Preface to the Special Issue "Practical and Ethical Dilemmas in Researching Sensitive Topics with Populations Considered Vulnerable"

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Conducting social science research is a complex process. In addition to the usual theoretical and methodological concerns, researchers have to contemplate several ethical issues and answer several questions: what impact will the research have on the various actors involved? What risks can arise? What strategies should be adopted? These and other issues, however complex they may seem, must emerge at an early stage of the research, so that researchers have time to mobilize themselves in the creation of coping mechanisms. In this initial phase of research preparation and planning, researchers must also seek to answer two important questions: will the research focus on a (potentially) vulnerable group? Will the topics in the research be (potentially) sensitive? If the answer is positive to at least one of these questions, researchers have a responsibility to search for or create solutions for any challenges that might (predictably) arise. This book fundamentally seeks to support all researchers who interact with vulnerability and sensitivity in the context of social research by providing various research experiences, as well as the elements that characterize them.

Whilst there has been some important debate about the theoretical, methodological and ethical issues of conducting research on sensitive topics and/or with vulnerable populations [1–3], the number of scholarly publications that are focused solely on these topics is limited and not up to date [4, 5]. The work published so far tends to focus on the emotional labour developed by researchers when doing these types of studies, and, in particular, on the strategies employed by them to safeguard the well-being of the research subjects, as well as their own well-being [6–10]. What this work also suggests is that the emotional impact of developing research with vulnerable populations and/or on sensitive topics should be understood as a form of risk, in the sense that researchers might be exposed to distressing events and accounts throughout the entire research process: from data collection to data analysis [11]. This recognition is important for researchers and ethics committees [12], and should involve the development of specific strategies to better support researchers, particularly those less experienced, such
as postgraduate students and postdoctoral researchers, who might feel unprepared to deal with these risks [13].

While undertaking our own work with topics that might be considered sensitive, and on populations that might be defined as vulnerable, we noticed that there was little information available in the field of social sciences about the backstage of conducting this type of research. This led us to organise a panel about this topic under the overall theme at the Portuguese Anthropological Association Conference in June 2019. The panel received over 20 submissions, and was a valuable opportunity for Portuguese, Spanish and Brazilian researchers in the field of anthropology and sociology to share and discuss their experiences. After this event, we reached the conclusion that it was important to create a space where other researchers from different disciplines could present their experiences of conducting research on sensitive topics and/or with vulnerable populations. Therefore, while we invited all the presenters in our panel to write an article for the special issue, the call was also open to all colleagues in the field of social sciences. With this book, we intended to build awareness about research challenges and opportunities, as well as to offer guidance for researchers who work, or intend to work, on sensitive topics and/or with vulnerable populations. The idea was to offer a place for researchers to share their experiences, namely in terms of the theoretical frameworks adopted, the methods applied, the strategies employed, and the risks accessed. Thus, colleagues were invited to write about the theoretical and practical dilemmas of conducting research with vulnerable populations and/or on sensitive topics.

The articles selected for this book intend, first and foremost, to stimulate reflexivity amongst the use of the concepts of sensitive topics and vulnerable groups. Within the field of social sciences, the concept of vulnerability has been used to define people who lack the capacity to make decisions, due to physiological/psychological factors or status inequalities, and/or who experience impairing conditions that might constrain or diminish their physical and cognitive autonomy [14, 15]. In this category, it is possible to include groups that are traditionally marginalized (e.g., people with HIV/AIDS), institutionalized groups (e.g., prisoners), groups without the mental capacity to consent (e.g., the mentally ill), groups that engage in risky behavior or have contact with/live in environments considered dangerous or impoverished (e.g., homelessness) [16]. On the other hand, the concept of sensitive topics has been used to describe themes that might be considered intrusive and/or harmful for research subjects and/or for the
researcher [17, 18]. Although sensitivity is relational—i.e., is negotiated and shared in the relationship with others [19]—it is possible to foresee sensitivity in certain topics, based on past experiences, and on a kind of established and shared knowledge around certain themes and subjects that might lead to negative emotions [4]. Generally, these topics concern issues that are considered taboo or stigmatizing (e.g., sexual practices), issues related to illegal or criminal practices (e.g., drug use) and personal issues that can cause discomfort (e.g., death) [16]. There is a very close relationship between the concept of vulnerability and sensitivity, since the research on groups considered vulnerable can lead to addressing topics considered sensitive, and vice versa [2, 5].

This first approach to the concepts under analysis allows the framing of the two axes of vulnerability and sensitivity, which structured the contributions gathered in this book. Although these concepts have been well defined in the literature [14, 15, 17, 18], it is important to bear in mind that these are broad and mutable concepts. As a matter of fact, in several articles within the book, it is possible to find different appropriations of the concept of vulnerability. Thus, the concept assumes various forms and meanings depending on the object, theories and methods mobilized. Daria Litvina, Anastasia Novkunskaya and Anna Temkina challenged more traditional definitions around the concept by characterizing doctors as being vulnerable. In an ethnographic study of a Russian perinatal center, the authors showed how a group that, generally, is seen as having a powerful and privileged position, can feel vulnerable in concrete situations when executing their professional duties, such as dealing with patients' suffering, carrying out complicated clinical tasks and dealing with regulatory bodies. The authors also proceed to the analysis of ‘existential’ and ‘moral’ vulnerabilities, thus showing the complex and multifaceted nature of the concept. Catarina Delaunay, Amélia Augusto and Mário Santos showed the ambivalent nature of the concept of vulnerability. Although the authors classified assisted reproductive technologies (ART) beneficiaries as (potentially) vulnerable subjects, due to the difficult decisions they have to make about the fate of cryopreserved embryos, they also claimed that it is possible to consider them empowered human beings, with the ability to make difficult choices responsibly and autonomously. In this way, the authors reinforced the complexity of the concept, and the need to analyze it contextually.

The concept of vulnerability has also been challenged for its overarching nature or for focusing only on certain individuals and groups [20, 21]. The risks associated with
its use might involve labeling, stigmatization, objectification and marginalization processes, contributing to the disempowerment of those who are considered vulnerable [22]. Indeed, the article by Ingfrid Matingsdal Thorjussen and Terese Wilhelmsen called attention to the fact that categorizing children in research, particularly those with disabilities and of diverse ethnic backgrounds, might lead to social inequality and discrimination against them, instead of protecting them. The authors highlighted the ways in which categories might shape the power relations established between the researcher and research participants. In addition to the inherent vulnerability of children, due to their biological immaturity, Thorjussen and Wilhelmsen made the interesting point that structural vulnerability, which is constrained by social and political forces, might lead children to be understood as powerless. The importance of reflecting critically on the use of certain categories was also outlined by Mathilde Cecchini, who spoke about the risks of reinforcing stereotypes and stereotypical reasoning when conducting research on these matters. Drawing upon the examination of what Cecchini defined as ‘ethically delicate moments’, she reflected on the strategies employed to overcome these challenges. Both Cecchini’s, and Thorjussen and Wilhelmsen’s articles offer illustrative examples of the important role of procedural ethics [23], and the need for researchers to critically reflect on their theoretical and methodological options. In addition to procedural ethics, it is also important to highlight the role of situational ethics, related to the specific and unanticipated dilemmas that emerge in the research field; of relational ethics, related to the reciprocity and recognition of the other; and exiting ethics, related to the researcher’s departure from the scene (from the research field) and the resulting impacts [24].

Pernille Skovbo Rasmussen and Anne Katrine Pagsberg stressed the importance of developing strategies to improve the involvement of vulnerable populations, such as children with disabilities, in social science research. The authors discussed within the article their methodological and ethical decisions when conducting research with autistic children. In a similar way, Paula Cristina Martins and Ana Isabel Sani highlighted the importance of some methodological strategies, such as ongoing consent, when developing research with children about violence practiced by significant others against them. While these children might experience ‘multiple vulnerabilities’ [25], due to their biological status as a child and to the fact that they have been victims of violence, the authors claim that they should not be excluded from research, as it is important to hear their voices. The authors also argued that in order to protect these children, ‘ethical symmetry’ [26] should
be promoted, and thereby researchers should involve children as much as they would involve adults. This issue was also approached by Ana Patrícia Hilário and Fábio Rafael Augusto, when they spoke about the strategies employed to conduct research with children with chronic pain. The authors discussed the challenges of accessing, recruiting and obtaining the informed consent of a doubly vulnerable population, such as ill children, and the importance of the use of certain methods in order to overcome these challenges. In this regard, John Michael Ryan's article is extremely important for advancing a methodological proposal to better accommodate the trans community. Being able to detail the numbers behind the trans community makes it possible to deepen knowledge about it, as well as to avoid creating labeling and stigmatization processes. Ryan’s article showed how important it is to adapt the data collection instruments to the individuals and groups on which the investigation focuses, otherwise researchers can, to a certain extent, contribute to weakening even more groups already considered vulnerable, such as the trans community [27].

The vulnerability of the researcher is an aspect explored in other articles, this option also challenges more obvious associations to the concept, by placing at the center of the equation the vulnerability of a group of individuals that, generally, is seen as having power and autonomy within the scope of research [16, 28]. Joana Catela discussed her level of immersion in the field as an ethnographer and the emotional labour resulting from the various negotiations that took place with the various actors of the nonprofit organization where the data collection took place. Lynette Sikic Micanovic, Stephanie Stelko and Suzana Sakic also reflected on the researcher's vulnerability in contact, more or less directly, with a population considered vulnerable, particularly people experiencing homelessness. The authors analyzed the emotional impact that ethnographic research can have, not only on the researchers who are directly in contact with the vulnerable population, but also on those who indirectly come into contact with the research data, such as transcribers and coders. Their research echoes the work of Liamputtong [5], who drew attention to the emotional impact that working on vulnerable subjects might potentially have on all the members of the research team.

Taking an alternative approach, Sharon Mallon and Iris Elliott brought together contributions from different qualitative researchers, with different backgrounds, seeking to make known various research experiences around sensitive topics. Through a roundtable, the authors discussed the emotional risks of qualitative research that focuses
on sensitive topics and the vulnerability that might arise for the researcher. Social actors
give meaning to the topics covered, so the sensitivity comes mainly from the way
individuals feel, construct, and interpret it. Research involves contact with different
spheres of social life, and this can lead to increased challenges, which the researcher must
be able to deal with. To face these challenges, it is important to share research
experiences, as Mallon and Elliott did in their article.

While the issue of the sensitivity of the topics studied appears to be less relevant
in the collection of articles for this book, it is important to acknowledge that most of the
authors clearly showed in their work how the use of certain theoretical, methodological
and ethical strategies might be useful for addressing this important issue. This was the
case for Catela in her work on food aid recipients; Litvina, Novkunskaia and Temkina’s
work on medical professionals; Delaunay, Augusto and Santos’s work on ART
beneficiaries; and Micanovic, Stelko and Sakic’s work on people experiencing
homelessness. All these authors adopted ethnographic methods and demonstrated how
immersion in the research field and direct and prolonged contact with the participants
might be beneficial for developing their studies on topics considered to be sensitive.
Additionally, authors have shown how important it is to adapt data collection instruments
in the face of a sensitive topic. Ryan reflected on the use of instruments such as audio-
computer-assisted self-interview (ACASI) as mechanisms that can contribute to the
avoidance of discomfort in research participants when the nature of the topic under study
is sensitive. Indeed, one of the main concerns when conducting research on sensitive
topics has been related to the way in which research questions are formulated and
transmitted to participants [4, 5]. Natalie Tyldesley-Marshall, Sheila Greenfield, Susan J.
Neilson, Jenny Adamski, Sharon Beardsmore, Martin English and Andrew Peet also
discussed the role of shadowing when conducting research on sensitive topics and/or with
vulnerable populations. The authors brilliantly illustrated in their article how shadowing
healthcare professionals at a pediatric hospital was helpful for the preparation of their
qualitative study on children and young people with serious health conditions and their
families.

Martins and Sani clearly showed how the interests of participants might be
weighed and balanced through the employment of certain ethical strategies when studying
topics with a sensitive nature, such as violence against children. The role of the Research
Ethics Committees (RECs) in monitoring the development of research projects and their
processes of communication with both researchers and research participants is highlighted by the authors. The important role of RECs in supporting researchers when conducting research on sensitive topics was also highlighted by Cecchini. The author claimed that one of the major challenges of this type of research was its degree of uncertainty. In order to overcome such challenges, Cecchini stressed the importance of the use of ethical reflexivity and ‘ethical sensitivity’ [29] throughout the research process. Rasmussen and Pagsberg, whilst sharing their experiences of conducting research with autistic children in their everyday lives and school experiences, showed the importance of reflexivity for overcoming certain methodological and practical challenges. Cecchini and Rasmussen and Pagsberg’s articles reminds us of, to a certain extent, the work conducted by Warin [30], who, in her study with children and young people, drew attention to the important role of reflexivity through the research process. Hilário and Augusto also made the point that reflexivity might help researchers to deal with the emotionality of conducting research on a sensitive topic, such as the chronic pain experienced by children. The authors also reinforced the role that the acknowledgment of emotions might have in leading to a better understanding of the everyday life of these children.

What this book also brings is the acknowledgment of the successes and failures of research conducted with vulnerable populations and/or on sensitive topics, opening the path for future researchers to avoid making the same mistakes. Indeed, this book intends to provide theoretical and practical tools that will allow researchers to improve their practices. This might be particularly important for postgraduate students and early career researchers who need to be better equipped when undertaking this type of research [31]. The book integrates several articles that explore a wide range of challenges and dilemmas relating to the development of social research and, particularly, to the vulnerability of the participants involved and the sensitivity of the topics covered. The reader will find a rich and fruitful space for theoretical and empirical reflection, where several researchers with different backgrounds shared their experiences and research paths in a rigorous and creative way.

References


[13] Emerald, Elke; Carpenter, L. Vulnerability and Emotions in Research: Risks,


[26] Christensen, P.; Prout, A. Working with Ethical Symmetry in Social Research


