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Current Perspectives on Research Ethics in Qualitative Research

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Abstract: In this article, we provide a brief introduction to the special issue on research ethics in qualitative research. We describe the general context within which our idea emerged to organize a special issue and present its design and, for purposes of transparency, some particulars with respect to the selection and review process. We sketch some of the common themes that are shared across parts of the paper set, including critical analysis of ethics codes and ethics reviews, the intricacies of informed consent, confidentiality and anonymity in qualitative research and questions of vulnerability.

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1. Introduction

The question of ethics has been a mainstay of philosophical inquiry for millennia—e.g., when the ancient Greek wondered about *phronesis,* that is, the nature of wisdom in practical action that inherently affects others (RICŒUR, 1990). In research involving human subjects, the phenomenon is much more recent (ROTH, 2004a). In the historical development of the debate, medical research ethics played a prominent role. For example, the Nuremberg Code (1947) constituted a key milestone. It was formulated in response to the inhuman medical experimentation practices under the Nationalist-Socialist regime in Germany and included principles such as voluntary participation and informed consent. Since then debates and ethics codes have evolved in many fields and disciplines throughout the world. Yet, during the 1950s and 1960s it was still possible to expose human beings to extreme physical and mental stress—such as testing the chemical weapons Agent Orange and Agent Purple on the Canadian Forces Base Gagetown (New Brunswick) without 1. informing nearby communities, 2. the consent of the Canadian and U.S. military personnel stationed there or distributing the agents, and 3. providing appropriate knowledge concerning the consequences of exposure (AGENT ORANGE ASSOCIATION OF CANADA, 2009). Also in the 1960s, an American psychologist conducted experiments where subjects were led to extreme distress when coaxed into punishing others by means of electroshocks (MILGRAM, 1963)—a study that is also discussed in this issue, albeit with a different focus (YANOV & SCHWARTZ-SHEA, 2018). These and other controversial research practices triggered outrage, public debate and political action resulting in the creation of a new ethics infrastructure. Human research ethics boards—called institutional review boards (IRB) in the US, research ethics boards (REB) in Canada, research ethics committees (REC) in the UK, as well as other names elsewhere—were created around the world to curtail such exposures. However, the implementation of such boards, which happened rather quickly in most Anglo-Saxon countries (Australia, Canada, New Zealand, UK, and US), has not occurred at the same rate in other parts of the world (e.g., Germany, see VON UNGER, DILGER & SCHÖNHUTH, 2016)—and their role in fostering ethical research practices remain unclear at least. In fact, they have drawn extensive criticism, in particular from qualitative researchers in the social sciences (CANELLA & LINCOLN, 2011; ISRAEL, 2014; VAN DEN HOONAARD, 2011). [1]

Yet, it is undisputed that the question of ethics also arises in qualitative research as "the emergent, dynamic and interactional nature of most qualitative research" involves complex ethical responsibilities (IPHOFEN & TOLICH, 2018, p.1). Nearly 15 years ago, this has led the editors of this journal to create a forum for debating ethical issues. Our purpose at the time was to evolve a community of ethical research practitioners rather than merely talk about and theorize ethics without actually engaging with the issues of practical conduct in the field and how research affects all those involved (ROTH, 2005). We wanted issues to be discussed that might otherwise not have a forum to be aired. An immediate concern was the different ways in which experimental psychologists and participant or activist researchers engaged with participants, how much input participants should or could have in the design of specific research projects. There had been signs in experimental research on drugs developed for AIDS that the involvement of participants improved on the quality of the (quantitative) research rather than watering it down (EPSTEIN, 1995). Other issues that arose at the time concerned the involvement of research participants as authors, and the particular (audience-dependent) conditions where it made sense to include them and when it did not. [2]

Various conceptualizations of research ethics exist and the topic has been at the center of a lively and heated debate internationally (HAMMERSLEY & TRAIANOU, 2012; IPHOFEN & TOLICH, 2018; VAN DEN HOONAARD, 2011; VON UNGER et al., 2016). The current controversies mainly revolve around the institutional regulation of research ethics, i.e., what GUILLEMIN and GILLAM (2004) aptly termed "procedural ethics" (p.263). In some national contexts, institutional ethics reviews are obligatory not only for medical research but also for social science research including qualitative research. As stated above, a substantial critique has formed pointing to the shortcomings and dangers of institutional ethics reviews and codified ethical standards and principles (e.g., HAMMERSLEY & TRAIANOU, 2012; ISRAEL, 2014; VAN DEN HOONAARD, 2011; VON UNGER et al., 2016). Negative implications have been described for scientific quality and academic freedom in general and for qualitative research in particular (e.g., VAN DEN HOONAARD, 2011). The institutionalized means for assessing research protocols are based on the medical and experimental sciences; they imply research situations and processes that may be inappropriate for qualitative research. The regulatory enterprise has thus drawn a lot of criticism. In fact, the defense against regulation has dominated much of the debate on ethics. Creating very real problems for qualitative researchers in many places, procedural ethics thus effected a narrowing of the debate. Some have argued that ethical conduct should instead be more aptly conceptualized as an ongoing, critical and dialogical engagement with the moral and political questions of conducting research (CANELLA & LINCOLN, 2011). In this spirit, qualitative researchers have recently started to reframe the debate and focus more on ethical concepts and issues relevant in their research practice (e.g., IPHOFEN & TOLICH, 2018). [3]

Ethical reflexivity is a core feature of qualitative research practice as ethical questions may arise in every phase of the research process (VON UNGER, 2016). For example, researchers ask themselves: will this project be worthwhile? Who will benefit from it? What are the potential risks for the participants? What are our roles and responsibilities as researchers? Who are we accountable to and what are we accountable for? Some of these questions have already been the focus of the *FQS* debate on ethics (see link above). These questions do not generally have easy answers, as ethics are intertwined with (university, state, field) politics in many ways (ROTH, 2004b) and remain open to re-interpretation and debate in fundamental ways. Such issues arise in the contribution by Caroline MEIER ZU BIESEN (2018), who discusses questions about the ethical positioning of the researcher in a field including Big Pharma. Political ramifications often exist as well, especially when indigenous groups are involved; and such ramifications were apparent in a recent study among the Bajau people, who exhibit exceptional diving skills. The investigators have come under fire because Indonesian officials claim that ethical protocols had not been followed when the researchers had taken DNA samples out of the country (ROCHMYANINGSIH, 2018). There was a local Indonesian research involved, but, according to other scientists, this individual had not expertise in the relevant fields (evolution, genetics) and only provided logistical support. The lead researcher, Eske WILLERSLEV (University of Copenhagen), on the other hand says that she has done everything that the relevant ministries in the Indonesian government had required and she was unaware of any wrongdoing. There are other mine fields as well, such as when qualitative researchers also engage in sexual relations with their research participants and especially if the participant is handicapped (ROTH, 2004c) or when qualitative researchers do participant observations at sex parties (WEBBER & BRUNGER, 2018), to name just a few. [4]

We thus designed the special issue to address ethical conduct and reflexivity as genuine issues of concern to qualitative researchers while scrutinizing and celebrating the diversity of research contexts, research approaches, and possible ethical positions and argumentations. [5]

2. Design of Special Issue and Process of Selecting Contributions

2.1 Design

The description for the contents of intended submission deliberately was cast wide: We hoped the special issue to reflect the diversity of the field as much as the diversity of issues that qualitative researchers associate with research ethics. Thus, we called for submissions addressing one of the following areas of debate:

1. Reflections of ethical issues arising in qualitative research practice, e.g., how do qualitative researchers experience ethical questions and challenges? How do they define and manage their roles and responsibilities? How do they present and justify their research to (potential) participants? How do they do informed consent (e.g., as a dynamic, ongoing dialogical process)? How do they anonymize their data without diminishing its hermeneutical value? However, is anonymization a realistic and appropriate aim at all? Do confidentiality clauses solve some of the problems arising from the threat to the privacy of the participants? Under which circumstances may pseudonymization be insufficient or inappropriate? These examples of "ethics in practice" (GUILLEMIN & GILLAM, 2004) discuss the questions, problems and solutions in the context of specific research studies.
2. Analysis and discussions of ethics codes, reviews and regulation including evaluations of experiences with *undergoing* or *conducting* institutional review (as a member of an ethics review board). What is the legal framework and the institutional setup of the respective review procedures? How does the specific context (e.g., region of the world, academic or community setting, field of study, etc.) affect the review process and the principles and standards that are applied? How are the laws and general guidelines interpreted? What are the implications? And also: how can qualitative research be reviewed and assessed appropriately?
3. Conceptualization of ethics relating to specific methods and methodologies (e.g., (auto-)/ethnographic research, biographical research, participatory research, research with indigenous peoples, etc.) and theoretical discussions of research ethics and ethical conduct in qualitative social science research. For example, how can critical or covert approaches be justified in ethical terms—in specific research situations? What are the ethical strengths and weaknesses of participatory research approaches?
4. How can research ethics and ethical reflexivity be fostered in teaching and methods training in undergraduate, graduate and post-graduate study contexts? What is the approach taken and how did it work out? [6]

2.2 Selecting contributions from submissions and editorial process

We received over 160 submissions in response to our call. The sheer number made our selection process difficult, as we could envision being able to work closely only with a more limited number of authors and author teams. Both editors of this special issue read all abstracts. We developed a simple, five-point coding scheme (-, -0, 0, 0+, +) whether to include or not include a particular proposal. For each proposal, we also wrote brief statements concerning any strengths, weaknesses, or other reasons for non/inclusion. All articles that both of us felt positive about (+, +) were selected. We then discussed those submissions that had received at least on plus (+) rating, which may or may not have led to an upgrading of the second rating. In this process, we ended up with 29 articles, twice as many as we originally thought to include. However, feeling that some withdrawals might occur we invited all 29. In the end, 7 of these withdrew for a variety of reason leaving us with the collection of studies that appear here. In our interactions with the invited authors, we encouraged authors to familiarize themselves with the debate concerning ethics in qualitative research, including the debate that already existed in the pages of *FQS*. [7]

The review process turned out to be extensive. All submitted articles underwent multiple review cycles until the papers were in their present form. Each editor was lead reviewer for one half of the submissions, but both editors read each paper in each cycle in its entirety. [8]

3. Overview of the Special Issue

Reading the manuscript set in its entirety, the task of trying to make sense emerged to be a daunting task. As journal conventions do not include subsections, as would be the case for books, which allow for special introductions to each of the sets of papers collected into a thematically specific part of the whole, the present contributions appear one after another, whereby the order does not reflect any hidden thoughts about quality. [9]

The first article was placed in its position because of its conceptual nature and overarching content, an argument for the use of a transactional (relational) ontology as a basis for research ethics (ROTH, 2018). Here, a clear distinction is made to the widely used interactional approach to treating relationality, which has serious consequences for how we think about and deal with the relationship between researcher and researched. The second paper also has a foundational dimension, as it discusses three key studies (by MILGRAM, HUMPHREYS and ZIMBARDO) that historically have been heavily critiqued because of the underlying deception and covert research practices (YANOV & SCHWARTZ-SHEA, 2018). The paper provides us with a fresh, different reading of these studies—the authors suggest not prematurely condemning deception and covert research practices, stressing instead the merit of these studies in scientific and societal terms. [10]

Four papers in this special issue focus on ethics codes and review procedures in a critical fashion: GUISHARD, HALKOVIC, GALLETTA and LI (2018) offer a critique of the guidelines of the American Psychological Association (APA) from the perspective of qualitative, community-based researchers. The authors reconstruct how the APA code of ethics evolved historically and use their own research experience and encounters with ethics boards to show where this code has apparent epistemological gaps. SANTINELE MARTINO and SCHORMANS (2018) address the paradoxical and disempowering effects of ethical review procedures in the context of research with people labeled with intellectual disabilities. WEBBER and BRUNGER (2018) scrutinize the foundations and procedures of risk assessments that form a key part of institutional reviews. In recent years, increasing attention has been paid to potential risks not only for study participants, but also for researchers. The authors question such risk assessments arguing that these carry problematic moral undertones that usually go unnoticed and have serious adverse effects in the field of sexuality research. Last but not least, an experienced researcher involved in the revision of the Canadian ethics policy (the Tri-Council Policy Statement) shares a critical autobiographical account of his efforts to make the national guidelines more appropriate for qualitative research (VAN DEN HOONAARD, 2018). Unfortunately, whereas some contributions mention undergoing ethics review *en passant* without problematizing it (e.g., REITINGER et al., 2018), our call for good practice examples of review procedures (e.g., in the context of academic or community-based ethics reviews) remained unanswered. [11]

The bulk of articles in this special issue, deals with ethical issues and challenges experienced in particular study contexts, i.e., with "ethics in practice" (GUILLEMIN & GILLAM, 2004, p.264). These include studies with people with dementia (REITINGER et al., 2018), biographical research with migrants (SIOUTI, 2018), research on political education in schools (KNOTHE, 2018), and multiple studies with displaced persons and refugees (AKESSON, HOFFMAN, EL JOUEIDI & BADAWI, 2018; DITTMER & LORENZ, 2018; FICHTNER & TRẦN, 2018; LESTER & ANDERS, 2018; MIKO-SCHEFZIG & REITER, 2018; VON UNGER, 2018) among other research contexts. [12]

Not surprisingly, a number of these contributions address the issue of vulnerability, e.g., as it relates to participants with disabilities (REITINGER et al., 2018; SANTINELE MARTINO & SCHORMANS, 2018), children (ESSER & SITTER, 2018), refugees and displaced people (FICHTNER & TRẦN, 2018; LESTER & ANDERS, 2018; VON UNGER, 2018), people in detention prior to deportation (MIKO-SCHEFZIG & REITER, 2018), families (including children) displaced by war (AKESSON et al., 2018), or those affected during disasters (DITTMER & LORENZ, 2018). Some contributions also address the vulnerability of researchers, for example, when undergoing ethics review by boards unfamiliar with the research field and prone to being overly protective and restrictive (GUISHARD et al., 2018; WEBBER & BRUNGER, 2018), or in challenging research situations (FICHTNER & TRẦN, 2018; GAZSO & BISCHOPING, 2018). This should not surprise, for researchers are as much subject and subjected to the conditions of the investigative field as they are its agential subjects (ROTH, 2018). One contribution presents an empirical investigation of how Polish researchers deal with confidentiality in the case of vulnerable populations (SURMIAK, 2018). [13]

An important question that we repeatedly asked ourselves concerned the ontology at work, especially when it comes to phenomena and concepts that are relational and thus cannot be pinned on the individual. For example, it has been noted that power does not have thing-like properties so that one person or institution could have it and another does not (FOUCAULT, 1975). Thus, a static view implying that a researcher always has power over the participants is inappropriate. Instead, power—or rather power/knowledge—is a relation, and a relation is an event (not a stick-like thing). An event is alive and is brought about through the cooperation of all participants, who are subject and subjected to the very event that is partially of their own making. Following BATESON (1979) suggesting that dependency, often ascribed to children, should not be thought of as a property of a person, vulnerability would likewise not characterize a child or a person with differential set of abilities. The idea of symmetry between researcher and researched, researcher and research participant, arises from (WEBBER & BRUGGER, 2018) or is explicitly discussed in three contributions (ESSER & SITTER, 2018; LESTER & ANDERS, 2018; ROTH, 2018). Symmetry also is a latent theme in a study concerning ethics and "disability," where the term is part of a politics that marginalizes some at the expense of others (SANTINELE MARTINO & SCHORMANS, 2018). [14]

Another important issue that arises from multiple contributions may be grouped together under the heading of "ethics of care." Here we would also group studies that question whether qualitative researchers have an ethical obligation to advocate (LESTER & ANDERS, 2018; MEIER ZU BIESEN, 2018), make available study findings to participants (NAIDU & PROSE, 2018), take special precautions for participants in the care of someone else (for children: ESSER & SITTER, 2018; for people with dementia: REITINGER et al., 2018), or even act on behalf of a participant (FICHTNER & TRẦN, 2018). [15]

Recent decades have observed tremendous cultural transformations arising from social media, the availability of new technologies, and new cultural practices emerging together with the technical means. Two studies investigate ethical questions related to video data available through Google, YouTube, or Facebook (LEGEWIE & NASSAUER, 2018) and audiovisual studies (KRUG & HEUSER, 2018). The former investigation examines five areas and their interplay in which online video research raises specific questions or promises unique potential—informed consent, analytic opportunities, privacy, transparency, and minimizing harm to participants—and reflects on how this may be used to inform practitioners and reviewers. The second investigation focuses on ethical issues arising from the very ways in which video data are recorded and produced using mobile eye-tracking devices. [16]

A number of contributions address the intricacies of gaining informed consent. Particular questions that arise for the problem of informed content in the case of intellectually disabled persons, such as when research involves people with dementia (REITINGER et al., 2018). The process of obtaining consent may be intertwined with other processes in a complex, tension-laden field where formal juridical demands of the participants' institution (e.g., school in the case of students) and the social space of the school with its specific demands and pressures of the various agents, who may become gatekeepers, and power/knowledge relations (KNOTHE, 2018; SIOUTI, 2018; VON UNGER, 2018). Such intricacies may also come into play in disaster research, especially when the victims are to become participants (DITTMER & LORENZ, 2018). When the victims already are traumatized, the process of informed consent may counteract the principle of minimization of harm. Informed consent therefore may be a hindrance and even cause harm. In some situations, it may thus be more appropriate to have verbal rather than written consent (SIOUTI, 2018; VON UNGER, 2018). Further special constraints arise when the research objects already exist in the public sphere, such as those people upload to social media, including YouTube and Facebook (LEGEWIE & NASSAUER, 2018). From the perspective of qualitative research, therefore, the particulars of the informed consent process need to be worked out anew in the specific contexts of the research field at hand (VON UNGER, 2018). One central question is whether informed consent is even necessary, for the materials used in the investigation already are public. As the analogy with studying the crowds in football stadiums shows, it may be impossible to obtain informed consent from all participants. Moreover, given that crowds constitute *social* phenomena sui generis, the phenomenon studied cannot be reduced to individuals and thus does not involve the individual as the source of data: Relations, forms of events, are the sources of data. [17]

Confidentiality and the associated anonymization of participants constitute an overarching theme across a number of studies. The term anonymization may lead to ambiguity and conflation between the terms anonymity and confidentiality. True anonymity is achieved when researchers do not know the identities of the research participants, such as when people respond to questionnaires submitted in a manner that does not tie person and data. This is hardly ever the case in qualitative research. Confidentiality, on the other hand, refers to the fact that researchers know the identity of the participant but commit to not revealing the person's participation and identity. But when the research design does not involve working with participants individually (e.g., in "self-contained" interviews), such as when research is conducted in a classroom or in the open offices of a start-up, then those present tend to know who participates in the research and who does not. A variant of this issue appears in one of our studies, which distinguishes between confidentiality *inside* and *outside* the refugee community where the research was conducted (AKESSON et al., 2018). Whereas there may be limits to maintaining confidentiality on the inside of the community, there is an obligation to ascertain confidentiality on the outside. The term anonymization refers to the fact that those particulars in the data are deleted that might allow readers to identify the person, institution, locale, etc. The most common practice related to anonymization is the use of pseudonyms. The strategy is important especially in the case of vulnerable participants, who might incur negative consequences for their contributions to the data. For example, in the case of refugees, anything that would allow backtracking a sensitive statement to an individual and participant could negatively affect their current situation or even their chances to stay (VON UNGER, 2018). Biographical research with migrants poses special challenges, because anonymization appears to run counter to the idea of biography itself (SIOUTI, 2018). One study in our collection is important in particular because it constitutes an empirical investigation into the strategies qualitative researchers (in Poland) use to ascertain confidentiality (SURMIAK, 2018). [18]

4. Coda

The present collection of studies concerning ethics in qualitative research bears testimony that the research community has come a long way from where it still had been in the 1960s, when research was conducted that obviously harmed participants and bystanders. It is exciting to see that qualitative researchers tend to treat ethics not as a code but as a characteristic of the relation between researcher and researched. Once we consider the relation as an event (rather than thing), it is immediately apparent that ethical questions never are resolved with some formal institutional approval of the research. Instead, ethical questions are aspects of human life and relations and thus continuously pose themselves anew, remain for a while, and die away only to be reborn again in some other form. [19]

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