not everyone looks at it the same way, you know. So then you will get a better view of it all.

When interviewing Eli and some of the other residents who also seemed to understand what the research was about, the first author let them sign their own written consent, even though they might forget doing so the next day, or even the next hour.

In this study we argued in favour of not using neuropsychological tests in the inclusion process. We thought that letting the participants go through neuropsychological tests would do more harm to the patients, than a more general evaluation built on knowledge about the patient over time (24). So the head nurse was asked to perform a holistic and comprehensive assessment of the patients, built on her special knowledge of the patients' abilities to understand the information given, their understanding of the aim of the research and their ability to understand the implications of the decision made. This also meant that we had to trust the nurse's assessment, but we also had to be open to reassess this judgment if necessary.

The first author had been in the units for six to ten weeks when some of the participants were asked if they wanted to participate in a more formal interview. The researcher had then got to know the residents better. Hence, the judgment, including the reassessment of the patients' competence to give their own written consent, was built both on attentiveness and experiences in the situations, but also on the residents' expression of how they understood the research. We thought that giving these participants the opportunity to sign their own consent would ensure that autonomy and integrity were maintained to a greater degree. We also thought that this would underscore that the consent process was a relational process, not only a procedural act that one as researcher should carry out at the

beginning of the research. This also shows that a moral sensitivity, including listening to the participants' opinion as well as attentiveness to the patients understanding of the study throughout the research is important.

The importance of moral sensitivity when informing about the dementia focus in research

One of the main principles in research ethics is to give full information to the participants about the research. When one, as a researcher, does not provide full information about a project, it may be interpreted as deception. To 'deceive' means 'to cause to accept as true what is false or give a false impression' (30). According to Benham and Korn deception demonstrates a degree of disrespect toward the participants' autonomy (30, 31), and it may undermine the trust that serves as a basis for all human interaction. It may also be understood as abuse of power by researchers. The principle of telling the truth may be one of the most fundamental principles in an ethics of duty, and a principle that has been much debated in philosophy, for example by Immanuel Kant (32). In other words, by deception one violates both the principle of autonomy and the principle of telling the truth. But telling the whole truth may also harm the patient. Some previous research including persons

with dementia has argued for not focusing on the diagnosis when informing about the project if the participants do not mention it themselves (1, 6). The fear of mentioning the diagnosis builds on an assumption that this may harm the patients because of the stigma associated with it (26, 33-35). Previous research shows that only few of the doctors inform the patients about the dementia diagnosis (36-38). And if the patient does not know about the diagnosis, it would be of little benefit and may be wrong that the researcher should inform about this.

Example 2:

As a researcher I always introduced myself and informed about the project the first day when I came to the unit. This was information that had to be repeated to remind the residents about my role in the unit. What I found challenging, though, was to inform about the focus on dementia. In the first unit, the special care unit for persons with dementia, the dementia-focus was not mentioned explicitly, although they could read about it in an information sheet in the unit. I did not want to focus on the diagnosis unless they said something about it themselves. I decided to mention the dementia-focus to some of the participants in the other nursing home after I had got to know them a little better. One of these patients commented on the dementia-focus when I talked with her about the project. This was a patient who suffered from dementia herself, but who was obviously not sure about her diagnosis, as she commented (from the field notes):

‘There are many patients here who may be suffering from dementia – you don’t have to be a doctor to notice that. You know, sometimes I think that I may have some of it myself. I forget things, cannot find my things and so ... But that’s common to most of the patients here, that we might have “some of it”. That’s something one has to expect as one gets older.’

It was the head nurse in the unit who gave the patients or the proxies the first information about the project. But the researcher had to repeat the information when she introduced herself. The decision about not informing about the dementia-focus to all of the participants in this project was based more on situational sensitivity and considerations taking account of the interest and vulnerability of the particular patient than on general rational principles. We felt that it was morally problematic to focus on the diagnosis if we did not know if the patients were informed and aware about the diagnosis themselves. One of the relatives also told about how angry her mother in law became when they told her about her diagnosis, so these relatives had decided not to focus on it any longer. One other reason why we did not want to focus on the diagnosis was that we wanted to signal that it was the person behind the diagnosis, and not the diagnosis in itself, that was the most important for the study. The participant should not be seen as ‘the demented person’, but as a person with a dementia (39).

As long as the doctors do not inform about this the diagnosis and as long as we do not know how the patient may react when being confronted with the dementia diagnosis it will be an ethical challenge to focus on it when including persons with dementia in research. Thus far there is no clear answer to how the researcher should deal with the dementia focus. And maybe there should not be a clear answer or procedures on how to deal with it either since patients may react differently when being confronted with it. The most important may be that the researcher judges what to do from patient to patient, and from situation to situation, in an open dialogue with the personnel who know the patients.

The importance of moral sensitivity when the researcher participates in the daily care

When researchers participate in daily care, they may participate in intimate situations. If the patients do not understand the researcher's role in the situation, this may confuse them and they may feel invaded by strangers. This may also be experienced as a threat to the patient's privacy. The ideal situation in research is a situation where the researcher and the participants interact in an equal relation. When including patients in research, this relation may often be seen as asymmetric, where the researcher is the one who has the power and the patients are the vulnerable ones. It is important that the researcher is aware of this power imbalance and respects the patient's autonomy and reactions in these situations (29).

Professional knowledge about the research field may also be required when participating in the daily care as a researcher. Such knowledge may enable the researcher to behave with sensitivity and respect in the situations (40). If the researcher is not sensitive, both with regard to her feelings and her cognition in the situations, she may ‘lose’ ethically important moments (12), and by this do harm to the participants. This may be even more challenging when the participants have limited verbal capacity, and cannot express their feelings and will clearly.

Example 3:

Asta was suffering from late stage dementia, and her verbal capacity was limited. She talked a lot, but it was often difficult to understand what she was saying, and I could not always be sure if Asta understood what my participation as a researcher meant. Most of the time, it seemed to be all right for Asta, but sometimes she seemed to be uncomfortable with it. There were times when she got more restless and anxious, and she could even become angry. We did not know why she became restless and angry, if she experienced pain, if she was anxious, or if it was my participation that disturbed her. As a nurse with experience from dementia care, I knew that it was usual that patients with dementia might get confused when there is more than one nurse in the bathing situation. I had no procedure to follow, but I used my knowledge from my previous work in a dementia care unit and I used my feelings in the situation. There could be several reasons why Asta became angry or anxious in the situation, and one of the reasons could be that she felt invaded by strangers. Not doing harm to Asta’s privacy and intimacy zone was more important than the research itself. Occasionally we therefore decided that it would be best for Asta that I left the nurse and Asta in the situation.

When the researcher participated in more intimate situations in this project, the head nurse was asked which of the patients she thought could be harmed by the researcher’s

participation. But neither the nurse who knew the participants or the researcher could foresee what would happen in the concrete situations. This underscores how unpredictable the moral challenges may be when one participates in the informants' daily life as a researcher. It also shows the importance of having some knowledge about the field where the research is conducted, but also the importance of being attentive to how the participants react to the researcher from situation to situation.

The importance of moral sensitivity when reporting the results

As researcher, you have an obligation to report your findings to the society, but it may not always be right to report all the information you get as a researcher. There may be a risk of doing harm to the participants, and maybe also to the relatives of the participants, if one includes and reports all the information one gets (41). This could for example be sensitive information that the relatives may identify and experience as understressing when they read the results of the research. When including persons with dementia in research, they may not always understand the implications of the research either. There is a risk that they will give sensitive information that they would not have let the researcher know if they understood the researcher's role. And the Helsinki declaration states that the respect for the participants is more important than the benefit for the research(42). This means that you have to be

careful with what you report and how you report it as shown in example 4 with the same participant as presented in example 1:

Example 4:

Eli was an 82 years old lady who had lived in the special care unit for persons with dementia for two years. Her dementia was her main problem and she was one of the patients who were assessed not to be competent to give her written consent, but I got her assent for the interview. Her proxies had given their written consent for her participation in the research. She could be more or less confused, but could have moments of lucidity. As researcher I had many informal conversations with Eli, in addition to the interview. One day, she showed me a book where her relatives wrote down when they visited her, so she could go back and see when they had been there. This book, she used as a diary too, where she wrote down her thoughts and feelings about how she experienced her life in the unit. What she had written there was of great interest to my research. Later I got an interview with Eli, and I asked her about this diary:

I: You have a book where you write different things?

Eli: Yes, I don't know where... Nobody should read that book, you know.

I: No, but you showed it to me one day.

Eli: Oh, did I?

In that moment Eli seemed to be a bit confused, and had forgotten that she had told me about the diary. The first time Eli showed it to me, I thought that it might be alright if I used the information I got. But in the interview situation I got a feeling of discomfort as a researcher. I felt that I had gone over a private border. I also got confused about what to do with the information. Could I as a researcher use the information, or should I put it away?

The situation above made the first author aware of how easy it is as a researcher to do unintended harm to participants when they go in and out between confusion and lucidity. Legally it could be accepted to use the information, since the researcher had got the consent from Eli's proxies, but morally and in addition to the Helsinki declaration it would be

wrong if the researcher sense that it would harm Eli. So in the situation with Eli, the researcher decided not to use the information she got from the diary. This also shows how important it is to use both sensitivity and rational principles when deciding what to include in research, to avoid risk or harm to the informants.

Finale reflections on research ethics and further research in dementia

Some may ask if it is justifiable to include persons with dementia in research if the challenges are so unpredictable and the solutions to a large extent depend on the researcher's moral sensitivity in the situations. And some may also argue that moral sensitivity is a subjective quality, and that if research ethics depends on the researcher's subjective moral quality, one cannot be sure if the researcher makes the right judgment in the situations. Moral sensitivity is not just a subjective quality in the sense that it only reflects the personal preferences of the moral agent (here the researcher). In fact moral sensitivity might truly reflect the essential features of a situation and is salient for proper moral reflection(21). So instead of avoiding research on vulnerable groups one could focus more on the importance of moral sensitivity in research and how researchers may develop this moral sensitivity.

We would also suggest that the researcher writes a log about which ethical challenges they meet and how they solve the ethical challenges that arise during the research. This could be

reported when presenting the research. If this was the case the researcher would be forced to reflect on ethical challenges and defend the decisions made, not only when writing the protocol to the ethics committee at the beginning of the research but throughout the research. This would also lead to more transparency and a better control of research activities.

One requirement could also be that researchers who participate in the daily care or in interviews with persons with dementia, have knowledge about the patient group. This knowledge could make the researcher more sensitive to what happens in the relation between the researcher and the informants. And as difficult situations arise one could require that the researchers consult and discuss what to do with health care personnel who knows the patient and has the competence to assess the patient's reactions. This is something that the Norwegian National Research Ethical Committee (NEM) recommends when including vulnerable people in research (43).

This means that one should not avoid research on vulnerable people because of the research ethical challenges instead one could focus more on these particular and interpersonal challenges. If one did not allow research involving persons with dementia or other vulnerable groups because of the moral challenges, new knowledge about the disease and how the disease is experienced by the patients would not be gained. Not including

vulnerable people in research may even increase their vulnerability (44). More knowledge may also reduce the stigma associated with the disease and lead to more openness around it. Excluding persons with dementia from important research may be unethical and also be a threat to their dignity (1, 5, 8).

Conclusion

This article shows that there are ethical challenges, and that these may also be unpredictable, when including persons with dementia in qualitative research. When encountering these challenges not only awareness of rights and the proper ethical principles is important, but a constant situational awareness of interpersonal cues, of what is important to the particular patient in the actual situation. This means that researchers has to be attentive and moral sensitive in their interpersonal relationship with patients and that research ethics is a never ending continuous affair when dealing with these patients. More research is needed on how to solve research ethical questions in practice if we as researchers want to show the participants that we respect their autonomy and privacy.

Acknowledgments

Anne KT Heggstad contributed to the idea behind this research, wrote the proposal, participated in data gathering and analysis, and wrote this article. Per Nortvedt contributed to the idea behind this research, participated in the data analysis, and critically reviewed the

article. Åshild Slettebø contributed to the idea behind this research, participated in the data analysis, and critically reviewed the article.

Funding

The research was funded by The Research Council of Norway.

Conflict of interest

The authors declare that there is no conflict of interest.

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