

Ethics Beyond the Checklist: Fruitful Dilemmas Before, During, and After Data Collection

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Abstract

In this article, we aim to contribute to current discussions about ethical conduct in qualitative research practice. We provide examples of how ethics is a recurring issue throughout a research process and not just an issue to safeguard procedurally. The examples on which we build our argument are based on three research projects from two countries, namely, Norway and Denmark, focusing on three different groups, namely, the elderly, parents, and children. Through our analyses of these ethical dilemmas, we aim to provide reflections on dilemmas encountered in three different qualitative research projects at three different stages, specifically before, during, and after data collection. We thus provide a way for researchers to frame their work with ethical dilemmas as a continuous process beyond the checklist. Furthermore, we frame complex ethical dilemmas as something not to avoid but as a continuous part of a fruitful analytical process.

Keywords

ethics, dementia, expert trespassing testimony, abnormal data, elderly, parents, children, ethical dilemmas

Introduction

As researchers, we are required to conduct research in an ethically responsible way. To that end, and given “the history of unethical studies” (Connor et al., 2017, p. 401), some form of regulation of research is needed. However, social science researchers are increasingly criticizing the way in which their research is expected to meet ethical criteria. Part of this criticism stems from the codes by which social scientific research is regulated, given that these codes are largely formed by bioethics (Bussu et al., 2020; Connor et al., 2017). The codes have traditionally involved four ethical principles: “informed consent, opposition to deception, safeguards to protect privacy and confidentiality and, ensuring accuracy in research results” (Connor et al., 2017, p. 401) but are argued to be based on a positivist paradigm that rarely fits with a social scientific and qualitative way of thinking about and working with research (Bussu et al., 2020; Connor et al., 2017; Pollock, 2012; Rysst, 2020). Rather, these current ethics processes are considered “a risk management exercise at the behest of the host institution or funding body” (Connor et al., 2017, p. 400, citing Tolich & Fitzgeralds, 2006, p. 72). As such, we are arguably dealing with a bureaucratic box-ticking exercise with a “one-size-fits-all legalistic approach” that discourages difference in an attempt to preserve the reputation of a university (Connor et al., 2017, p. 406) and that in practice does little to help the

researcher deal with various ethical dilemmas (Guillemin & Gillam, 2016). At the same time, default positions of research ethics have occurred, including ones which Sinha and Back (2013) refer to as *ethical hypochondria*. It is argued that paternalistic research ethics guide our research processes which, for instance, leave us with the idea that good research practice should automatically include anonymity, something which can also be argued to silence and exclude the voices of participants (Bussu et al., 2020; Connor et al., 2017; Sinha & Back, 2013). Furthermore, it is argued that some research ethics processes are more bureaucratic than effective in ensuring ethical conduct of research; signed informed consent forms, for instance, do not necessarily ensure that participants are properly informed about what they are consenting to (Bussu et al., 2020). Thus, not only can we talk of ethical hypochondria (Sinha & Back, 2013); research procedures may also in some instances be considered as “empty” ethics (Pollock, 2012).

When treated as a box-ticking exercise, ethics is institutionally imagined as something researchers do *before* a

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research process begins. Many of us who have conducted qualitative research, however, recognize that ethical dilemmas and considerations occur continuously during a research process (Whiteman, 2017). Consequently, we are often unable to make detailed plans ahead of a research process because ethical dilemmas can arise unexpectedly and not fit a formal and predictable framework (Beaulieu & Estalella, 2012; Rysst, 2020). As Whiteman argues, “the autonomy and expertise of individual researchers becomes subsumed within the regulatory gaze of procedural ethics” (Whiteman, 2017, p. 384), thereby undercutting researchers’ integrity (Pollock, 2012). Consequently, various researchers argue that ethics processes should be ongoing, iterative, and understood as a process rather than merely as a (bureaucratically complex) procedure (Connor et al., 2017; Pollock, 2012; Whiteman, 2017).

The aim of this article is to contribute to the discussions that problematize the way in which qualitative research ethics is perceived institutionally, to underscore the importance of doing qualitative research, even when it is ethically challenging, and to dare to go beyond the standard ethics checklist, as many of us already do (or want to do). As suggested by Guillemin and Gillam (2016), there are “at least two major dimensions of ethics in qualitative research,” namely, procedural ethics—that is, the checklist—and “‘ethics in practice’ or the everyday ethical issues that arise in the doing of research” (Guillemin & Gillam, 2016, p. 264). By research in practice, Guillemin and Gillam mean that researchers should be able to recognize ethical dilemmas when doing research, think them through, and respond appropriately (Guillemin & Gillam, 2016). This also implies that, as argued by the researchers mentioned above, researchers need to think of ethics beyond the standard checklist. In doing so, we suggest that ethical issues in various parts of a research process prompt certain part-specific dilemmas. We also aim to show that complicated ethics processes can be analytically fruitful; when faced with an ethical dilemma, one may also encounter important data and key findings of potentially high societal relevance.

Cases Throughout the Research Process

As we will demonstrate in the following analysis, various ethical dilemmas that researchers need to consider and handle are prompted throughout the different stages of a qualitative research process. We will also argue that ethical dilemmas are not only hurdles to be overcome but also opportunities for enlightenment and deeper understanding of the field being researched.

To build our argument, we analyze three ethical dilemmas we have encountered individually *before*, *during*, and *after* data collection. We analyze these three dilemmas to present examples of how ethical dilemmas can

occur throughout the research process and what they can contribute to our analysis and understanding of the object of research. The case dilemmas stem from three research projects conducted in two Scandinavian countries, namely, Norway and Denmark. The projects in question are qualitative studies and focus on different populations: one of the Norwegian studies focuses on the elderly, the other on 12-year-old children, while the Danish study focuses on parents. The two projects conducted in Norway were both approved by the Norwegian Social Science Data Services (NSD). The Danish project was approved by the Institutional Review Board of University of Southern Denmark. The specific methods of the projects are further described in the case analyses presented below.

Before Data Collection: Informed Consent and Individuals Not Yet Diagnosed With Dementia

The stages of qualitative research that occur before data collection, for instance, include “procedural ethics” (as phrased by Guillemin & Gillam, 2016). This includes the part of the research in which we as researchers go through the institutionally provided checklist and tick the relevant boxes confirming that our research is ethical (based on a positivist paradigm). In principle, we do not question the relevance of this process. As argued in the introduction, regulation of research is necessary, and it is not a bad thing that we have to consider ethical issues before we start the data collection process (Connor et al., 2017). However, the standard checklist does not sufficiently adhere to the aims of qualitative research. In this first case, as in the other two, we will explore a case that goes beyond that standard checklist, a case that shows the complexity of needing to consider ethical dilemmas *before* collecting data in a research process.

The research project on which we build this case was conducted by the second author [“M.H.”] in 2018. The research project studied the use of a specific technology developed to bring people together. The technology in question is a communication device named Komp developed by the Norwegian start-up company *No Isolation* to combat loneliness among the elderly (Oppedal et al., 2019; Rasmussen et al., 2021). Komp is a communication device consisting of a screen with only one button (on and off) that can be connected to an app that allows users to send pictures and messages and make video calls, all of which appear on the screen. The Komp device is located with the elderly person, while the app is installed on the mobile phones of the elderly person’s friends and family. An unlimited number of relatives can be connected to the Komp device via the app. Komp has been developed with older users with low digital competence in mind. The connection and use of the technology are so simple that in principle everyone should be able to use it.

In this study, M.H. interviewed elderly users of Komp and their relatives. The study was part of a larger qualitative study of use and user experiences commissioned by the Norwegian Cancer Society and the Norwegian Directorate of Health (Oppedal et al., 2019). The aim of the larger study was to explore whether the technology is suitable for counteracting loneliness among elderly people. The dataset included 43 telephone interviews with Komp users (21 elderly users and 22 of their relatives) as well as three home visits with elderly people in which field interviews were conducted. An excerpt from an interview with a female elderly user of Komp is presented below. The excerpt relates to the issue of competence to consent and is an example of an ethical research issue that must be decided on before the research process begins. However, the excerpt also expresses a certain level of ethical ambivalence:

Interviewer: How do you think the Komp communication technology works for you?

Elderly user: I'm happy with the Komp. It is easy to use, and it is nice to get pictures from close family. Pictures of the grandchildren in particular are nice to watch. They grow so fast. [. . .] It was my brother, Knut, who got me the Komp. He's good to have. He's helping me a lot. Although I now work less at the nursing home and have more time, it is good to get practical help and support.

In this quote, the informant talked about her brother Knut and about working at the nursing home. However, this 93-year-old informant did not work in the nursing home, but rather lived there. Knut was not her brother, but her son. Otherwise, she answered most questions adequately and was able to share important experiences of the technology. This means that she was an important informant who provided significant information and experiences of a welfare technology developed specifically for her age group. Formerly, the informant had worked as a physiotherapist in a nursing home for over 30 years, and at the time of the interview, the staff often let her lead the gymnastics class if she had the energy to do so. In other words, her stories were close to reality. Nevertheless, the informant is part of a growing population in our society affected by dementia; a population that is growing because the population is getting older. Dementia, however, does not strike overnight, complicating the consideration we as researchers must (and should) give to how participants affected by dementia can participate in research. The ethical dilemma we wish to extract from this research project is how researchers should deal with the question of informed consent in situations where the interviewees may not be fully competent to consent because they are in the process of developing dementia, even though neither the informant nor the informant's relatives yet experience dementia as a problem (Hammersley & Atkinson, 2019).

The principle of informed consent is a contested issue in qualitative research. What, for example, constitutes informed consent? For instance, as argued by Guillemin and Gillam (2016), a signed consent form often merely provides evidence that a researcher has ensured proper documentation of a procedure rather than proving actual informed consent (Guillemin & Gillam, 2016). When it comes to vulnerable populations, informed consent is even more tricky. According to Pollock (2012), “[t]he bioethical principle of autonomy requires that research participation should be voluntary, informed and undertaken by persons with capacity to make independent decisions. This formally excludes all persons lacking such capacity from involvement in research” (p. 6). According to this principle, the perspectives of vulnerable populations, including elderly who may be affected by dementia and who are the target group for welfare technologies such as Komp, would be excluded from research. This is problematic if we want to better understand and care for individuals affected by dementia. Rather than *protecting* these populations, Pollock (2012) therefore argues that these restrictions *constitute harm*. As further argued by Novek and Wilkinson (2017), excluding the perspectives of individuals with dementia “reinforces negative stereotypes and contributes to social exclusion” (p. 1043). Based on these arguments, we should therefore insist on interviewing people affected by dementia in various ways. However, still recognizing the ethical dilemmas that arise when conducting research with people affected by dementia (as M.H. also experienced), various aspects should be considered to ensure safe research practices, such as to “[d]evelop a plan to communicate sensitively with participants who may be unaware of their dementia diagnosis,” “[t]ailor interview questions and communication styles to participants’ communication abilities,” to “[d]evelop a strategy to deal with participant distress, and pay attention to verbal and non-verbal signs of distress” (Novek & Wilkinson, 2017, p. 1045), and to “attain sufficient knowledge of dementia before partaking in research” (Novek & Wilkinson, 2017, p. 1052). M.H.’s project represents a different dilemma from that of having or not having dementia. The informant M.H. interviewed was not diagnosed with dementia, but M.H. could tell that the informant was showing symptoms of the diagnosis. However, it can be considered ethically offensive to question the consent competence of a person considered to be of full legal capacity. Excluding someone because of a researcher’s concern about dementia is problematic, and when faced with this dilemma, M.H. went along with the informant’s story, deciding that making the informant aware of her inaccurate statements might be hurtful. This dilemma points to an important aspect to consider before collecting data, namely, that the categories in which we are supposed to place our data collection often cannot catch all the dilemmas we encounter. Before data collection, we must thus accept that

we cannot prepare for the unexpected, making it complex to consider of ethical dilemmas before data collection.

As it happened, M.H. interviewed several people in her research project who she was sure were unable to provide informed consent: Some did not understand or remember that they were taking part in a research project, some thought it was a follow-up call after a cancer treatment they had undergone, and some thought M.H. and the other researchers in the group were the designers of Komp looking for feedback on the product. In most cases, M.H. and her research team found ways to clear up any misunderstandings along the way, but it was clear that at times, they compromised on the issue of informed consent. Nevertheless, the number of people who fall between competence and incompetence to consent due to dementia is growing, at the same time as they constitute an important target group for welfare technology. This undoubtedly makes it important to understand their perspectives on the digitization of banking, welfare, and health care services, among others. They can talk about the problems they encounter and the solutions they find. But it is precisely this group that would be excluded if researchers were to slavishly comply with the ethical requirement of informed consent. Nor do they have guardians to consent on their behalf. Consequently, the only way to gain an understanding of these informants' experiences is to avoid following the research ethics checklist slavishly.

In M.H.'s research project, informed consent was a marginal problem. However, it highlights an important issue for a growing population in modern society in terms of democratic governance and citizenship. Not least, it reveals the dilemmas associated with an individual's transition from non-vulnerable to vulnerable. People who are considered to be legally competent have not only rights but also obligations which they cannot necessarily meet. Can they provide informed consent, or should they actually receive help from relatives? The relatives of an individual who has not yet been diagnosed with dementia may already be forced to break the law by accessing information on their behalf using their credentials and codes. The ethical dilemmas we encounter as researchers thus help reveal some important societal issues.

During Data Collection: Expert Trespassing Testimony During Interviews

Qualitative research is often unpredictable in nature throughout the research process (Mishna et al., 2004), and the ethical dilemmas we encounter in qualitative research cannot always be foreseen or safeguarded by adhering to a protocol (Pollock, 2012; Woodgate et al., 2017). *During* data collection, qualitative researchers who are in synchronous contact with informants can find themselves in situations in which they have to respond quickly to dilemmas they were unprepared for. As described by Pollock (2012), “[o]n the ground immediate judgements must often be made

about unanticipated events and opportunities which fall outside the formal specification of how a study should be conducted [. . .]” (p. 7). In this kind of situation, the ethical procedures that preceded data collection can be of little use. Woodgate et al. (2017) thus encourage researchers to follow their “gut feelings” and work through ethical dilemmas through “sustaining mindful presence.” Similarly, Sperling (2022) suggests being guided through research through “ethical mindfulness” and, as argued by Pollock (2012), “[t]he greatest protection for participants in qualitative studies is for adequately skilled and experienced researchers to conduct and supervise research” (p. 9). Nevertheless, acting ethically on the spot can be difficult. Guillemain and Gillam (2016) suggest a scenario in which a researcher has been told about the sexual abuse of a child. In this situation, researchers have to decide how to respond; for instance, Guillemain and Gillam suggest that researchers must instantly consider what tone of voice to use, which words to use, and whether or not to take it up. Similarly, Woodgate et al. (2017) question whether it is appropriate to tell a youth living with anxiety that she is beautiful if she talks about despising her body; another decision a researcher would have to make instantly during a conversation. In yet another study, Sperling experienced being asked to engage in participants' plans to end their life by accompanying them to a country in which this is legal, something that could have posed a legal risk to himself (Sperling, 2022).

The case we wish to discuss relating to ethical issues that may arise during data collection is from a research project conducted by the first author (“M.N.”). The project aimed to analyze Danish parents' digital media engagement in relation to the human papillomavirus (HPV) vaccine. HPV is a sexually transmitted infection associated with various health issues such as cervical cancer, genital warts, and anal cancer. The vaccine against HPV was introduced as a part of the Danish childhood vaccination program in 2009, and the introduction was initially successful (Sander et al., 2012; Suppli et al., 2018). However, a few years later, the vaccine came under considerable media scrutiny in Denmark, followed by a decline in vaccination uptake (Nordtug, 2022; Suppli et al., 2018). For the project, M.N. interviewed 18 Danish parents (16 mothers and two fathers) who were deciding on the vaccine for their daughters, aged between 10 and 13. The interviews were conducted between January 2018 and June 2019, after the vaccine had been under media scrutiny, and M.N. interviewed parents from varied educational backgrounds including short-cycle education, further and higher education, vocational training, and basic compulsory education. At the beginning of the interviews, M.N. referred to herself as a “media scholar.” Even so, she received questions about the medical and pharmaceutical aspects of the vaccine, topics that were largely outside her area of expertise. One such conversation went as follows:

Sam: Has anything new happened in the research field [on HPV vaccines]? Do you know anything about that?

Interviewer: I actually know very little about the medical part of it. I know that there have been some changes, I mean, they've, there have been some different versions of it [the HPV vaccine]. I believe that the one that came first, there were a couple versions of the HPV virus that were covered, and now I believe there are more versions of the virus that are covered. There are kind of, there are quite a lot . . . but I'm actually, I don't really have a good grip of the medical-technical or what you might call it, unfortunately. I know more about how people act in relation to it.

Sam: Yeah. So.

Interviewer: So unfortunately, I don't.

Sam: No, but then I'd like to say that the development of it, I think it would be nice to get some information about that. How far along they are, because when it was first introduced there were many side effects and many people reacted to it, and that's what I've seen. So some more information about how far they've come, whether it's been significantly improved and so forth. And maybe there has been some [improvements] and I just haven't seen it, but I would like to see that. [. . .] It also makes me worried. So. So because of that it's hard for me to make a decision because I want what's best for my child. But if I'm not entirely sure of how things stand with the vaccine, then I'd rather not put it into her body.

[. . .]

Interviewer: So that's kind of, I really want to provide all these good answers about the actual vaccine, but that's not at all what I, what I'm able to do.¹

On the surface, the informant seeking information about the development of the vaccine might not immediately appear as an ethical issue. However, being asked about something outside your field of expertise as a researcher is not unproblematic. As seen in the above quote, M.N. was reluctant to provide information about the vaccine to the informant. Her reluctance was due to a fear of providing a testimony the informant would consider an expert testimony. Ethically, it may be problematic for researchers to testify outside of their domain of expertise (Gerken, 2018). However, this is not a clear-cut case. Even though M.N. is a media scholar, she had naturally read about vaccines as well as seeing as she was at the time of the study exploring media in relation to the HPV vaccine. From what M.N. had read about the HPV vaccine, mainstream medical positions suggested that vaccination against HPV could improve public health. Following the information available at the time from the Danish Health Authority, M.N. could therefore, with considerable certainty, have said that the vaccine was considered safe. As the informant in question ultimately wanted to know whether it was safe to vaccinate their daughter, providing testimony about

the vaccine might therefore, (a) ease the informant's worries and (b) persuade the informant to vaccinate their daughter (and thus follow the official recommendations). However, providing testimony about the perceived safety of the vaccine was problematic in the interview situation in question. Even though M.N. introduced herself as a media scholar, it could be argued that by introducing herself as a researcher who wanted to talk about vaccination, she put herself in a situation in which informants might consider her an expert on vaccines. Arguably, one cannot expect non-researchers to know exactly what a media scholar is and thus what M.N.'s area of expertise is. Testifying outside her domain of expertise was therefore morally problematic, as researchers should not pretend to be experts on issues they *think* they know about (Gerken, 2018).

Yet, bluntly refusing to meet an informant's desire for information is also questionable. After all, the informant had allowed M.N. to come to their home and hear their thoughts about vaccinating their child. Moreover, the informant appeared genuinely concerned. Trying to balance between wanting to meet the informant's need for information and not wanting to give the impression of being an expert on vaccines thus became an ethical dilemma—and one that had to be considered in the few seconds available between turns in the conversation. In a (possibly clumsy) way, M.N. therefore tried to say what she thought she knew while trying to make sure she did not give the impression of being an expert. In doing so, she followed Gerken's suggestion for expert trespassing testimony in relation to media appearances, which are arguably also suitable in interview situations: "When S provides expert trespassing testimony in a context where it may likely and/or reasonably be taken to be expert testimony, *S should qualify her testimony to indicate that it does not amount to expert testimony*" (Gerken, 2018, p. 310, original italics).

In a subsequent analysis of this encounter (and others), M.N. was able to reflect on her own role as researcher. Interdisciplinary research poses certain ethical dilemmas, and questions as to when one is an expert on what is not set in stone. Reading information on a health authority's website does not make one an expert, but it might be argued that meeting some of the informants' unmet requests for information could help resolve some of their frustrations—especially for those for whom searching for such information themselves was a hurdle (Nordtug, 2022). In cases like this one, dilemmas thus also revolve around balancing obligations to help informants while not exceeding or trespassing outside one's own area of expertise.

After Data Collection: Analyzing Abnormal and Deviant Data

Compared with when one is collecting data and might have only a few seconds (if that) in which to make decisions on

how to act ethically, the ethical dilemmas that appear *after* data collection will often allow researchers to think through their dilemmas in a more comfortable time frame. The case we wish to discuss relating to issues after data collection stems from a research project conducted by M.H. in 1998 (Haldar, 2006). The case regards analyzing collected data that stand out as abnormal and deviant. The case is based on narrative data in the form of stories written by almost one hundred 12-year-old students from six school classes located in three areas in Norway: a rural area, a city, and a suburb. Each student was asked to pretend they were 35 years old and write about their imagined future from the perspective of family life. The stories written by students who wanted to participate were submitted to M.H. in unmarked envelopes that were handed out to each student for that purpose. M.H. emphasized that no one would know who had written the stories, that the narratives would be anonymized using numbers that were assigned to each student, and that only they themselves would know. M.H. also told them that she would select some narratives and invite the writers to an interview using only their assigned number. The students could identify themselves if they wanted.

Despite the wide variety in the approximately 100 stories, one stood out. It made a strong impression on M.H., and many questions arose about how she should handle the story itself and how to handle her own reactions. These questions are the primary focus of this analysis. The story in question is presented here (the story was written at a below average linguistic level, and we have tried to keep the English translation as close to the original Norwegian text as possible without compromising the meaning of the text):

I am 32 years old and have finally got a girlfriend. My first girlfriend. She is so beautiful. But mom and dad just bother me and say aren't you going to have sex soon? But they have nothing to say, they have had it too, otherwise I would never have been here anyway. But I realize that they are special, very special. But it is not my fault, and that is good at least. But love goes its own way, except that we love one another more and more. We start thinking like mom and dad, maybe more too.

Now we have finally had sex, and I am finally going to be a dad. I wonder how that will be. It is probably all right. I'm going to move in with my girlfriend. By the way, her name is Thea Olsen. But I call her "my little Thea." Suddenly one night "my little Thea" woke me up and said we must go to the hospital right away. I got so nervous that I almost ran over an old man. But the only thing that happened was that he had a heart attack, so he had to be driven too. When we arrived, I had to find a doctor and a midwife. But the only thing I thought about was of course finding a midwife. So, I just let go of the old man and said to him: "It was your fault that you were standing in the middle of the road, so I can't be bothered helping you, because I'm going to be a dad."

Finally, Dad. I didn't have to go to work for a month. That was the best thing of all. But now I must go to work again, and it's some shit, to put it bluntly. By the way, it was a girl. The cutest girl there is, and I mean it. Now she is 3 years old and in the age of trouble. It's hell. Her name is Bea, but her nickname is "Suck Sarah." It's because she whines and sucks and doesn't quit. (She uses a pacifier).

Yes, I will be a dad again, because after Suck Sarah has gone to bed, we spent the whole evening and night FUCKING!!! That's what's nice. But I feel bad for "my little Thea" because she gets the semen in her mouth, hair, and all over her. I don't understand that she bothers to lick my cock, although I like to lick her pussy. But either way, we're going to the hospital again. The exact same thing happened; except I almost ran over the wife of the man who had a heart attack. She had it too, and the same thing happened this time, but it didn't matter. Except that mom and dad bullied me as usual and said I now had the hang of sex, men, and women.

This time I got a boy, and his name will be Tom. His nickname is "Shit kid." Now I am starting to think we have a big enough family. But "my little Thea" does not, so we just kept on having sex and we learned it better, better and better.

We now have 7 children. I think that is enough, but she keeps going and going. We now have 12 children. Now I don't care so much about them anymore. But then she got really mad at me and said that her children would no longer be mine if I kept going like this. So, I had to sharpen up, and we continued with the fucking. It was bad luck because next time we got twins. It was quite embarrassing because I couldn't tell the difference between them. Their names are Falk and Vincent. [. . .]

I decided to leave them and never come back. Well, since I thought I wouldn't miss them, but I must say I did. I have never missed anyone so much in my entire life. I missed the 15 kids and my old girlfriend. Now I start to CRY!!! Hulk, hulk, hulk, hulk. Yes, I am going back. Hope she forgives me, otherwise I'll commit suicide. She's still gorgeous, and the children are gorgeous, very gorgeous.

She is so nice to me. She let me come back on one condition; that I had to care more about the children, and I did. I tell you I did.

We had lots of sex every night, so we did not sleep too much. I took the children to school and kindergarten every day, so I had to wake up at 07.00. I had to drive them, and it took 3 hours just that. But the sex life just went on and on.

Today's my birthday. I'm turning 50. We don't bother having sex anymore. She thinks I'm old, way too old. I think it's just fine!!!!!!!!!!!!!! I THINK SEX IS NONSENSE, JUST NONSENSE!!!!!!!

On reading this story, M.H. initially felt confident that it was primarily a cry for help, not a story about the future.

Incest was one of the first things that occurred to her. This led her to consider two main dilemmas which were also intertwined: first, she felt she needed to determine how to potentially help the student who wrote the story and whether the student actually needed help, and second, how to analyze the story.

First, M.H. felt she needed to investigate if the informant needed help due to both the narrative and the visual presentation. One thing that struck M.H. while reading the narrative, in which sexual encounters were frequently described in unappealing terms, was that the author behind the story was in fact a girl, not a boy. She was the only student who changed their gender identity in the story. M.H. initially believed that the protagonist of the story was a 35-year-old man, despite occasionally identifying with “my little Thea” with her hair full of semen and occasionally with the kids. Regarding the visual expression, this informant had, unlike any of the other informants, provided a decorated envelope—a possible way to stand out. The vocabulary comprised words and phrases which M.H. did not associate with that of a young child. Furthermore, the layout of the typewritten story appeared to express anger: “fuck” as well as other charged words were written much larger than the other words, and some words were followed by up to 10 exclamation marks. In contrast, the text was surrounded by a hand-drawn flower table in bright colors and hearts in various colors, one of which was colored black with a brown thorny stem. The contrast between the visual expression and the narrative of the story made M.H. feel she should do something for this informant. If children disclose being abused by adults, there are protocols researchers must follow (Woodgate et al., 2017). However, the child had not actually disclosed abuse, so M.H. was only dealing with a hunch. Previous research has also found that “researchers often make ethical decisions based on their individual beliefs that generally overexaggerate the vulnerability of survivors” (Woodgate et al., 2017, p. 4), and that young people have found that adults (which researchers typically are) tend to overreact to discussions about sensitive issues such as suicide (Woodgate et al., 2017). Mishna et al. (2004) discuss a similar issue when exploring ethical dilemmas that occurred during a study about the bullying of children. In that study, however, children wrote that they were being bullied and thus experienced hurt “in a way that clearly did not fit within the legal definition of abuse” (Mishna et al., 2004, p. 458), while the researcher conducting the study was “obligated to maintain the child’s confidentiality and autonomy as much as possible” (Mishna et al., 2004, p. 458). However, as Mishna et al. (2004) further argue, “by not acting on information that a child is being hurt means that adults—in this instance the researchers—are not protecting the children” (p. 458). M.H. decided to share her concerns with professionals with various knowledge and experience in the field of child abuse. The professionals did not believe that M.H.

was facing a victim of incest. The partly liberating and angry and partly humorous way in which the informant had expressed herself gave no reason for suspicion. However, the professionals suggested that M.H. inform the school students about where they could get help if something was difficult at home or if they had experienced something difficult and had no one with whom they could talk about it. M.H. therefore told the children that if their stories about romance and family life had provoked bad memories or experiences, they could contact someone at the phone numbers and addresses M.H. provided. M.H. was thus able to provide help without potentially identifying a girl who had been promised anonymity. However, ethical dilemmas like these are almost impossible to know how to act on before they arise and must therefore be addressed as they arise.

Second, M.H. questioned how to analyze the story: How should she analyze the story if it was, as she initially thought, the story of a victim of abuse? When she discussed the story with others, some thought that M.H. should keep the story out of the research project because they believed it lay outside her aim to deal with serious trauma, as the other stories she had received lay somewhere on a scale between hopeful and problematic futures. Others felt that M.H. should not exclude the story from her analysis and that the narrative was no more problematic to analyze than the others. If one does not include these kinds of stories in analyses, abnormal conditions are only addressed when a research topic focuses on the abnormal, and that is arguably a problem: We can escape abnormal conditions too easily in research, as they become something we can categorize as deviations. However, the “ordinary” is heterogeneous, and deviations are and will always be part of the ordinary. As such, when gathering information from 100 children, the chances are that some children will have experiences that do not fit with the constructed and non-specific idea and ideal of the ordinary; some may, for instance, have experienced incest or other kinds of abuse. Consequently, the heterogeneities and deviations should be expressed along with the ordinary, even if the study is not designed to study deviations. Some of the professionals M.H. talked to recommended that the story be given a place in the research project as a testimony to the overarching, violent, and incestuous sexuality that also exists in our culture. This mirrors Ronai’s (1995) arguments that stories of child sex abuse should not be hidden away and shrouded in silence. Nevertheless, as she later felt convinced that she was not dealing with a victim, M.H. considered that her interpretation of the story had been met with little resistance. Everyone she consulted believed there was something abnormal and perverted about the story. However, with a more curious and open attitude that did not automatically consider the child a victim, the story became an exciting and imaginative text. A quite different author came into view, one who took advantage of the privilege of anonymity and the space for

imagination, and who trusted M.H.'s promise that she could write anonymously and uncensored as far as her own imagination went—an example of how girls both before and now have been taught *not* to write. In M.H.'s new reading process, layered levels of interpretation emerged, where reflective loops of gendered notions announced their intricate entrance (Haldar, 2006).

Discussion and Conclusion

Being ethical is a complex and messy task when working in research (Whiteman, 2017). Moreover, in doing research—and with time (and new technologies)—many ethical dimensions are changing (Beaulieu & Estalella, 2012; Hesse et al., 2018). Even so, the knowledge to be gained from qualitative studies is important, and even complex and messy qualitative studies *should* be conducted (Ramcharan & Cutcliffe, 2001). In conducting these studies, it has been argued that researchers should continually address ethical dilemmas during the research process, something we have also argued in this article (Goncalves, 2020; Mishna et al., 2004; Sperling, 2022). In the three cases described above, we present different dilemmas in various parts of the research process in three different research projects focusing on three different parts of the population and from two different countries. The dilemmas are all suggestive of how ethical dilemmas can provide qualitative researchers with deeper understandings of the research situation. Thus, one can gain important analytical insights when faced with an ethical dilemma. Instead of trying to avoid situations that are ethically complex, we as qualitative researchers should assess their analytical value at all stages in the research process. Ethical dilemmas that do not already appear on the checklist are a valuable part of knowledge creation and should not be underestimated.

In this article, we propose that researchers should frame the “ethical part” of their research not just as a procedure but also as an analytically important process that may come into play before, during, and after interacting with informants through data collection.

The different parts of a research process demand various kinds of work and will vary from project to project. *During* data collection, for instance, being asked a question face-to-face will require researchers to answer quite promptly, and though they may be well prepared, they risk being caught off guard. This was the case for M.N., who went with her gut feeling when responding to a query outside her area of expertise. This kind of response can come off as clumsy and imperfect. Following one's gut feeling, as suggested by Woodgate et al. (2017), may nevertheless be necessary during data collection when there is little time to reflect on how to respond to a dilemma. As researcher competencies improve, researchers should feel competent to provide good answers. Furthermore, being caught off guard may say

something important about the situation in question, such as what was not considered, and why. These questions can help researchers to reflect further on the research topic in question.

Before data collection begins, however, following one's gut feeling is not always adequate. Planning to interview vulnerable populations, for instance, may require researchers to do their homework on what makes populations vulnerable (Novak & Wilkinson, 2017). In situations like the one M.H. found herself in when interviewing elderly people who may be affected by dementia, for instance, it may be ethically considerate to read up on dementia to be prepared for what may occur during data collection. The likelihood of dementia becoming an issue can be impossible to anticipate. However, even if one anticipates problems, that should not necessarily entail that one should not proceed with the research. Thus, as qualitative researchers, we must insist on not letting risk assessments based on positivist principles guide our research ethics practices. We must insist on this as our opportunities for conducting research may otherwise be limited when it comes to involving research participants in various ways (Connor et al., 2017; Rysst, 2020). These limitations may stop us from conducting important research on topics that are, for instance, sensitive or that involve populations that are vulnerable (Pollock, 2012). For instance, the testimonies of individuals transitioning from non-vulnerable to vulnerable due to dementia are invaluable. We need to learn from their experiences and not let positivist ideas of ethics prevent us from engaging with their testimonies. We must also accept that we cannot anticipate everything before the research process begins.

After data collection, researchers may have more time to reflect on their dilemmas. These reflections can then provide analytical value to the study. The ethical dilemma over a young child's sexually explicit story from the third research project made M.H. realize that she had had a simple and naive “reality” in mind regarding what the children's stories about the future should express when she created the assignment. She had therefore not planned how she would handle serious situations if they were to arise. However, handling the situation ended up being an important part of the analysis. In the case of the children's stories, M.H. found an ambiguity in the case story which allowed multiple interpretations. Namely, it was due to processing her initial reaction to this story and the ensuing ethical questions that M.H. was able to read the story differently. Through her various readings, M.H. found that the story provided an important perspective for understanding gender, age, and family life, and learned that there can be fuzzy boundaries between analytical interpretations and moral prejudices.

As our cases show, facing ethical dilemmas in research can be analytically fruitful. The dilemmas may, for instance, prompt us to consider issues we otherwise would not have considered; they may open our minds to new societal

matters, and they may provide new perspectives on our analyses. As qualitative researchers, we must therefore insist on continuing to research topics that may prompt ethical dilemmas, even though they do not fit the positivist paradigms on which current checklists are based. Consequently, research ethics are not simply procedures of “informed consent, opposition to deception, safeguards to protect privacy and confidentiality and, ensuring accuracy in research results” (Connor et al., 2017, p. 401), but rather continuous and fruitful parts of knowledge creation that we should embrace as opportunities to learn more about the world we study.

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Note

1. The quote was also analyzed in the first author's (unpublished) PhD dissertation.

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