Ethical challenges embedded in qualitative research interviews with close relatives

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Abstract
Nurse researchers engaged in qualitative interviews with patients and spouses in healthcare may often experience being in unforeseen ethical dilemmas. Researchers are guided by the bioethical principles of justice, beneficence, non-maleficence, respect for human rights and respect for autonomy through the entire research process. However, these principles are not sufficient to prepare researchers for unanticipated ethical dilemmas related to qualitative research interviews. We describe and discuss ethically challenging and difficult moments embedded in two cases from our own phenomenological interview studies. We argue that qualitative interviews involve navigation between being guided by bioethics as a researcher, being a therapist/nurse and being a fellow human being or even a friend. The researchers’ premises to react to unexpected situations and act in a sound ethical manner must be enhanced, and there is a need for an increased focus on the researchers’ ethical preparation and to continually address and discuss cases from their own interviews.

Keywords
Ethics of care, healthcare research, qualitative interview, relatives, researcher–participant relationship

Introduction
This article contributes to the discussion of inevitable ethical questions related to qualitative research interviews in healthcare research in the light of bioethics and ethics of care. A main issue for the qualitative researcher is to delicately balance a wish to gain as much knowledge as possible of the research phenomenon with compassionate and respectful questioning in the situation. The researcher–participant relationship is decisive and constitutes a major challenge, running the risk of being either too close or too distant. The researcher may be seen as a researcher, a therapist, a counsellor or a healthcare professional by the interviewee. Ethical aspects of researcher–participant relationships when doing qualitative research require attention.

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research interviews that concern experiences of health and illness are sparsely discussed in the nursing literature, and few studies address ethical aspects of interviewing relatives, the focus of this article.

It is well known that illness affects not only the patient but the whole family. Healthy relatives of seriously or chronically ill patients may be understood and acknowledged as vulnerable in terms of being research subjects. Research documents that spouses living with a person having a chronic illness are deeply involved in their partner’s health and illness. The spouses feel vulnerable but have to be strong and enduring, they might be heavily burdened and are in social and relational transitions, and they might experience ‘a shrinking life’ and lack of couple identity.

The impetus for this article is our own ethical challenges when doing qualitative research interviews with spouses of patients either living with a chronic neurological condition or going through fast-track surgery. With reference to Aristotle, Brinkmann and Kvale suggest that researchers learn from discrete cases in order to improve their ethical proficiency. Based on two cases from our own studies, we discuss two questions: ‘which ethical aspects are embedded in the researcher–participant relationship when interviewing relatives?’ and ‘how does one act ethically soundly in unexpected interview situations?’ Finally, we present suggestions for future ethical considerations when planning and conducting interviews with close relatives.

Background

Individual interviewing is an acknowledged method for collecting data in qualitative health research. Yet, interviewing entails many challenging aspects. As a research method, it comprises gaining knowledge, possibly therapy and always asymmetric power relationships. These aspects of interviewing are intertwined and expose the researcher to ethical challenges. Research that involves human beings serves both scientific and human interests. The unique intimate atmosphere that is created in the interview (which often takes place in the interviewee’s home) requires that the researcher pay sensitive attention to the integrity and well-being of the interviewee and to the boundaries for what questions to ask.

The qualitative research interview is characterized as a meeting of strangers engaging in an interview related to a certain topic, where the topic is decided by the interviewer. During the interview, the researcher is posing questions to gain knowledge of a certain phenomenon. The interviewee is assumed to provide that knowledge by replying to these questions. Thus, the interview is governed by the interviewer who dominates the one-way dialogue and decides the procedure of the interview situation.

This power asymmetry, in part, demands considerable attention to what groups of persons are being interviewed. Interviewing relatives, patients, and ill or potentially vulnerable people requires reflexivity and ethical skills from the researcher who must be able to identify the special needs of every individual person. The researcher’s capability to establish trust and confidentiality to get the most out of the interview is often addressed when discussing methodological issues. There will always be a tension between ethical considerations and the necessary engagement of the researcher in qualitative research relationships. As stated by Brinkmann and Kvale, the researcher and participant interact and affect each other during the interview. It can be regarded as an ongoing relationship where the personal and social identities of both the researcher and participant are at stake.

Researchers must acknowledge themselves as main instruments in the research process. This becomes quite obvious when doing repeated interviews with the same individual. The parties get to know each other, and the knowing affects their relationship and might be a strength to the research study. On the contrary, repeated interviews may cause blurred boundaries between doing research and caring for the participants. The participants may perceive the researcher as a counsellor, and their relationship runs the risk of developing into a false or fake friendship.

Interviewing both patient and spouse either separately or as a couple offers great possibilities for knowledge development. Establishing a research setting where each of the participants can share thoughts and
The researcher may impose uncomfortable conditions for the patient or even pretend fake friendship to get the most out of the interviewee. Likewise, the power relationships between interviewer and interviewee need special attention to make them transparent for both the researcher and the interviewee. Accordingly, doing qualitative interviews with patients and close relatives requires ongoing reflection on one’s skills as an interviewer and on what questions to ask. The research process must be guided by reflection on relational issues, on constant awareness of the participant’s reactions when answering the questions and on the here and now protection of the participant’s human rights. The question is whether and how it is possible to anticipate such issues. Kidd and Finlayson categorize ethical issues of human inquiries in two ways: as ‘charted territory’, which refers to the safe navigation of bioethical principles, and as ‘uncharted water’, which refers to unforeseen ethical dilemmas that arise to a greater extent than anticipated. Charting the waters thus requires researchers to renegotiate and rethink ethical positions on a daily basis. We must continuously be attentive to the situation and what good will come of the research.

**Narratives of interviews with spouses**

The empirical basis for our ethical discussion comprises two cases developed from phenomenological studies of being close relatives to sick patients. The two cases build on our interview data and are created for this article. The studies involved both patients and spouses, and the interviews took place in the interviewees’ homes. One study concerned experiences of participating in a fast-track programme after a cancer operation; the other focused on living with Parkinson’s disease. The relatives’ experiences were in both cases included to get a deeper knowledge of patient life and a holistic view of family life with severe illness.

During the interviews, the spouses’ suffering became quite clear. We realized that being a relative to an acutely or chronically ill family member requires a lot, and more than we had anticipated. Attention to the spouses and their daily life caused reactions that touched us as nurses and human beings and confused us as interviewers. The relatives revealed unique caring needs that seemed to be suppressed. As researchers and interviewers, we were left with doubt that we might not have handled these situations in the best possible way.

In the following, we present the two cases as examples. The cases demonstrate our reflections on ethically challenging interview experiences with the spouses. We use cases as they give thick contextualized descriptions of particular situations and thus may function as eye-openers for moral actions. Particular examples help researchers to evaluate their research practice and become ethically proficient qualitative researchers learning what is and what is not ethically justifiable. Following which, we will describe, compare and contrast ethical challenges perceived in the cases, extract common themes and discuss these in light of bioethical principles and ethics of care, as we assume that these go together in qualitative research.

**Norlyk’s case**

My case is about a wife, Susan, whose husband had undergone surgery for colonic cancer. Susan’s husband had participated in a fast-track programme, which meant he was discharged home 3 days after surgery. The interview focuses on the lived experience of being a close relative to a patient participating in a fast-track
programme. This specific interview took place 10 days after surgery, and Susan and her husband were at
that time still waiting to get the final answer from the hospital about the biopsy.

The interview apparently went fine. Susan and I seemingly had a quiet and nice conversation; however, I
noticed that she was a fast-speaking person. Around 15 min into the interview, the telephone rang, and
Susan asked me to turn off the recorder while she answered the phone. After a few minutes, she returned
and told me it was somebody from the hospital who wanted to talk with her husband regarding a research
project he participated in. Then she sat down and began sobbing uncontrollably. I did not know what to do. I
was surprised and a bit confused because initially during our conversation, Susan had seemed calm and
composed. I decided to remain seated and told Susan that I truly understood her anxiety and that she was
in a very tough situation. After a few minutes, she stopped crying and told me that she felt extremely tense at
the moment. Any message from the hospital made her very upset. After a short break of silence, she took the
initiative and continued the interview. Again I was confused; should I cancel the interview or what should I
do? While I was thinking, Susan kept on telling me about her experiences we had talked about just before the
phone rang. It seemed to me that she was very determined to continue with the interview. Unfortunately, I
did not ask Susan whether it was okay to continue or whether she would prefer to cancel the interview. Dur-
ing the rest of our conversation, I noticed that Susan was sitting with her arms crossed and tight to her
body. Her body language clearly demonstrated that she was weighed down by sorrow. Once in a
while, she seemed to lose her concentration, but every time she pulled herself together focusing on
the interview, answered my questions and kept on telling me about her experiences. This impressed
me. My body kind of responded to the ambience in the room. I worried about her. After ending the
interview, I wondered how I had handled this situ-

Haahr’s case

During a longitudinal interview study, I did repeated interviews with both patients and spouses separately
through the span of 1 year. It soon became evident to me that the spouses were a vulnerable group of partic-

participants. They were not used to the attention to their specific experience of being in the particular situation
of living with a partner with a chronic illness. Several spouses became very moved when they were asked to
talk about everyday life from their perspective. Sometimes they would cry. In particular, one spouse caught
my attention. This spouse was female and she was not much older than me. Generally, the interviews with
this woman were frank and full of reflection. The interviewee was very open-hearted and would talk about
whatever came to her. Sometimes she would be sad and occasionally she would cry. I remember the first
time she cried and I got a bit insecure about what to do. Touched by her story, and the confidence she
showed me, I remember I just sat there, waiting, pausing and giving her time. I sensed that she did not want
to stop the interview, but I was not sure I was doing the right thing. I aimed to show her that it was okay to be
sad, and I also told her that it would be okay to stop the interview. However, she wanted to carry on and in
that sense I felt I let her decide what to do.

The following interviews were also long, deep and trustful. It turned out that this was the first time she
had told ‘her story’. She clearly put into words how talking about her life experiences had made her think
more about her life and their whole life situation. This acknowledgement made a strong impact on me as a
researcher and fellow human being. It made me both glad and startled, wondering what unintended positive
as well as negative effects engaging in a research interview would have on the interviewee. It made me
address the question of what characterizes a research interview and made me reflect on the role of the
researcher. When are you seen by the interviewee as a researcher, a counsellor, a nurse, a therapist or maybe
a friend and how should you react to that? What were the ethical aspects of conducting these particular inter-
views for my research purpose? I knew that all participants were recruited according to bioethical
guidelines. They were continuously made aware of the possibility to withdraw from the study at any time, and I always made sure to debrief the interview. Still, I doubted my capability to act according to ethical principles and to use my nursing background in the situation.

**Ethical challenges embedded in the cases**

What characterize these cases are the unpredictable and tense emotional moments of the spouses’ reactions during the interviews. Both researchers were taken by surprise; they were personally moved and also confused. The spouses’ reactions put them in a dilemma of what was the right thing to do there and then. The situations made them hesitant. Would it be okay to go on with the interview or should it be stopped? Would it be possible to ensure both sound research and ethical conduct? Both cases concern dilemmas between being a researcher, a therapist/nurse or just a fellow human being open to the suffering of the other. Despite different contexts, both cases have comparable features and present several similar dilemmas to consider. They both illuminate the following:

- The relationship and the power dynamics between researcher and spouse of a seriously ill patient;
- The spouse, the ‘well person’ in the family, as being more vulnerable than expected;
- The challenge of being a qualitative researcher, a nurse and a fellow human being;
- The researcher’s tension and role confusion in unanticipated and sensitive situations;
- The therapeutic elements of qualitative research interviewing.

From an ethics perspective, both cases demonstrate questions of beneficence/maleficence and respect for autonomy as well as questions of care and sensitivity during the interview. In the following, these matters will be discussed in relation to the dilemmas embedded in the two cases, but first, we will present our theoretical framework.

**Bioethical principles and ethics of care**

The theoretical framework of this study comprises the four bioethical research principles, namely, respect for autonomy, beneficence, non-maleficence and justice and ethics of care as understood by Tronto and others. As researchers, we are guided by the formal bioethical principles. The researcher must consider that the study is based on justice, beneficence, non-maleficence, respect for human rights and respect for autonomy. In an ethics-of-care perspective, the researcher must always be attentive to the situation and what good will come of the research. The bioethical principle of respect for autonomy refers to each individual’s right to hold views, make choices and take actions based on personal values and beliefs. Respect for autonomy obligates researchers who engage in research involving human participants to disclose information and ensure that this information is understood and that the decision to participate in research is based on voluntariness and understanding. The bioethical principle of beneficence entails all forms of actions intended to benefit others, and non-maleficence refers to the obligation to not inflict harm on others. Related to healthcare research, harming someone means setting back the interests of the research participant, maybe for the purpose of research. In research, the probable benefits should outweigh the risk to participants. This means that the potential risk of harm to participants should be the least possible and that the importance of gaining this specific knowledge should outweigh any risks. The bioethical principle of justice refers to ethical decision-making. It builds on fairness and equality based on universal rules and impartiality. In a justice perspective, respect for autonomy, objectivity and a positivistic rationality are guiding norms.

In an ethics-of-care perspective, bioethical principles give way for attributes such as holism, reflection and context. Ethics of care refers to attentiveness, responsibility, competence and responsiveness as
well as empathy and maintaining of harmonious relationships through caring.\textsuperscript{35–39} Ethics of care considers the specific needs of a specific individual in a specific situation independent of universal principles and rules.\textsuperscript{32,46} The hallmark is the notion that human beings are interdependent and that relationships make humans vulnerable and dependent. Thus, ethics of care refers to caregivers’ sensitivity, responsiveness, clinical wisdom and moral competence.\textsuperscript{35,37,47,48}

Overall, the bioethical principles and ethics of care cannot but guide qualitative researchers. The objective of the former is to do ethically good research; the objective of the latter is to do well in human relationships in general.

Discussion

The cases clearly demonstrate that it is not enough to know the bioethical principles, their interpretation is essential. The principles are abstract and universal in nature and need to be contextualized. The cases reflect several ethical dilemmas and demonstrate the challenge to carefully balance being a researcher, a therapist/nurse, a fellow human being or even a friend. These challenges are commonly addressed in healthcare research with a focus on the researcher–participant relationship and on similarities and differences between a research interview and a therapeutic interview.\textsuperscript{1,28} The researchers in the two cases were challenged on their interviewer role. As argued elsewhere,\textsuperscript{32} the situations described are examples of researchers trying to navigate in ‘uncharted water’, rethinking their ethical positions.

Both interviewers were caught in precarious situations when spouses reacted unexpectedly. Turning to the formal bioethical principles as a guide to act desirably in these sensitive situations, one could argue with the principle of respect for autonomy that participation must always be voluntary and that continuing the interview to achieve research data could be considered a violation of the respect for autonomy. On the contrary, we could argue that it would be more harmful for the interviewee if we just ended the interview. Could it, in fact, be considered helpful for the participants, arguing with the principle of beneficence to share their painful thoughts and experiences?

Benner\textsuperscript{49} argues that ethical decision-making in healthcare must be guided by wisdom and an understanding of the situation. She points out that ethical actions are relational and guided by a wish to do what is right and that ethical wisdom, understood as the internal moral voice, and bioethical principles, understood as the external voice, must be integrated.\textsuperscript{49} Thus, the bioethical principles provide a sense of direction, but the principles should always be accompanied by an inner moral understanding of the specific situation. In the above-mentioned cases, the researchers ostensibly showed sensitivity and listened to both the external and the internal voices of ethics. Still, they were puzzled; their moral understanding became blurred because of the complexity and emotionality of the situation.

In an ethics-of-care perspective,\textsuperscript{37} the researchers were attentive to the suffering of the interviewees, and this attentiveness made the researchers vulnerable. With reference to Levinas, Nortvedt\textsuperscript{37} argues that ‘Being open to the world also involves a passive receptiveness in which one is made vulnerable by the vulnerability of the other’. In our cases, the researchers’ passive receptiveness made them embodied, engaged and affected by the situation, leaving them puzzled and confused.

One might say that the bioethical principles and ethics of care fuse when it comes to avoiding doing harm and being sensitive because without sensitivity it is easy to harm others. It is not unusual for qualitative researchers to touch on sensitive topics. It is well known when researching lived experience that the character of the interview, that is, the intimacy and trust between the researcher and the researched and the profound wish to fully understand research participants, is engaging and demanding. The researchers and the researched are merging their worlds during the interview.\textsuperscript{26,50} Dahlberg et al.\textsuperscript{51} address this issue and acknowledge that a research interview quite often is the first time that the interviewees have been asked how they felt and given the opportunity to express their thoughts and feelings.\textsuperscript{51} The authors suggest that
the researchers explicate to the interviewee what they observe, when the interviewee is touching on a sensitive topic. They argue that we should trust every person’s ability to choose whether to let go of the natural defence mechanisms or not. Thus, guided by the ambience in the particular situation, the researcher must be able to act with responsiveness in a manner that does no harm to the participants. Brinkmann and Kvale argue that prevailing forms of warm, empathic interviews can be ethically questionable; with reference to power relations and manipulation, they argue that the challenge for researchers is letting ‘the objects object to what we as researchers do to them and say about them’. Accordingly, we should be open to or maybe even invite participants to question the purpose, the form and content of the research interview.

The spouse in Norlyk’s case appears to show responsiveness towards the researcher. Her reaction can be seen as a wish to continue the interview and an indication that she experiences comfort and care in the situation. However, she could also have felt some kind of pressure realizing that the interview was important for the researcher. In Haahr’s case, the interviews could be interpreted as having elements of being therapeutic. The relationship between the interviewer and the interviewee had characteristics that the interviewee might regard as a false friendship. This relationship was established through iterative in-depth interviews with a spouse who was burdened by her husband’s chronic illness. The researcher and the spouse were of the same age and both women. The spouse appeared to have confidence in the researcher and seemingly was in need of talking to someone who was interested, engaged and sensitive to her needs.

In an ethics-of-care perspective, the spouses can be seen as having responsiveness to the openness and care they felt from the researchers. However, the opposite could also be the case. The question is whether we as qualitative researchers, in our eagerness to get in-depth knowledge about our study phenomenon, are unknowingly creating a relationship that may be referred to as fake friendship with the interviewee. And that we then actually do harm to the interviewees and to ourselves exceeding research professionalism. Brinkmann and Kvale claim that the kindest interviewers are the worst and may be the most manipulative. Our cases do not imply fake friendship, but writing this article made us attentive to the possibility. We agree with Brinkmann and Kvale that faking friendship is an ethical challenge for the interviewer and a matter to be reflected on, especially when doing repeated interviews with the same participant.

The intimate relationship that in-depth interviewers experience, we will argue, puts them in a vulnerable position that requires ethical awareness and concern for the suffering that the participants might reveal. Still, however, they are first researchers. Their focus is collecting knowledge of a special phenomenon; they have to stick to their focus and at the same time be sensitive human beings. In unexpected interview situations, the researchers have to oscillate between the holistic ethics of care and the bioethical principles with their more abstract approach. Bioethical principles and ethics of care have to go hand in hand. Dickson-Swift et al., in a grounded theory study interviewing 30 qualitative health researchers who had performed research on sensitive topics, found that the researchers had ‘blurred boundaries’ in their relationships to the interviewees, who were all interviewed more than once. The authors suggest, also in regard to the health and well-being of the researcher, that the researcher discusses these issues in advance to give clarity to research versus therapy and to minimize the blurred boundaries in the researcher–participant relationship.

During the moments of openness and responsiveness described in the two cases, we as researchers may have been just as vulnerable as the spouses. Our attentiveness to the spouses made us vulnerable. Our responsibility and a sense of being in charge of the course of the interview were at stake, and we both questioned our competence as qualitative researchers. We were puzzled, aware of the bioethical demand not to hurt the research participants in any way, considering the right thing to do. But maybe our reflections and actions in the situation were the right things to happen? Our cases highlight the dilemma of, or the shortcoming of, acting in an objective or rationalistic manner. They show how ethics of justice is tightly linked to ethics of care in the sense that both emphasize the responsibility of being equally concerned for those being vulnerable, in difficult situations or morally distressed.
Tronto\textsuperscript{35} argues that the four dimensions of ethics of care, attentiveness, responsibility, competence and responsiveness must fit together into a whole; they are to be integrated through reflections, clinical wisdom and making judgements about conflicting needs. Similarly, with reference to Levinas, Nortvedt\textsuperscript{48} states that in healthcare, justice must always be tempered by concern for the concrete other person. He puts emphasis on the responsibility towards the other.

In both cases, the interview was disturbed and resumed after a suitable break. The retrospective reflections presented in this article support the beliefs that the researchers’ responsiveness to the situation might have made a difference for the spouses. Ending the interview, which was considered in the cases, would have been unethical in both ethical perspectives.\textsuperscript{35} An attentive and responsible qualitative researcher does not leave a participant in distress but stays and listens to sense the development of the situation and to end the interview properly and professionally.

Generally, our background as nurses enhances the vulnerability of researcher and interviewee.\textsuperscript{46} The fact that nurses in qualitative research engage in lived experiences of the other leaves nurses vulnerable as researchers, with an ethical commitment and responsibility that are not guided by principles or rules only. For this, we need clinical wisdom and a sensibility towards the other.\textsuperscript{37} Sensibility means being emotionally attentive and empathically open to the other. Empathy was especially apparent in Norlyk’s case, which describes how she herself as a researcher sensed the suffering of the other in her body. She experienced being vulnerable. This embodied, empathic being with the other is addressed by Churchill.\textsuperscript{34} When we are in a close-up encounter with a research participant, we are always embodied in the situation, feeling the other’s experience bodily.

**Conclusion**

Ethical challenges when conducting qualitative interviews in healthcare research are far more complex than the researcher might anticipate. Every interview is unique and offers unexpected moments that require the researcher to be an ethical, knowledgeable and sensitive human being. Qualitative research interviews are enclosed by the challenge of navigating between bioethics, being a researcher, being a therapist/nurse and being a fellow human being or even a friend. Therefore, to improve ethical efficiency and to enhance the researchers’ premises to act and react to unexpected situations in a sound ethical manner, we argue that researchers continuously address, analyse and discuss cases, using their own experiences of conducting interviews. It becomes important to know oneself as a qualitative researcher, as a professional and as a human being to recognize prejudices and assumptions you have through human and professional experiences and to be aware of the knowledge and power you possess through your profession and societal position. This researcher ethical awareness also entails knowing and acknowledging one’s own vulnerability, which comes apparent in the researcher–participant relationship and in difficult interview settings where being a human being always overrules the researcher role in ethical dilemmas.

Ethical reflection and self-reflection need increased attention in the education of qualitative researchers. The researcher reflections and actions in each situation are highly personal; they should be valued and discussed. Addressing the qualitative researcher’s capability to handle the researcher–participant relationship, as well as knowledge about how to act ethically when unexpected situations occur, make excellent subjects in future research education that touches on ethical matters.

**Conflict of interest**

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