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Practical and Ethical Dilemmas in Researching Sensitive Topics with Populations Considered Vulnerable

Edited by
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MDPI

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About the Editors

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

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 Mattingsdal 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, Novkunskaya 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.

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Guest Editors

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Acknowledgements

Customizing Methodological Approaches in Qualitative Research on Vulnerable Children with Autism Spectrum Disorders

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Abstract: Children with autism spectrum disorders often suffer from poor school inclusion, loneliness, and poor quality of life. Suitable support options for overcoming these risks are lacking, partly because children's perspectives concerning their support needs are unknown. We need to improve the involvement of children in social research. However, involving children with autism in research is not always simple, and there is scant literature on qualitative methods for addressing challenges related to involving children with unique characteristics such as autism. Children with autism may lack mimetic expressions to reflect their feelings, and they may answer questions very briefly despite having a nuanced perspective on the issue addressed, thus leaving the researcher with few indicators to act upon. Consequently, it can be difficult for the researcher to "read" the child, assess ethical important moments, and adapt the methodology to the individual child. Based on a qualitative study of 22 children with autism in the capital region of Denmark, this article offers reflections on methodological and practical challenges in involving children with autism in research. Matching expectations between researcher and child, staying open to communication forms, and posing precise questions are shown to be important to have insight into the children's perspectives.

Keywords: qualitative method; children; autism spectrum disorders; methodological challenges

1. Introduction

Children are increasingly recognized as important agents in the research on children's everyday lives and wellbeing. Within the new sociology of childhood, children are not only viewed as "subordinates" to whom adults should speak but also as important social actors who should be involved and recognized as having legitimate voices of their own [1–4]. This sociological childhood agenda is in line with the requirements of the United Nations Convention on the Rights of the Child (UNCRC) (1989), prescribing that children have the right to express their views freely in matters affecting them. Children are essential receivers of social support, and this is why researchers demand increased recognition of children's own perspectives in organizing welfare services aimed toward children [5–8]. In line with this growing demand to involve children in societal planning, the literature on methods and ethics in research on children has expanded over the past decades [7,9–12].

However, there is a paucity of research and methodological literature describing how to involve vulnerable subgroups of children with unique characteristics, such as developmental disabilities including autism spectrum disorders (henceforth referred to as "autism"). An increasing number of children are diagnosed with autism. In fact, some studies estimate that the prevalence of autism among children has increased 20– or 30– fold since the 1970s [13]. These children constitute an exposed group in society that needs research attention in order to improve their well-being and

educational development [1]. Nevertheless, the perspectives of children with autism are only presented in research to a limited extent [14,15], and the studies involving children with autism do not focus on the development of methodological, practical, and ethical learning.

Autism might influence the way that we as researchers should involve the child in our research for other reasons as well. For example, autism causes difficulties in social interaction, social communication, and social imagination, meaning that understanding indirect talk or hints, reading facial mimics, and imagining other people's thoughts and feelings can be difficult for individuals with autism, and communication in general, especially with strangers, can be a challenge for autistic people [16–18]. In qualitative research, interaction and communication are essential for gaining insight into the unique perspectives of individuals, and autism is naturally challenging in relation to participating in qualitative research.

In addition, autism is often, but not always, correlated with a high risk of psychiatric comorbidity, such as depression or anxiety [19–21], as well as poor school and educational performance, loneliness, poor social inclusion with peers, and poor quality of life [20,21]. For these reasons, children with autism can be vulnerable and difficult to include in research. Examining the school well-being and everyday lives of children with autism is a delicate process, as the topics might be sensitive for the child. Moreover, while school well-being can be a sensitive subject for children without autism, the challenges are enhanced due to their inherent communicative difficulties as well as difficulties in "reading the social game", that is, imagining other children's emotions and talking about abstract concepts. Children with autism can be viewed as a unique group that requires, if not reinterpretation, then adaptation, adjustment, or customizing of the qualitative methods typically used for research purposes, which is the focus of this article.

Neither autism nor childhood is considered a fixed concept; rather, they are sociocultural flexible categories [22] associated with overall understandings that are constantly being developed in line with societal approaches to health, childhood, and normality [23]. This might explain why there seem to be very few studies that link qualitative research methodology with childhood research as well as with autism research. Indeed, there is virtually no literature examining methods and practices for involving children with autism in qualitative research [6,24]. Consequently, this article set out to explain the methodological and practical knowledge gained from a qualitative study conducted with 22 school-aged children with autism, living in the capital region of Denmark. The overall purpose of this article is to encourage more research on the everyday lives and well-being of children with autism, as demanded by researchers in the field [5,14,15], by sharing methodological learnings.

2. Methods and Empirical Data

The qualitative study of 22 children represented in this article is part of a larger mixed-method research project on the everyday lives and school experiences of 65 children with autism. The results concerning the children's school well-being and everyday lives are reported elsewhere (first author), whereas this article will focus on the methodological and practical knowledge gained. The conduct of the study is based on the first author's experience working with children and adolescents with autism in institutions and school settings (more than 10 years), which provides a broad insight into how children with autism can be viewed as a unique group for qualitative research purposes. Furthermore, this study is based on experiences gained from spending one month observing diagnostic processes in outpatient clinics of the Mental Health Services in the Capital Region of Denmark. These experiences with autism pedagogy and autism diagnostic processes mean that the children have been met with a professional knowledge of their possible challenges, but, at the same time, they have been met with an openness and ignorance of their specific personal living conditions. The absence of in-depth knowledge of the specific children in the study has increased the opportunities for the children to provide their own perspectives on everyday life and school well-being. In line with Parsons [14] and Preece and Jordan [15], it is our experience that children with autism would like to be included in research concerning their daily lives, and this is what motivated this study.

2.1. Participants and Recruitment

The 22 children who took part in the qualitative study were 9–15 years of age and had all undergone a diagnostic process in outpatient clinics in the Capital Region of Denmark and received an autism diagnosis prior to the study. They were all mild to moderately influenced by their autism, meaning that they had understandable language and could engage in the ordinary school environment to some extent, possibly with personal teacher support. Some of the children had a concurrent diagnosis such as anxiety (6/22 children) or attention deficit hyperactivity disorders (7/22 children); however, autism currently posed the most significant challenge for all of the children in this study though in slightly different ways. While some children had difficulties with making inappropriate comments or showing a lack of empathy in various situations, other children had difficulties with abstract and hypothetical thinking, or in sharing peers' interests, or challenges due to sensory sensitivity. All children in the study had different challenges in several areas of the autism spectrum. About half of the children (12/22 children) had an Asperger's diagnosis within the autism spectrum while the remaining children had various other forms of autism disorders. They were all diagnosed according to the ICD-10, which is the classification system commonly used in a Danish clinical context.

Ten of the 22 children were recruited for face-to-face interviews through the outpatient clinics by the end of their diagnostic process. The recruitment was based on a strategic selection aiming at diversity in the participant group in terms of age and gender. By interviewing the children singly, the possibilities for individual adaptation of the conversation with the child and for deepening the understanding of the child's perspectives are optimized.

Twelve other children were included in the study through repeated informal conversations conducted in the Center for Autism Denmark (CAD), where the first author spent six months conducting participant observations in two network groups, one each for girls and boys. Participation in the groups made it possible to get closer to the children in more informal settings and situations. The purpose of the network groups was to enable the children to meet their peers with autism, share experiences, and practice social skills. The group meetings were held one evening per week and included dining together as well as various activities, such as playing cards, board games, table tennis, billiards, painting, drawing, or engaging in other creative pursuits. Most of the children in the two groups (7 out of 12 in the boys' group and 5 out of 8 in the girls' group) repeatedly took the initiative to converse with the first author during the group meetings, either alone or in pairs. In contrast, the rest of the children in the groups either scarcely communicated in general or did not show much interest in the research purposes despite being invited to share their perspectives during the meetings; therefore, they are not mentioned in this article.

2.2. Procedure and Researcher Role

The first author conducted the ten interviews in each child's home, as recommended in the childhood research literature, which highlights that a safe environment for the child facilitates a more confidential conversation [10,25,26]. Prior to interviewing the children singly, their parents (or one of them) were interviewed to make both parents and children comfortable with the child interview and to prepare the first author for the meeting with the child, as also recommended in other studies involving children [25,27]. Both the children and their parents received written and oral information about the study; both types of information were adapted in each situation to fit the child's age and school level. All children were told that answering questions was voluntarily and that they could withdraw from the study at any time without being asked for explanations, but none of them chose to do so.

Prior to the participation study in the network groups at CAD, all implicated children and their parents received written information about the study and were advised about the possibility to opt out of participation (no one elected to opt out). Additionally, I (the first author) introduced myself and the purpose of the study orally at the beginning of the study and throughout the six months in the two network groups. During my repeated informal conversations with the children and young people in the groups, I struck a delicate balance between not becoming too close to the children

(as to leave them with the feeling of becoming close friends) and being close enough to gain their confidence and enable open conversations with them. I purposely shifted conversational partners during the evenings and did not allow one child to feel chosen over the others while being open and approachable to all children during the meetings. During informal conversations as well as in the interview situations, I tried not to assume "a teacher role" or portray myself as a "young person" like themselves (see also [10] p. 255 discussing researcher roles as "least adult" roles). Instead, I followed my own open-minded and friendly approach, which involved being present and respectful without being intrusive. During conversations, I tried to use the children's own wordings and to test my understandings of the children's perspectives by asking the children to elaborate on their answers and by presenting my understandings of their statements; sometimes, the children would correct me, in other cases they agreed.

2.3. Ethical Approach

The study has been based on a situational ethical perspective [28,29], implying a moral obligation to listen respectfully to the children and making it a priority to ensure that all conversations were considered comfortable for the children so that they had positive feelings about their ability to contribute. Children are not necessarily always self-aware of what they think and feel and what their own perspectives are until researchers try to formulate them in cooperation with the children. In other words, children's perspectives are dynamic constructions created in their interactions with the researcher [10,30–33]. Accordingly, my interviews and conversations were based on my conscious attempts to position the children actively in the knowledge construction. For instance, I encouraged them to choose conversation themes and to control their pace in the conversations as much as possible. As Prout [34] noted, the inclusion of children's voices in research "has added new complexities and uncertainties to the research process" [34] (p. 482), and so I attempted to be both humble and cautious in managing the conversations with the children in addition to obtaining their informed consent to participate. Obtaining informed consent is not a single act, but rather a process that should be repeated throughout the research [35]. Thus, I frequently mentioned my purpose of being present and sometimes reminded the children that they could end our conversation whenever needed. Ethics in qualitative research with children is a dynamic process that is constantly shaped and reshaped throughout the process, and it is influenced by streams of "new values" in the ethnographic discipline [36]. The researcher should accept all researched subjects as social actors and "respect them and protect them equally" [36] (p. 205), whether being a child or an adult, female or male, illiterate or literate, etc.

For the sake of confidentiality, personally identifying information has been removed, and all names cited in this article are fictive. The study has been approved by the National Data Protection Agency (Journal No. 2012-58-0004) and the Local Ethics Committee (Protocol No. H-16017801) and has observed the rules of the Declaration of Helsinki of 1975.

2.4. Methodological Approach

While ethical principles should remain the same for all individuals since all people have the same ethical rights despite age, gender, ethnicity, and social background, as stated by Tulebaeva [36] (p. 204), methodologies should vary, and the approaches to participants and ways of gaining insights into the participants' perspectives should be adjusted as needed. Some researchers in the field of childhood studies emphasize that children are competent and therefore should be treated no differently from adults when involving them in research [37] (p. 165). However, a review of methodological issues in conducting qualitative research involving children concludes that there *are* differences between studies involving children and those involving adults. For example, power relations are by nature unequal when adults conduct research involving children [38]; likewise, there are inherent disparities in cognitive development, communication skill levels, and worldviews of children and adults [10] (p. 1258). For these reasons, my methodological starting point has been based on commonly accepted standards for research involving children, which are different from those involving adult

participants [9–11,25,38]. These standards prescribe, for instance, how the researcher should consider the design of the research settings and tools, including the questions posed and language used, as children, like adults, can be sensitive towards leading or biased questions [7,10–12]. The scope and content of the interviews and informal conversations in this study were adjusted depending on the child's readiness to talk about different matters of everyday life and their individual interests, experiences, and challenges in school and home affairs.

The methodological approach in this study was based on the knowledge that children's autism might cause them difficulties in social interaction and communication [16–18,39]. Hence, each child has been involved according to her or his individual preferences concerning communication framings (sitting, walking, playing in while talking, etc.), language use, thematic focus, and duration of the conversation. However, customizing qualitative research to each specific child is challenging for many reasons. I cannot read the children's minds concerning their preferences during the interview, and I do not always recognize their bodily signals since I do not know them well enough and because body language can be limited by autism. This article shares our learnings and practices as well as ethical considerations related to this process of involving children with autism in research.

Since there were few existing studies to lean upon in the methodological planning of this qualitative study, many questions arose prior to the qualitative data collection: What are the criteria for successful involvement? When is sufficient involvement of children in research achieved? How is a study planned considering the fact that children are very differently challenged in terms of social interaction and communication? While some children with autism lack mimicry, gestures, and eye contact, other children with autism are very lively in terms of body language and expression, although they may have difficulty thinking hypothetically or understanding their own feelings as well as difficulties answering open questions. In this study, we operated with both a semi-structured interview guide and an open interview guide, which were applied or even mixed as needed. In addition, pictograms, which are simple pictures of school and everyday situations, were introduced in some of the interviews to initiate and stimulate an open dialogue with the children. These different approaches and methodological experiences using them will be discussed further in this article.

2.5. Data Analysis

Notes from informal conversations were made partly during and partly immediately after each group meeting, and all interviews were recorded and transcribed verbatim. Notes were also made at the end of each interview, concerning what went well or not well in involving the child in the study, what the atmosphere was like during the conversations, and an impression of the child's openness to actively participate. Inspired by interpretative phenomenological analysis [40,41], transcripts and notes were read and re-read thoroughly and the first impression of the methodological attention points were noted. Subsequently, exploratory notes on the data were made, and interpretative conceptual questions about the findings were asked and discussed by the authors: What challenges did I face in the conversations? When did the conversations succeed in having the child address everyday life matters? What methods or approaches seemed useful or not useful with this child group? What type of questions and researcher roles motivated the children to talk?

During the analysis, we examined what happened in the communication with the children prior to their unfolding of their perspectives or demonstrating the opposite behavior by keeping quiet or not responding. A conversation depends on at least two actors, which is why in this study it was assumed that the interviewer (first author) was crucial for motivating a response from the child and creating an open conversation. We tried to " . . . understand what it is like, from the point of view of the participants, to take their side", as recommended by Smith and Osborn [42] (p. 53), and to " . . . find out how individuals are perceiving the situations they are facing, how they are making sense of their personal and social world" [42] (p. 55). At the same time, we also tried to " . . . ask critical questions of the texts from participants, such as the following: What is the person trying to explain? Is something leaking out here that wasn't intended? Do I have a sense of something going on here

that maybe the participants themselves are less aware of?", as Smith and Osborn recommend [42] (p. 53). In the analysis, we looked for factors that might have influenced the insights gained from the children, and we also examined situations in which involvement of the children seemed to succeed or fail, respectively. Looking across the themes emerging from transcripts and notes, some overall methodological and practical themes could be clustered as illustrated in Figure 1. The themes will be unfolded in the Findings section.
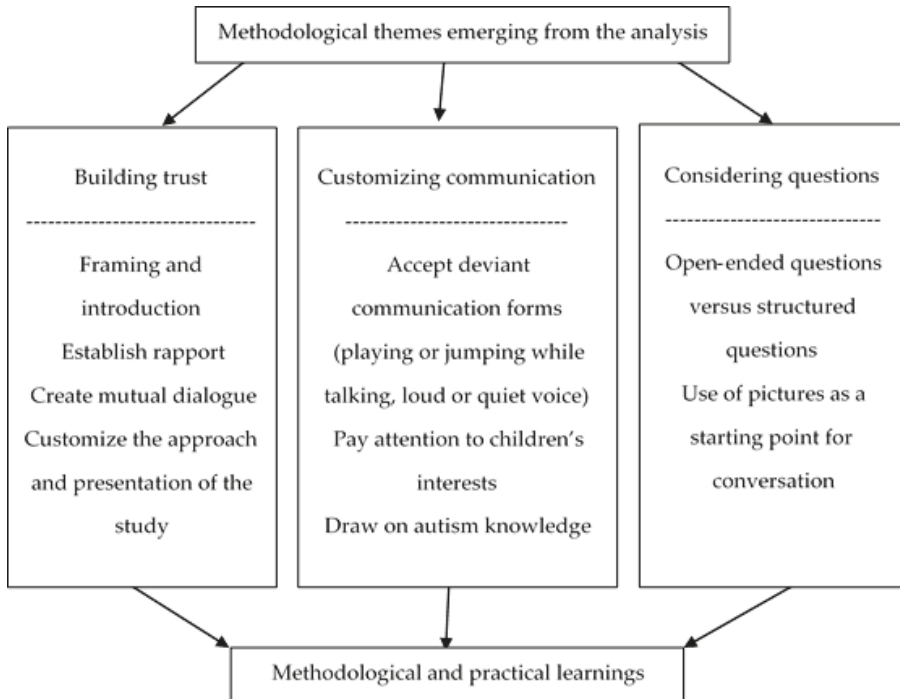
Figure 1. Themes from the analysis.

3. Findings: Methodological and Practical Learnings

We will begin the presentation of the study findings and learnings with two examples illustrating some of the methodological and practical challenges experienced in this study involving children with autism:

[Notes from an interview] In my interview with 13-year-old Elias, I had a hard time encouraging him to say more than monosyllables. Elias speaks in a monotone and a low voice and avoids eye contact, leaving me with the impression that he is not very comfortable with or not interested in sharing his perspectives on matters of everyday life with me, which is why I finished the interview early. However, the next day, Elias' mother wrote me an e-mail indicating that he enjoyed the interview and would like to participate again soon.

[Notes from a second interview] In my interview with 10-year-old Albert, I elaborated on the text of the information letter prior to the interview in the hope of facilitating a "mutual conversation" with Albert, inspiring him to talk. The letter also described my desire to hear about Albert's interests, not just about his school and family or friends. When I arrived at Albert's house, he was in his room, lining up role-playing swords to show me, and I barely had time to introduce myself before he began to tell me all about role-play, weapons, shields, armor, characters, and where to play. His voice gradually

became louder, and he ended up almost shouting eagerly about role-play while he jumped around and imitated a fight with his sword. Though I sometimes interrupted with simple questions about school, family, and friends in an attempt to lead the conversation in other directions, Albert simply disregarded my questions or gave short answers and then continued to talk about role-play.

The examples show in different ways the overall key aspects or themes found in the analysis (see Figure 1) that are particularly important to consider methodologically when involving children with autism in qualitative research:

- building trust with the child and customizing the presentation of the interview purpose;
- customizing communication and being prepared for alternative conversation forms and topics;
- considering questions carefully in terms of being closed versus open-ended.

These overall analytical themes are in many ways also relevant to research with children in general (and sometimes adults too); however, this study shows that autism reinforces the need for attention to these points. We will return to the question upon the findings being relevant to research with children in general in the Limitations section.

3.1. Building Trust and Customizing Preparations

The preparation of each child was considered relevant prior to the interviews because autism often causes a weak theory of mind, meaning that it could be difficult to imagine an interview scenario and prescribe a strong need for predictability and preparation [16,18]. Accordingly, the preparation regarding the time, place, duration, focus, and purpose of the interview as well as the child's right to interrupt at any time, if desired, was written in an information letter, designed individually, and based on the parents' information about the child. If the parents reported that the child was having difficulties in school and generally did not enjoy talking about school, then school was not mentioned in the letter. The intention was to create a positive approach to the child and the interview. In addition, the parents cooperated in preparing the interviews with the children by making agreements in advance with them about where the interview should take place, whether a parent should be present (one child chose so), and whether the child would like to do any specific activity, such as drawing or puzzles, while talking (most of the children chose to). As such, the parents became both important gatekeepers and co-workers (as also described in [25,27]) in the oral preparation together with the child. In some cases, the preparation work paid off in the sense that some preliminary maneuvers during the interview were skipped and the children seemed confident about the situation. Consequently, some of the interviews started quickly, as in the following example with nine-year-old Asta, who almost corrected the interviewer concerning the purpose of the interview:

[Notes from an interview: I have just arrived in the family kitchen, where Asta prefers to talk. Asta's mother moves to the living room and closes the door. I introduce the study.]

Me: I would really appreciate it if you could help me by telling me about yourself and how you spend your time. I can see that you are wearing a t-shirt with horses; do you like horses?

Asta: You forget to say that you would also like to hear about friends and school; you wrote that in the letter.

Me: That is right. Would you like to tell me about your friends and school? Where do you go to school?

Asta: [tells me the name of the school, the school address, how to get there, and which class and specific building she is in] ... but my parents are trying to get me into another school, so I do not know for how long ...

Me: Okay.

Asta: ... and if you want to hear about friends, I have one friend, and she is on holiday right now ...

In the case of Asta, the preparation seemed to succeed in having her tuned in to the purpose of the interview, thereby opening up the possibility of my asking further questions concerning the topics of school and friends, which she mentioned herself. In contrast, in other interview situations,

the preparation caused the child to overdo it, as in Albert's case (introduced in the example in the beginning of the finding section). Albert almost prepared a full speech beforehand about the discipline of role-playing. He had taken my introduction letter quite literally, mentioning that "I would like to hear about your interests and leisure activities" among other quotes. This example illustrates a potential pitfall in preparing the child for the interview: the risk that it could be a "failed interview" [43] (p. 717) in the sense of not providing knowledge "on the research agenda" or only providing limited knowledge. If the preparation, including the introduction letter, is too unfocused, inviting the child to talk about whatever he or she wants to, the researchers' risk receiving unfocused information from the children rather than specific insights into their perspectives on their well-being and school inclusion as intended. The child (with autism) often has difficulties in deviating from what he or she assumes to be the planned conversational topic and in catching the conversation partner's hints to change topics during the talk.

Another risk is "a silent interview," as in the case of Elias (presented at the beginning of the findings section), who used few words and avoided eye contact, at least in the first part of the interview. It is difficult to infer from the situations if such "silent interviews" are due to incomplete information and preparation about what an interview is about, the child's communicative challenges, or the researcher's inability to motivate the child to engage in mutual conversation. Since Elias mentioned to his mother after the interview that he would like to participate in the study again sometime soon, his case might illustrate how some children (with autism, as well as in general) need more time to become comfortable and develop rapport with the researcher [44,45]. It is commonly advised in the literature that the researcher should build the child's trust and help him or her to relax and feel comfortable with the situation. Rapport cannot be developed by an introduction letter or an oral preparation talk from the parents; it is a process that takes time [10,11,30,33], particularly with children with autism.

By spending time with the network groups at the CAD, I experienced how some children needed time before interacting with me, whereas other children were curious and outgoing from the beginning. Moreover, while I was constantly aware of making contact with the children, I did this from a distance to allow them to feel free to reject or approach me on their own initiative. Overall, it was easier to develop rapport with the children in the network groups compared with the interview situations (see also Greig & Taylor [44] and Wilson & Powel [45], who recommend spending time with children to build rapport), in part because I had more time to let the children get to know me. Developing this kind of rapport, that is, reciprocity and mutual trust, was effective in engaging the children in the research and making them share their perspectives promptly and spontaneously. Spending time with the children in the network groups for six months made it possible to meet them in more informal settings, resulting in unprepared conversation topics presented by the children themselves and providing unique insights into their perspectives. As the following extract from a spontaneous conversation illustrates, the children's reflections, which could be difficult to predict before the interview, can occur spontaneously:

[Fourteen-year-old Tobias and I talk while preparing dinner together for the rest of the group.]

Me: Are you looking forward to the weekend?

Tobias: I hate [the] weekend; my mother just destroyed the idea of [a] weekend. She just suddenly without warning said this morning, "On the weekend, we are going to Jutland to visit your uncle." She knows that I have a complete meltdown when faced with such unforeseen things.

Me: . . . and have you reminded her how you feel about that?

Tobias: No, because I know the answer. She just says that it is a good learning [experience] for me to not always plan everything, but she cannot see how I feel inside; I am burning. That is also why I started to pinch myself. Look, my arm is all red (. . .). My mother doesn't know anything about how I feel; she understands nothing.

The intimate forum of being alone with Tobias while occupied by a common activity and not having to talk face to face supported Tobias' liberated and spontaneous expressions based on his original reasoning (as demanded by Piaget [31]), not just random answers in an attempt to satisfy

the researcher. Such personal sharing of the children themselves took time and mutual trust and primarily occurred some months into my participant observations at the CAD. Furthermore, insights into the children's perspectives often emerged from more confident situations, such as when I drove 13-year-old Eric home after a network meeting. During our moments alone in the car, having known each other for some months by that time, Eric shared his feelings of discomfort about attending the local mainstream school, as he was the only one in class with autism:

Me [chatting while driving the car]: So, what about the new class? Do you like this class better?

Eric: I hate my class; every day is a fight to survive bullying. I do not know why it is like that, but it is . . . . It is hard to fit in their [classmates'] universe to perfection and with precision, not to say impossible, since I do not share their views and interests.

Eric also expressed his desires and dream of being a chemical engineer, leaving me with the impression of having gained insights into his perspectives on his everyday struggles with autism and with coping in a mainstream school.

Some of the children's personal sharing demanded ethical considerations, not least in cases where the children reported severe loneliness, experiences with bullying, violence, or drug experimentation. In these situations, I asked the children if they had someone to talk to about their situations, a teacher or a parent for instance, and in some incidences I talked to the network teacher confidentially about the issues that the children were dealing with, which she was always aware about already.

3.2. Customizing Communication with the Specific Child

Pramling [46] states that it is the researcher's responsibility to engage the child in conversations by addressing topics that the child has an interest in as well as to "create a trustful contact with the child, for without the child's engagement and willingness to work together with us we cannot learn anything from him/her" [46] (p. 26). Other more recent studies stress the importance of the researcher's self-preparation [27,39] in relation to gaining insights into the child's everyday life through the child's own mediated perspective. Thus, childhood researchers emphasize that questions should be planned in accordance with the child's age and cognitive level, interests, capabilities, and willingness to talk about certain topics. I found that preparation regarding interview topics and ways of addressing the themes was not always a simple task in terms of having the child with autism participate in conversations in the best possible way. In many cases, thorough preparation was necessary in relation to the children's autism and possible challenges as well as to their individual interests. For instance, I found it advantageous when approaching the children in interview situations to have basic knowledge about their personal interests and their daily living conditions in order to meet them on their level.

Children with autism sometimes have special interests that can differ from those of their peers, such as a fascination with trains, computer programming, Japanese manga comics, advanced mathematics or chemistry, famous movie scenes, and cars or trucks (a boy I met in this study even knew all about moped engines). Without preparation, it can be difficult to build conversations around some topics concerning the children's interests. Therefore, having an idea about these interests can be advantageous during the interview or informal talk. It can serve as an icebreaker, opening the dialogue by talking about something that the child enjoys. It can also allow the researcher to gain a quicker understanding of the child's reference point, such as when mentioning names from Japanese comics during the interview or when reconstructing a scene from a movie, as 13-year-old Jacob did in an informal conversation. Here, he is citing a scene from *Lord of The Rings* (a character in the film that is wavering between good and evil, with each aspect having a nickname):

Jacob: . . . so when she [his mother] says that I cannot play anymore [computer games], she does not know how it is like. "Gollum needs his precious" right, but "Sméagol says no, but Gollum needs" . . . . You know, sometimes, gaming is the only way that I can relax . . . .

I experienced the pitfall of not knowing anything about the child's interests in the case of Peter, a 14-year-old boy at the CAD, who knew all about a certain computer game and "live[d] his parallel life in this game," as mentioned by one of his peers. Peter made some initial attempts to converse with

me during the network meetings, but I often fell short in truly engaging with his invitations since he was absorbed by his gaming world, which he spoke a lot about. My inadequacy was due to my lack of knowledge about the specific game universe. Thus, it seemed that I was never really able to offer anything in a mutual conversation with Peter, apart from being a passive listener. Sometimes, it seemed sufficient for Peter that I was willing to listen to his detailed explanations about the computer game, thereby serving as an "acting apprentice" in his universe [38], and Peter would continue to talk for a long time. In other situations, Peter sought others to share his gaming experiences that could interact more actively with him and understand his parallel world better.

Furthermore, I found that preparation related to the child's individual challenges or vulnerabilities was important in some cases in order to involve him or her ethically and comfortably. Most of the children in this study were newly diagnosed, and half of them were exhibiting depression, ADHD, or anxiety symptoms as well. Some parents claimed that their children would probably withdraw if I mentioned autism or other diagnoses because they had not yet become familiar with or accepted their diagnoses. In other cases, the child had not yet been made aware of the autism diagnosis by parental choice to prevent the child from feeling labeled or disabled; these children only knew they were having challenges but not that there was a name for these challenges. Accordingly, I avoided confronting or mentioning autism in the interviews. However, it occasionally happened that the child him- or herself talked about autism or these unlabeled challenges, showing how the pre-impression of the child, given by the parents, could pose a potential risk (as well as certain advantages) since the researcher might limit the conversations unnecessarily. In other situations, preparation concerning the child's individual challenges or vulnerabilities was shown to be important. For instance, Jacob's parents told me about his severe difficulties in making friends in school, which I took into account in the interview by not assuming that all children had friends in school; thus, I approached the subject carefully. Learning from previous studies (e.g., [33,37]), I found it useful in some interviews to bring up sensitive topics by relating what other children had said about being challenged in school or not knowing how to make friends, thereby making it easier for the child to share such experiences. This technique seemed to work with some of the children, whereas others obviously could not relate to a story about someone they did not know. Autism often causes difficulties in mentalizing and hypothetical thinking, and that can probably explain why only some conversations benefit from the technique of citing examples.

Conducting research on children with autism demands "bracketing" or "setting aside" assumptions and beliefs [38] about childhood in order to avoid presuming that all children have friends or enjoy school and typical interests, such as sports. Moreover, researchers need to "bracket" their preconceived notions about conventional ways of communicating when studying children with autism. This study has shown that knowledge about autism is important for understanding and handling situations when children either talk loudly or are very quiet, come very close to the interviewer's face during conversations (one almost sat on my lap), or show limited or inappropriate facial expressions. It is also essential to be prepared for alternative conversation forms, such as children preferring to spin around while being interviewed, doing puzzles, or working with a Polybius square while talking and thus making minimal eye contact. However, reading other people's body language in mutual communication is so deeply embedded in most of us that deviations from our communicative instincts are quite demanding. In Elias' case (as presented in the examples in findings section), I was keenly aware of the potential symptoms of autism but still failed to rely on this knowledge in my understanding of the situation, misinterpreting his (lack of) facial mimicry, quiet talk, and few words as lack of enthusiasm.

3.3. Structured versus Open-Ended Approaches

Some qualitative researchers claim that information obtained from free recall, also called an unstructured or open interview, is more likely to capture the unique perspective of children, as opposed to receiving responses to questions from the perspectives of adults [7,30,33,47]. In a study comparing structured and unstructured interviews with children (without autism), Steward and Steward [48] found that open interviews allowing the children to speak more freely yielded more in-depth information.

Consequently, the authors advised interviewers to begin with an open-ended question to elicit a spontaneous narrative and then ask direct questions to fill in the blanks in that narrative. However, they also concluded that some children with poor language and communication skills found the task of free recall more frustrating and tiring compared to a more direct approach. In this study, I found that letting the children "warm up" with easy, structured, and simple questions was often advantageous, as also reported by Irwin and Johnson [25] in their study on young children. In this study, some children needed more encouragement and structured questions to start talking. When they felt comfortable with the situation, they were then able to handle more open-ended questions and contribute with their own perspectives, expressing liberated and spontaneous convictions, as illustrated by the following excerpt from a planned interview with 13-year-old Nanna:

Entering the living room, I find Nanna doing puzzles at an amazing speed, with 1000 pieces filling the entire table where she is seated. She glances up shortly and vaguely says "hello" without making any facial expressions. Her mother tells me that Nanna had been looking forward to the interview. I introduce the purpose of my presence and thank her for allowing me to visit her. After a few more sentences, I start asking Nanna if she does many puzzles. Nanna says "yes." I proceed by asking her if she has interests other than doing puzzles. After a pause long enough for me to consider it difficult to get Nanna talking, she says two words: "music videos." She continues to gaze at her puzzle and put the pieces together. I change the subject by asking her about school but receive only short answers. I return to the topic about music videos and ask what types of videos Nanna likes, trying to motivate and engage her to use more words. As soon as I get Nanna to tell me about music videos, she uses many more words and explains, "Making the videos myself on YouTube makes me forget about my anxiety, and I totally forget about time and place".

When the agreed 25 minutes is over, I take the initiative to end the conversation by thanking Nanna and confirming how useful her participation has been. Almost interrupting, Nanna replies by telling me about one of her teachers: "Once, we had an English teacher who told me that I should control my anxiety, and I tried to tell him that it is really hard to control because if it was that easily done, no one would have anxiety . . . . But he just told me to stop feeling that way, and that I am a bright girl that could do so".

The conversation continued for a while. Every time I attempted to end it out of respect for the agreed-on duration of the appointment, Nanna continued talking, presumably because she had been motivated to talk, although it initially took a long time to obtain her engagement, build rapport, and gain her trust.

It could be argued that structured questions lead the children towards certain answers instead of inviting liberated or spontaneous expressions [30,31]. Nonetheless, in many of the interviews precise and limited questions were necessary to get the child to talk at all and to align with the research areas of interest, as shown in the following excerpt from an interview with 13-year-old Elias:

Me: How about school—is there a subject in school that you particularly like?

Elias: [long pause] I'm not sure what you mean; uhmm, if I like a subject, is it the teacher you mean, or the books, or what we do in the subjects? How do you mean like the subject? I do not understand . . .

Later in the interview, I asked Elias whether there were school subjects in which he was particularly clever. He replied, "I'm not sure I am the right person to answer that question; to be sure, you should ask my teacher." The precise question in this case would have been whether Elias himself believed he managed well in some subjects or if he found some subjects easy to learn. During another interview, I asked 11-year-old Victor if he found any particular subjects in school interesting, and he replied, "domestic science," and we talked for a while about this subject. Later in the interview, it became clear that Viktor would not have domestic science in school until two years later, but the question that I posed was not specific enough to capture this fact, as I only asked what he found interesting.

In the CAD network groups, the need for precision and structured questions was further observed. During an informal conversation with five of the 10–14-year-old girls, a YouTube video was shown by

the teacher responsible for the group in order to start a debate on situations in which they should or should not tell others about their diagnosis. When the video was finished, the teacher asked, "What did this video show you?" One of the girls remarked, "The second time they were filming in the restaurant, the fork was in another position than the first time. I think that was a mistake." Another girl added that the tablecloth resembled one that her grandmother had. The girls were concerned with certain detached details in the video and obviously did not pay as much attention to the big picture or the message conveyed in the videos. Helping the girls focus on a concrete question about the message in the video then enabled them to contribute with their own perspectives on "who to share that you have autism with"; they just needed specific guidance.

Finally, this study showed how open-ended questions could still be difficult despite being accompanied by visual aids, such as pictograms or simple drawings of a school, home, or family, as recommended in some contexts when studying children with autism (see, e.g., [49]). In this study, the use of visual aids was tested in some of the interviews, but we found some inherent challenges, as the pictures were not individually suited to each child. As 10-year-old Alfred commented, "I do not know these cards. I only know some other cards we have in school, and they look different, so I cannot speak about the ones you have." The other children simply looked at the picture cards that I presented without responding or just answered "no" when asked to talk about the cards. Obviously, the pictograms that were unknown to the children did not encourage conversation or make them elaborate more on their everyday lives and well-being; rather, they seemed to annoy or confuse them.

3.4. Limitations of the Study

This study provides insights into how 22 school-aged children with autism, in given contexts (interviews or group-evenings) respond to given methodological approaches, undertaken by a given researcher. Thereby, the study is not comprehensively providing insights into how school-aged children with autism in general interact in qualitative research. Only school-aged children who are mild or moderately influenced by their autism were included in this study, and it is unknown whether the findings are valid for other groups of children with autism. Likewise, it is unknown to what extent the findings are valid for children without autism. Literature within methodology in childhood studies indicates that children in general are sensitive towards building trust with the researcher, and that some flexibility concerning interview form and topics are needed, particularly when researching with younger children. However, children without autism are in general described in methodological literature as being less sensitive towards open-ended questions and towards the preparation prior to the interview or conversation. We believe that this study illustrates methodological and practical attention points that are particularly important when studying with children with autism. However, more research is needed to decide which methodological customizations are needed for different subgroups of children. In time, it will be possible for subsequent studies to be conducted with other samples of children with autism, and, gradually, more general claims can be made about methodology in relation to children with autism.

Furthermore, a limitation in this study concerns the use of methodological approaches (interviews and informal conversations). Qualitative approaches such as diaries, videos and focus group interviews have not been examined in this study. Further research is recommended concerning the use of different qualitative approaches.

4. Conclusions

Qualitative research involving children in general, and especially with children with autism, can be challenging, unpredictable, and uncontrollable and can make it difficult for the interviewer to use standard interviewing principles [10,25,30]. It is not always easy to gain fully informed consent from a child, to compose information letters targeting a child prior to an interview, or to ensure common expectations for the interview between the researcher and the child. Furthermore, it is not always easy to initiate an open and spontaneous dialogue with the child, to encourage him or her in a

natural way to address the research subjects that the researcher has a particular interest in, or to read and interpret his or her signals (e.g., body language) during the interview. This is especially true when the child has an autism spectrum disorder, which often involves challenges in social communication and social interaction.

In this article, we have reported methodological experiences in involving children with autism in qualitative research regarding their everyday lives and well-being. Children with autism are often represented by parents or teachers, and thus their individual voices and perspectives are excluded from research participation, partly due to the lack of research knowledge on how to involve this group of children. The young participants in this study have shown that it is both relevant and methodologically possible to involve children with autism in qualitative research (as also found in [14,15,39]), but it is also necessary to be aware of certain conditions.

First, it is important to build trust with the child and to make preparations for planning the qualitative research with the child. This includes an information letter targeting each specific child to ensure common expectations for the interview between the researcher and the child as well as to give the child an idea about the possible scenarios in an interview. For a child with autism, it may be difficult to imagine what a conversation with a stranger will entail, and the child will often need guidance beforehand. In this study, we have experienced the potential pitfall of "preparing the child too much," that is, not leaving room for a more spontaneous dialogue, while receiving requests from both parents and children for detailed preparation.

Second, preparation concerns the researcher's readiness for more deviant communication forms, methods, and topics. Some examples are having an interview while the child is doing puzzles or spinning around in a chair, communicating without eye contact or proper mimicry, as well as being prepared to communicate around computer games and Japanese manga comics. In this study, we have experienced how difficult it can be to read and interpret the body language of a child with autism during the interview as well as for the child to read the interviewer's body language and spoken hints about shifting conversational topics. Important findings include the need to avoid interpreting the body language of a child with autism based on general assumptions about bodily communication and to be very explicit as a researcher in the communication with the child.

Furthermore, this study has shown that it might be beneficial to begin with precise and limited questions, specifically addressing the conditions that are relevant to the child and thereby clarifying the researcher's intentions regarding the communication. Similar to Teachman and Gibson's [27] findings from their qualitative interview study involving another minority group of children with health conditions (see also [47]), we have found it optimal to combine approaches, such as asking more detailed and close-ended questions to begin with and then posing more open-ended questions when the child has "warmed up." Each interview or conversation should be customized. For instance, if picture cards or other visual materials are used in an interview, they should be well known to the child, resembling those used in his or her school class or at home; otherwise, the pictures could confuse the child.

Such learnings and shared experiences might be useful when conducting qualitative research involving children in general, some of whom require extra guidance and precision as well as preparation and detailed explanations. However, this need is even greater for children with autism, as they often have difficulty imagining situations that they have not yet experienced as well as understanding unwritten rules and assumptions about proper communication form and detail orientations. More research is called for in order to gain more generalizable knowledge upon conducting qualitative research with children with autism, and how it differs from qualitative research with children in general.

The fact that children with autism possess mindsets and modes of expression that, in many aspects, differ completely from those of the researcher who interacts with them places great demands on the researcher to set aside any presumptions about communication and social interaction in the interviews and conversations. Developing rapport with a child with autism might take time and

requires the researcher to become familiar with the individual child, for example, regarding specific autism symptoms, special interests, or any particular challenges in everyday life that could be addressed appropriately. Furthermore, methods allowing the researcher to develop rapport with the child over time are preferable to one-time conversations with the child. Reviewing the field of childhood studies and methods concerning the involvement of children with autism reveals that this group's voice remains under-represented in the literature. For this reason, this study calls attention to sharing experiences and practices in this field.

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An Exploration of the Practical and Ethical Issues of Research Using Multi-Visual Methods with Children Affected by Chronic Pain

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Abstract: This paper intends to encourage further reflection on the research methods and approaches used to enhance the voices of children with chronic conditions. Visual methods (e.g., 'draw, write, and tell' and photo elicitation interviews) have been described as the most appropriate ways to develop research with children as they allow room for children to share their lived experiences in their own terms and to actively participate in the research process, by giving them the opportunity to act as co-researchers. In fact, the use of these methods also contributes to empowering children and mitigating the power differences that exist between the adult researcher and young participants. Drawing on an ongoing study on the experience and management of chronic pain in childhood, this paper provides insights on the usefulness of using these multi-methods to address (potentially) sensitive topics with a (potentially) vulnerable group. The ethical and methodological challenges faced by the researcher when conducting research with ill children in the healthcare context are addressed. The paper looks at the dilemmas of studying chronic pain in childhood and highlights the ways in which multi visual methods can help children in the meaning making of chronic pain.

Keywords: social research; visual methods; children; sensitive topics; vulnerable populations; chronic pain

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1. Introduction

There is a lack of knowledge about the daily living experiences of children with chronic pain, and what is known focuses either on children and families' encounters with medical professionals [1] or on the impact that caring for a child (i.e., someone who is under 18) with chronic pain has on family relationships [2]. There is a need to understand how children and their families live with and manage chronic pain. The broader qualitative study discussed within this current article intends to fill this gap and offer insights on the experience and management of chronic pain in childhood by listening to the voices of children [3]. Although it is known that children with chronic pain have important knowledge of their affliction [4], perceptions and beliefs about chronic conditions have mostly been collected from healthy children [5–7]. Pain is difficult to communicate through language [8], therefore we believe the use of multi-visual methods can enhance our ability to understand the experience of chronic pain in children by enhancing their agency and right to participate in research on matters concerning their health and well-being [9].

Because of its inherent nature, chronic pain is a sensitive topic which can evoke powerful emotions and therefore be emotionally demanding for the researcher and research participants [10,11]. This is amplified when vulnerable subjects such as children with chronic conditions are involved. Children with chronic pain might be considered a doubly vulnerable population as not only do they lack the ability to make some personal life choices and personal decisions due to their age (e.g., about their diet or schedules) [12]; but they might also experience diminished autonomy due to their chronic

pain [13]. By saying that children with chronic pain are a doubly vulnerable population, we are not suggesting that children's agency should not be recognized. The right of children with chronic conditions to participate in research should not be undermined due to their double vulnerability [14]. This assumption draws upon the belief that children are able to make sense of their chronic pain and should be offered the chance to express themselves in their own terms [15]. We hope that the use of multi-visual methods, namely through the use of drawings and photographs, will make it easier for children to express what it is like living with chronic pain [16–18]. The focus of this article is to describe the ethical and practical aspects of using multi-visual methods for conducting research on children's lived experience of chronic pain.

2. Vulnerability and Sensitivity in Social Research Involving Children

There is an extensive debate surrounding the ethics of social research with children. However, it is possible to reduce the main arguments to one question: How different are children from adults? The answer to this question may involve words such as 'vulnerability', 'incompetence', 'irresponsibility', and 'powerlessness', referring to the idea that children are not as capable as adults of making sensible and rational decisions and of providing valid sociological data [19]. In addition, childhood can be interpreted as a phase in which the child is 'under construction', a phase that culminates with the arrival of adulthood ('becoming child'), as opposed to the idea that the child is a social actor, who actively participates in its development and has valid ideas and opinions ('being child'), which implies that during this transition phase, the child lacks a set of universal skills that make it impossible for him/her to be taken seriously [20].

It is crucial to explore children's perspectives on issues that concern them or are close to them. Thus, in this article, children are considered to be active social agents capable of thinking and reflecting on their condition and what surrounds them [21–24]. Now, defending children's participation in social studies does not imply disregarding the (potential) vulnerability of these actors. In fact, there is a set of characteristics that can place children in the category of vulnerable subjects, such as being subject to the authority of others [25], as well as their lack of ability to make some personal life choices and personal decisions due to their lack of life experience [12]. In addition to this (potential) 'structural' vulnerability, due to its transversality to child status, it is important to mention a second level of vulnerability related to the existence of a health condition (i.e., chronic pain) that may restrict their autonomy [13,25].

If, on the one hand, the use of the concept of vulnerability makes it possible to categorize the children involved in the present study, on the other hand, it is a concept that has been challenged precisely because of the broad character it can assume in relation to certain social groups [26]. Thus, it is assumed in this paper that not all children with chronic pain are equal, but it is also assumed that there is a strong likelihood that they will be subject to a double level of vulnerability, even if it is contextual (depending on the subject and the environment). If we add to the subject's vulnerability the topic's sensitivity, the research becomes significantly more complex. Like the concept of vulnerability, the concept of sensitivity also raises questions: What constitutes a 'sensitive' topic? What are the requirements? In a similar way to the concept of vulnerability, the concept of 'sensitive' topic is also contextual, as sensitivity varies according to the situation and the participants, who have their own system of beliefs, values, and cultural norms that guide them [27]. The sensitivity of the topic is usually expressed through the manifestation of certain emotions (e.g., anger, frustration, fear), not only for the participants but also for researchers themselves [10,11].

Conducting social research that focuses on (potentially) vulnerable subjects and on (potentially) sensitive topics can pose several challenges in relation to the recruitment process, the process of access to the research field, and the process of obtaining informed consent, for example [23]. In order to overcome these and other challenges, it is important to incorporate awareness of vulnerability and sensitivity into the research design by selecting methods to address these (potentially) challenging aspects. In the case of social research with children, it is possible to find different types of specific challenges related, for example, to power differences, parental gatekeeping, and children's competences.

Faced with these challenges, Kutrovátz [28] states that the combination of traditional and innovative techniques allows the creation of strategies to minimize these challenges.

In this paper, we will explore the 'draw, write, and tell' technique, as well as photo-elicitation interviews as methods that give voice to children with chronic pain in a non-invasive way and that value the perspective of these actors by using a specific language adapted to their reality. Using drawings and photographs gives children the ability to communicate in a way that is familiar and close to them [28]. In this way, children are given the opportunity to approach the topic of chronic pain in a way that makes them feel comfortable, portraying through drawings and photographs, their medical condition on their own terms. In addition, the 'draw, write, and tell' technique and the photo-elicitation interviews allow a change in the usual power dynamics that are established between researcher–researched. It was thought that the use of these methods would make the relationship between adult researchers and younger participants more egalitarian [9], although absolute 'ethical symmetry' [29] might, to a certain extent, not always be achieved due to the (potential) vulnerability of the participants and the (potential) sensitivity of the topic under study. These and other aspects are discussed in the following sections.

3. The Everyday Life of Children with Chronic Pain: What We Know and What We Really Need to Know

While there is some work on children's experiences of post-operative pain [30] or cancer-related pain [31], little has been said about the experience and management of children with chronic pain and their parents. For this study, chronic pain will be defined as that which lasts more than a month beyond the normal course of an acute disease, healing, or injury [2]. The experience of chronic pain refers mostly to headaches, followed by recurrent abdominal pain, back pain, and musculoskeletal pain [32]. Despite its prevalence (20% to 35% of children and adolescents worldwide suffer from chronic pain), the condition is under-researched and, due to a lack of clinical guidelines, many children do not receive appropriate pain management [33]. This can have severe social, psychological, and physiological consequences for children; the comprehension of their embodied and living experiences is essential in order to develop proper pain management strategies and therefore to enhance their overall quality of life [30].

Healthcare professionals' beliefs and misconceptions or even lack of knowledge on pain management in childhood tend to compromise adequate pain relief and lead to suboptimal care [34,35]. The quest for a diagnosis and treatment tends to be characterized by frustration and despair, as most of the time healthcare professionals are unable to identify a physical cause and, thereby, tend to blame the child or the family for the condition [1,36]. Indeed, the experience and management of chronic pain by children and parents tends to be marked by uncertainty due to the contested nature of chronic pain [37]. The complexity of assessing pain in children, particularly chronic pain, might be one of the reasons that explains the lack of effective proper pediatric pain relief [35]. Pain has been described by parents as being one of the most challenging and difficult aspects of caring for a child with a chronic condition and they often complain about the lack of clear guidelines to inform and help them effectively manage their child's pain [30].

There is a lack of knowledge about the daily lives of children with chronic pain, and what is known mainly arises from children who suffer from chronic conditions. Chronic conditions have a disruptive effect on children's lives and on the lives of their parents [38]. Parenting children with chronic conditions might also be characterized by uncertainty associated with the timing of symptoms [39]. This might lead parents to be in a state of constant alert for their children [40]. Furthermore, it is not only parents who are affected by the chronic condition of their children, research has shown that siblings assume caring responsibilities when a brother or sister suffers from a chronic condition [41]. Chronic conditions can also be detrimental to family relationships as the healthy child may feel the need to compete with the child with a chronic condition for equal parental attention [42]. Notwithstanding, this body of literature has shown the challenges of living with a pediatric chronic condition in the family setting; how children live with and manage chronic pain in their daily life has not been explored in detail.

The purpose of the study within which this article draws on and its methodological approach will be outlined in the next section.

4. Methods

There is little understanding of the needs of children with chronic pain and the needs of their parents [2], which can be explained by the scarcity of information available about living with chronic pain in the family context [43]. The ongoing study, within which the current paper is based, intends to fill this gap by providing insights into the family experiences and management of chronic pain in childhood. The key research questions that this ongoing study intends to answer are: (i) How do children and their parents experience living with chronic pain? (ii) What meanings do children and their parents attribute to the condition? (iii) In what ways do children and their parents manage chronic pain? (iv) How does the condition shapes family practices? Portugal offers an interesting context in which to explore these issues as it has been marked by a scarcity of information on pediatric chronic pain and of resources available to children with chronic pain [44].

A qualitative approach will be developed. A key challenge when conducting research on sensitive topics with children is the recruitment process [23], since access to children is very controlled by various adults (e.g., parents, teachers, and health professionals) and entities (e.g., schools and hospitals) [45–48]. It is expected that the recruitment of participants through a multidisciplinary chronic pain unit, located in a general hospital in Lisbon, Portugal, will help to mitigate such challenges. This might be because parents tend to feel safer when the recruitment contact is made through a known professional and/or institution and they therefore may be more likely to consent to the participation of their child [49]. As chronic pain is a sensitive topic, we expect that not all children who are being followed in the multidisciplinary chronic pain unit will be willing to participate in our qualitative study. Therefore, the sample will be constituted by twenty children, aged 7–10 at the time of recruitment, who suffer from chronic pain. We will target this age group because children are able to relate to pain physically and begin to have an awareness of their body [50]. The sample size has been established based on convenience criteria defined in informal conversations with the healthcare professionals of the chronic pain unit prior to fieldwork.

Prior to recruitment and data collection, ethical approval will be obtained from the general hospital, where the participants will be recruited. Ethical approval has been granted by the host research center of the research project. Written informed consent will be obtained from the children and one of their parents, with the understanding that participation will be voluntary, that they will have the right to refuse to participate in the completion of any task or to answer questions, and to withdraw from the study at any stage without consequences. Their right of privacy, confidentiality, and anonymity of data will be respected. A consent sheet with information about the aims of the study, what will be expected from them, and their rights, if they decide to participate, will be provided. An age appropriate information sheet will be given to children [41] and consent will be obtained from children and their parents separately [19]. It is hoped that this dual process of consent will guarantee children's autonomy to participate in research, as well as recognize the parent's responsibility to ensure the protection of their child [51,52]. A social constructivist thematic analysis has proposed by Braun and Clarke [53] will be employed. The themes will thus be derived deductively from the different sets of data collected.

5. Results: Employing Multi-Visual Research Methods for Studying Children's Experiences of Living with Chronic Pain

Within the research context, one of the main challenges was how to address children's agency. This is premised upon the belief that children are capable of making sense of their living experiences and should have a voice on matters concerning them [15,54]. The United Nations Convention of the Rights of the Child (1989), namely Article 12, is at the heart of this belief. The following sections intend to show how the use of multi-visual methods (i.e., 'the draw, write, and tell' technique and

photo-elicitation interviews) would enhance children's agency by offering them more autonomy and control over the research process [9], as well as to demonstrate how these methods might be helpful to overcome the difficulties that might arise from studying a chronic condition like chronic pain.

5.1. The 'Draw, Write, and Tell' Technique

Drawing is a fun, therapeutic, and educational activity that enables children to develop their ability to imagine and communicate [55]. In addition, drawing enables children to express experiences that may be more difficult to describe otherwise (e.g., through language alone). Drawing also gives children time to reflect on the questions they are asked and the message they want to convey, which leads to a different level of reflexivity [56]. The 'draw, write, and tell' method has been traditionally used in the fields of psychology and education. More recently, this method was used in other fields of knowledge, such as sociology, and it has enabled, for example, an understanding of how children look at health issues [55,57–59].

The 'draw, write, and tell' method [57] will be used for children to complete their first task and will take place in the chronic pain unit in a private room. Children will be asked to think about what chronic pain means to them, draw it on A4 blank paper using crayons, write their thoughts on it, and then tell the researcher about it. The children will be asked to not draw their name or the name of their family members or friends to protect their privacy and confidentiality [17]. Using the picture as background, the researcher will be able to ask the child questions about the topic. After the conversation, the researcher will take a photo of the drawing and will give the original to the child as a way of thanking them for their participation [60] and safeguarding the 'ownership' of the drawing [61]. It is important to give children something in return, something that may even provide parents/family members with some clues about the research (e.g., the questions posed) and about how children see and interpret their own condition.

The 'draw, write, and tell' method will enable us to make children's interpretations key in data collection [57]. Indeed, it was thought that the danger of misinterpreting what the children want to express would be overcome by giving them the chance to interpret what they have produced [19]. The child will be positioned as a participating subject in the research process [16,62], through an approach that might be familiar to them as most school age children (e.g., 7 to 10 years old) produce drawings, write, and talk about them at school or at home for fun [63–65]. The 'draw, write, and tell' method will enable the researcher to work *with* children instead of the traditional approach of working *on* children [64] and we believe that this would help to diminish power differences between the adult researcher and young participants [17]. In fact, this method contributes to empowering children, making them co-researchers, i.e., agents capable of producing and interpreting knowledge about themselves [29]. In addition, the opportunity to approach sensitive topics through drawing allows the child to talk about their condition indirectly, for example, by choosing to assign their characteristics and symptoms to a character in their drawing.

The sensory and embodied experience of chronic pain may be shared through the 'draw, write, and tell' method as children might be able to communicate their lived experiences whether through drawings, verbally, or using written words. In this sense, and as referred to by Pope and colleagues [55], (p. 43): "Young children are capable of expressing subjective concepts such as their experiences of pain". The use of this technique has been proved to be successful for studying children's beliefs of health and illness, in particular, of chronic conditions like cancer [61]. The child will be positioned as the 'expert' of the chronic condition in the sense that they would be invited to interpret their drawings orally or in writing [63]. In addition, the researcher will also take field notes that incorporate unspoken behavioral aspects (e.g., expressions and body language); in this way it will be possible to add elements to the research that can give clues about what is said and what is not [55]. Through drawings, children might express issues or thoughts that they might not want to express through language, which might precipitate negative emotions that the researcher must be prepared to deal with [17,61,63]. It is expected that the experience of the researchers in conducting research with vulnerable populations on sensitive

topics will mitigate any negative feelings or situations that could emerge. Nevertheless, an agreement will be made with the psychological team of the chronic unit where fieldwork will take place that, if needed, they will provide emotional support to our young participants.

5.2. Photo-Elicitation Interviews

At the end of the first task, the researcher will give each child a digital camera and an instruction sheet explaining what the child should do with the camera and how to use it. Children will be invited to use the camera during approximately a one-month period to take photos on three topics: (i) How I live with chronic pain; (ii) How I manage chronic pain; (iii) How I think my family and friends see my chronic pain. The photo-elicitation interview with children will be scheduled one month after the cameras had been given to them. Photo-elicitation interviews have been found to be particularly appropriate for studying everyday life and therefore it shows the potential for studying the experience of chronic pain in childhood [66]. Indeed, through photography, children will be able to capture and describe the sensory and embodied experience of chronic pain and the impact that it has on their daily living. It was thought that the taking of photographs would be an enjoyable and fun experience for children, offering them a certain degree of control over the research process [16,67]. As with the 'draw, write, and tell' technique, this method also promotes child empowerment, allowing them to make decisions about the content they want to create and discuss [68].

Photographs have been described as a powerful instrument as they might evoke memories, emotions, and reactions that might be difficult to capture through words in purely verbal interviews [69]. Through photographs children might be able to display issues that otherwise would be invisible or hidden albeit important for understanding the experience of chronic pain in childhood [18]. It is believed that photographs will more accurately reflect the children's embodied and lived experiences than other methods such as drawings [9]. It is hoped that inviting children to take photographs in their own environment will help, to a certain extent, to minimize the sensitivity of the topic under study [23]. While it could be argued that photographs will enable children to construct a particular story of themselves, it will be expected that the framework established by the researcher at the beginning of data collection, about what topics should be covered by the children in their photographs, will help to minimize this risk [66]. In addition, photographs are "socially produced artefacts" and thereby offer a "partial and incomplete" representation of children's pain lived experiences [70] (p. 100).

The photographs taken by children will not be analyzed but instead will serve as a visual prompt for them to talk about the topics they were asked to photograph. The children will be asked to describe the photographs and an interview schedule will be used by the researcher to ensure that the same topics will be covered in all the interviews [41]. The topic of chronic pain, due to its inherent sensitivity, will only be introduced by the researcher at the end of the interview in order to give the child enough space to feel secure and comfortable enough to talk about it [71]. Nevertheless, it is believed that having a visual prompt such as a photograph will stimulate children to talk about their living experiences [18,67,72]. This could be a cathartic and/or therapeutic experience for children, as the chance to talk about their living experiences might provide them an opportunity for emotional release, albeit we might consider this a non-anticipated and beneficial effect of the study and the methods employed [10]. In a similar way to Birch and Miller [73], we use the term therapeutic to refer to an emotional process by which children might reflect and come to an understanding of their lived experiences.

The photo-elicitation interviews will, preferably, be conducted in the child's home as it has been found to be the space where children tend to feel more comfortable [74,75]. When interviewing children in their own homes we need to be flexible as we might have to negotiate some compromises in relation to the space where the interviews will be held, unlike what could happen if interviews were conducted in an institutional setting such as the hospital. Indeed, we are aware of the impossibility of controlling the environment surrounding the interview, where the existence of noise and the lack of conditions (e.g., the absence of a table, lack of space, or the arrangement of furniture) might condition

the interaction with the child [76]. We will also try to seek a balance between the professional researcher and 'good guest' status [77]. Parents will not be present during task completions in order to give children enough space to express themselves in their own terms [74], unless the child expresses a wish for them to do so and will feel safer in their presence. Nonetheless, given the unpredictability inherent in conducting interviews in children's homes, we anticipate some difficulties in managing the presence of adults [76]. All these issues will have to be managed as they arise, and we will use our 'moral and emotional judgment' [78].

Before the photo-elicitation interview takes place, although written informed consent of children will be obtained at the beginning of the research process, the researcher will ask children if they still want to participate. We hoped that 'process consent' [79] will enable children to have control over research participation [80]. We will be prepared for the possibility, particularly as we will be working with children with chronic conditions, of informed dissent (i.e., "the capacity and opportunity to 'say or express no'" [81] (p. 152) through verbal avoidance or changes in body language, and thus will facilitate the child's non-participation in every stage of the process without compromising their well-being [17]. We will again use our own 'moral and emotional judgment' to interpret situations and responses [78] in order to take the best ethical decisions to protect the child [82].

At the end of the photo-elicitation interview, we will print a set of photographs and give them to each child as a way to thank them for their participation [60]. Although the consent of children would be obtained regarding the use of the photographs taken by them in research outputs and future publications for over 15 years, it is hoped that this will, to a certain extent, safeguard the 'ownership' of the photographs taken by the children [70]. The cameras will be offered to children after the photo-elicitation interview by way of thanks for their participation.

6. Discussion

There is growing recognition of the importance of giving voice to children in social research [83,84], particularly in matters concerning them [48,85,86]. Visual methods have been described as the most appropriate way to develop research with children, due to their flexible and interactive nature [66], as well as potentially enabling active participation of children in the research process [87]. Indeed, these methods are child-centered and might allow room for children with chronic pain to share their lived and embodied experience in their own terms [88]. The use of techniques which are familiar to children such as task-based methods are considered the best way to create a safe environment where children feel comfortable speaking with a non-familiar adult [3].

Researchers need to be prepared for the everyday difficulties of working with vulnerable subjects (e.g., children) on sensitive topics (e.g., chronic pain) which might emerge across the research process and cannot be anticipated [89], related to the interactions, the expectations they generate, or the spaces where they occur [77]. In fact, this type of research incorporates a high level of unpredictability which leads the researcher to adopt anticipatory and situational strategies. Reflexivity or ethical mindfulness [80] might help to overcome the "everyday ethical issues that arise in the doing of research" [89] (p. 263).

Working with vulnerable subjects on sensitive topics might be an emotionally demanding experience for researchers, who also need to be well prepared for dealing with the emotions of participants, as well as their own emotions [90,91]. Researchers need to be good communicators and be able to establish a trustful relationship with the participants [92]. A self-reflexive approach might be helpful to deal with the emotionality of the research encounter [93,94]. Within this context, emotionally sensed knowledge, i.e., the "knowledge sense *through* or *by* emotion" [95] (p. 748) might be key for enhancing researchers' understanding of the phenomenon under study [96]. Indeed, the acknowledgment of emotions might facilitate researchers' understanding of potential sensitive topics from the point of view of populations considered vulnerable [97].

7. Conclusions

Any research with populations considered vulnerable on potential sensitive topics might be bound up with ethical and methodological pitfalls [49]. This article has described some of the challenges of studying the embodied and lived experience of chronic pain by children in the family setting and how the use of multi-visual research methods might be helpful for overcoming such challenges. While it is possible to anticipate some of the challenges that may arise from this type of research, there are several aspects that emerge from it which are unpredictable [89], leading to the need to adopt a critical and vigilant stance regarding the research practices and their implications. This article suggests that the adoption of self-reflexive strategies might prepare researchers for dealing with the practical and ethical dimensions of the research [98] and illustrates how reflexivity is a powerful "methodological tool" [99] (p. 302).

Although the present article is not based on the analysis of concrete empirical data, the reflections presented are framed by the mobilized literature and the authors' experience in participating in research projects on sensitive themes and involving populations considered vulnerable. Overall, this article adds to the literature by demonstrating the complexity of developing research with children (i.e., a vulnerable population) on chronic pain (i.e., a sensitive topic); suggesting, through practical and ethical dilemmas, the importance of adapting research procedures to the actors and the context in which the interaction occurs even at an early phase of the research; by enhancing the procedural character that this type of research assumes, in the knowledge that vulnerability and sensitivity are present in all phases of the process. It therefore highlights a less visible aspect of the research process itself and the importance of adopting a critical and reflexive approach.

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Article

Exploring the Role of 'Shadowing' as a Beneficial Preparatory Step for Sensitive Qualitative Research with Children and Young People with Serious Health Conditions

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Abstract: This article aims to explore and record the role of shadowing in preparation for a qualitative study involving children and families with sensitive health issues. The researcher was engaged for a study involving qualitative research involving paediatric patients (those under 18 years old) and their families, but was unfamiliar with a hospital environment and interviewing children and young people (CYP) with a serious health condition. The researcher 'shadowed' healthcare professionals (HCPs) at a children's hospital during their day-to-day work in order to prepare for the research interviewing. From shadowing, the researcher gained: familiarity with a hospital environment, organisational processes, and medical terminology; an understanding of the appropriate ways to refer to patients; confidence and competence in talking to children with serious health conditions; and resilience to becoming upset during interviews while hearing patients' distressing stories—they became 'desensitised'. Shadowing can therefore be highly beneficial for researchers undertaking research in unfamiliar contexts, environments, and populations prior to interviewing.

Keywords: shadowing; qualitative research; research methodology; CYP; paediatric patients; interviews; sensitive research; chronic illness; brain tumours

1. Introduction

1.1. What Is Shadowing

'Shadowing' has a somewhat ambiguous character in social science due to its similarity to qualitative observation methods, especially that of participant-observation [1]. Though more commonly used as a data collection method in organizational research, it is not commonly recognized or critiqued in social science literature more generally [2]. This is at least partly due to the fact that shadowing is a technique used not for the purpose of social science but for vocational learning [3]. Shadowing, or observing another and what they "*actually do in the course of their everyday lives*" [3] (p. 1482) while carrying out their job, enabled the researcher to learn about the role, the tasks involved, and to supplement their understanding of the occupational environment [4].

In medicine, shadowing is commonplace in learning and is often expected to reinforce theory learnt in classrooms and expand knowledge [5,6]. As such, it is a normal component of the hospital environment, and young patients often feel that they are always watched by strangers [7]. Among others, the properties of shadowing that are distinct from observation methods are a focus on the individual (not department) for learning and understanding roles [1]. However, the shadowing this article subsequently describes was for the benefit of the researcher's understanding and did not involve a systematic collection of information for subsequent analysis [8]; therefore, it cannot be classified as research.

1.2. Context of Research

Though there had been studies exploring patients' views and understanding of their medical images [8–13], the perspectives and understandings of paediatric patients (those under 18 years) was a gap in the literature that needed addressing [12]. Shadowing was undertaken as a first step to gain a greater 'feel' and understanding of the context before the commencement of a study to explore what young patients with brain tumours and their families felt, understood, and valued from seeing Magnetic Resonance Images (MRIs) during their meetings with healthcare professionals (HCPs). Just as a literature review is a valuable prelude to research, though not research itself, shadowing was undertaken to better understand the perspectives of future research participants, the environment of the hospital that they frequently occupied, and how to converse with them to gain detailed and descriptive responses.

1.3. 'Sensitive' Research

For this study (for more detail and the main study interview results, see [14]), the focus was on the patient families' perceptions, opinions, and understandings of their world, and so a qualitative methodology seemed the most appropriate [15]. While there is no agreed upon definition of what a 'sensitive' topic is, it could generally be understood as those that are "*private, stressful or sacred; could potentially cause stigmatisation or fear; and are areas of controversy or social conflict*" [16] (p. 654). It is increasingly being recognised that being a researcher on a qualitative study, especially one involving listening to participants' painful or emotionally-charged experiences, such as those of a sensitive nature, can have a negative emotional impact on the researcher [17]. Measures such as debriefing, or 'self-care' should be taken to protect the mental well-being of the researcher, in order to avoid long-term effects such as vicarious traumatisation or 'burn out' [17,18].

While the topics that are regarded as sensitive often vary based on context, as well as cultural norms and the values of those undertaking the research [16], much health research "*focuses on aspects of life that may be considered sensitive*" [19] (p. 12). Being a parent of a child with a serious health condition, such as brain tumours, is known to be stressful [20]; and research on the topic potentially causes them "*anxiety about reawakening painful memories*" [21] (p. 507). While the parents of children with any form of cancer fear for their future,

> "*within cancer types differences in experiences have been shown, with, for examples, pediatric [sic] patients' parents experiencing more fear if their child had a brain tumour than if they had leukaemia*" [22] (p. 2).

Children and young people (CYP) are often deemed to have "*relative vulnerability*" compared to adults [23], were also going to be asked to recall potentially painful experiences of illness and hospitalisation, which might cause anxiety, discomfort, or fear [24].

For the study, a research fellow with experience in qualitative research methods was therefore engaged, though they were a layman to the research environment. Not being from a HCP background, familiar with a hospital environment, or in speaking to children with a 'serious' health condition, were seen as important knowledge gaps to address [25], and shadowing HCPs, where the study was based, was seen as a way to address them. This article aims to explore and record the role of shadowing in preparation for a qualitative study involving children and families with sensitive health issues.

2. Methods

2.1. Ethics

All subjects gave their informed consent for inclusion before they participated in the study that the shadowing was in preparation for. The protocol was approved by the West Midlands Black Country Research Ethics Committee (WM/16/WM/0490).

2.2. Preparing for the Study: Prior to Shadowing

A number of steps were taken by the researcher in order to prepare for undertaking the study: reviewing the literature, speaking with HCPs, observing and taking notes, asking questions, and writing up notes and reflecting (Table 1).

Table 1. Steps taken by the researcher to prepare for interviewing children and young people (CYP) with serious conditions (including shadowing).

Activity	Aim
Reviewing the literature	Gain an understanding of the issues and 'journey' for the participants that may be discussed in interviews. Gain experience of hearing similar emotive experiences to desensitise to them.
Approach healthcare professionals (HCPs) to arrange meetings	Learn about processes, culture, and rationales for the 'way things are done' (or supposed to be done) from HCP perspective.
Shadowing: Observing and taking notes	Gain 'feel' of environment, culture and medical terminology in process. Gain experience of hearing similar emotive experiences to desensitise to them.
Asking HCPs focussed follow-up questions (when appropriate)	Clarifying terms, nuances in language, actions, and reasoning not fully understood.
Writing up notes and reflecting	Making learning more explicit, and clarifying what not fully understood.

2.2.1. Reviewing the Literature

In preparation for interviewing, the researcher read journal articles and books on: the 'power' of the image [8,26]; how patients (and their families) understand and experience living with cancer [27,28]; how doctors communicate results and medical information [29]; epistemology and methods for researching in health [15,30]; methods for researching CYP [31,32]; experiences of hospitalised children on aspects of their care [27,33]; and NHS information for young patients with brain tumours [34]. In addition, the researcher watched online videos of children with brain tumours describing their experiences [35,36].

The Principal Investigator (PI) was keen that the researcher would become less likely to be distressed hearing about a family's experiences during a research interview, which could negatively affect the researcher and research—they hoped to desensitise the researcher. Desensitising is a part of HCPs' socialisation into the role and helps them to cope with the emotional demands of their work [37]. After this literature review, the researcher did feel less likely to become distressed while hearing the patients' and parents' stories. Desensitising was also an anticipated outcome for the shadowing.

2.2.2. Speaking to HCPs

The researcher spoke to HCPs based at the children's hospital where the research was to be based, including paediatric oncologists and nurse specialists, about how they showed MRI images to families, the various responses they received from families, and the perceived benefits for families. This helped the researcher learn the usual processes and rationales for interacting with patient families regarding MRIs.

HCPs also arranged mornings or afternoons when the researcher could shadow them. Due to the consideration for the families by the HCPs, families were not shadowed when they were in an acutely challenging period, such as being told of a relapse (their tumour returns after being surgically removed or reduced by chemotherapy or radiotherapy), or that they were starting palliative care (care needed for those at the end of their life).

2.3. Steps in Shadowing

2.3.1. Appearance and Body Language

The researcher wore dark clothing to be less 'eye-catching', aiming to 'blend into the background'. The HCPs would explain to the patient family the purpose of shadowing at the outset and gain verbal consent for the researcher to be present. The researcher was prepared to wait out of sight and earshot if the family objected to their presence, although none did. (The researcher wore a hospital identity card in order to access the hospital, which may have given the mistaken impression that they were a HCP, though it no doubt enhanced the legitimacy of their presence.) When introduced, the researcher smiled at first, sometimes said 'Hi' then avoided eye contact and tried to become invisible to the family they were shadowing. Obviously, anything heard was confidential.

The meetings observed were mostly 'check ups' or 'routine' appointments to discuss scan results or new symptoms found in the young patients. (None had their diagnosis or a relapse disclosed to them in the presence of the researcher.)

In meetings, the researcher would sit in the corner, away from the family, not interrupting or distracting the conversation. On the wards and other sites, they tended to stay close to the person they were shadowing, and not position themselves between the HCP/s and the CYP. Generally, their body positioning was 'open' to avoid being intimidating or intrusive, for example, they did not cross their arms, nor sit close enough to the families to invade their 'personal space'. The researcher tended to keep still and aimed to be unnoticed by the family. They kept their expression neutral or lightly smiling so as to be non-threatening and to avoid attention [38].

2.3.2. Observing and Taking Notes

The researcher aimed to observe as much detail as possible: what people said, how they said it, and their body language. Whilst the researcher discreetly carried a pen and a small notebook (or a piece of paper) to take notes, they only used these when they felt this would not be a distraction, and would not make the patient family feel uncomfortable or less willing to discuss things with their healthcare team. Any words or events that stood out as interesting or unusual were jotted down (such as the researcher's surprise at how often the word 'poo' was used) and wrote up in full as soon as the researcher got an opportunity to reflect on them later.

2.3.3. Asking Questions of the HCPs

The researcher tried to keep an open mind, to not assume anything, and always be thinking of questions to ask HCPs, such as 'What is that?', 'Why are you doing that?', or 'What's that noise?'. After the patient family had left the room or were out of earshot, the researcher was able to ask the HCPs questions to clarify anything not understood, while always being careful to maintain confidentiality. The researcher also had the possibility of being able to make comments to HCPs such as 'I never would have realised *x*!' or 'They were really interested in *y*!', which would often lead to an explanation from HCPs and the development of the researcher's understanding. '*X*'s parent is on a food restriction diet at the moment, which might be why they were so focussed on their child's eating, while the child thinks they're eating as usual.' Or 'Yes. Bowel movements and their contents are some of the main concerns that parents have when coming to see us. Cancer and its treatments frequently mess up these rhythms' [39].

2.3.4. Reflecting

In their head, the researcher could often still hear the words, accent, tone, and pitch of the observed speakers, as well as facial expressions and body language, for hours afterwards. They would aim to write up notes in full as soon as possible to aid accurate recollection. Writing up the reflections became quicker as they became more familiar with the process. Previously meaningless acronyms and terminology became familiar (though not necessarily more intelligible) to the researcher, so writing was a way to ensure that they did "*not necessarily adopt or reproduce*" [40] (p. 19) the views of the HCPs or families, but instead interpret and reflect on them.

The researcher wrote about more descriptive elements, such as what happened or was discussed in that specific session, and used square brackets to separate questions, assumptions, feelings, and 'impressions' (how they 'read' people or situations, for example, 'This is something close to their heart').

Sometimes it would help to print the notes out, so that the researcher could 'see' what was actually written. They would then 'tidy up' the document, linking thoughts and information and rearranging sentences and paragraphs so that they would read more coherently. They considered how the direct words or phrasing from patients (especially more colloquial expressions) might be misinterpreted by a reader (or themselves in the future) as well as thinking about how they could make sentences clearer and more succinct.

They would reflect on and highlight any similarities or differences to previous shadowing sessions, if these were brought to mind. They reflected on why there might be similarities or differences in order to make wider patterns or generalisations that might be useful when interviewing. The researcher found it easier to just write down everything they could think of (as in a stream of consciousness) and then return to it after working on a completely different task or the next day. If more stories or thoughts came to them when re-reading, then these were added.

Though they found it difficult, the researcher forced themselves to be honest and, self-critical, by adding how they thought they could have been more effective during shadowing and whether they might have misunderstood words or contexts. Initially, they only observed while 'shadowing', though eventually took a more active role. From the notes made during the shadowing process, four major areas of benefit emerged: a greater familiarity with the hospital environment and processes; an appropriate use of language and terminology; talking with CYP with serious health conditions; and desensitisation (Table 2).

Table 2. Illustrative examples from shadowing notes.

Area of Benefit	Illustration Extract from Shadowing Notes
Greater familiarisation with hospital environment and processes	I asked what the noise was that I could hear, and was told that it was an IV [intravenous] drip after being asked 'You've never been on the wards before then?' (*Nurse Specialist 2, Ward, p. 5*)
Appropriate use of language and terminology	The first patient had had many investigations after being diagnosed, and many problems that didn't seem linked to their cancer. [I have never heard the word 'poo' used so frequently in a half hour session.] (*Nurse Specialist 1 and Oncologist, Clinic, p. 4*)
Talking with CYP with serious health conditions	The YW [Youth Worker] took a cue from the patient's shirt. 'I don't think you're wearing a Star Wars shirt as a random thing.' The YW asked about whether they had seen Episodes 4–6, and said that that was what their generation had watched. [I reflected that making explicit the age gap would be something I would avoid doing since I would assume that it would make YP [young people] focus on the differences between us or think that they couldn't 'relate' to me.] (*Youth Worker 1, Ward, p. 23*)
'Desensitising' (against emotional upset)	I found it upsetting to be next to a child who was continuously crying and after hearing all the things they had been through, and the long term damage that their necessary and unavoidable treatment had caused, and had to stop myself from crying in the ward. [. . .] I am aware that if I start thinking about it again and think about having to explain it, it will set me off again so I will avoid this for a while. I guess that this is what the PI [Principal Investigator] wants to desensitise me to . . .] (*Nurse Specialist 2, Ward, p. 6*) [1]

[1] Extracts are followed by the role shadowed, the location, and the page number from the notes. [. . .] shows where lines have been removed that were not relevant to the point illustrated.

3. Results: Benefits from Shadowing

For six months, prior to the study, oncologists and nurse specialists were shadowed in 'consultations' (meetings with the patient families to discuss a patient's progress, effects of treatments, and scan results) or on the hospital wards on their regular clinical duties. Occasionally they were shadowed off-site while they were interacting with patients and their families. Youth workers and play facilitators were shadowed in the play centre or off-site buildings (Table 3).

Table 3. Number of shadowing sessions and roles shadowed.

Role (Number Shadowed in Role)	Sessions	Clinic	Wards	Play Centre	Offsite
Youth worker (2)	8	0	5	0	3
Nurse specialist (2)	5	0	4	0	1
Paediatric oncologist and nurse specialist (1)	3	3	0	0	0
Play specialist (2)	2	0	2	0	0
Play & recreation facilitator (2)	2	0	0	2	0

3.1. Greater Familiarity with Hospital Environment and Processes

Shadowing familiarised the researcher with the hospital environment (the sights and sounds to which the researcher was unaccustomed, such as the electronic intravenous fluid drip). This also taught the researcher useful codes of conduct, such as dress codes (short sleeves on the wards due to infection control rules), which was found useful when undertaking interviews on wards, including one in an isolation room.

The researcher had also imagined that the children's cancer ward would be a relatively quiet place, with a lot of upset or scared-looking children, and sombre-looking families. This was not the case. The ward was often quite noisy, with families experiencing "*fun, joy, living and learning*" [27] (p. 341), and the families usually smiled upon the HCP's approach.

In the literature review, the researcher had read about different 'patient pathways', or ways to reach the consultant—referral from a general practitioner (GP) for symptoms or from, for example, a hit to the head, which resulted in a scan that discovered a brain tumour. However, through speaking with HCPs, these concepts became less abstract and more tangible when hearing patient families talk about how they progressed through the hospital systems and departments, and their 'battles' and delays to get their child seen by the relevant doctors and diagnosed [41].

In shadowing a nurse specialist at a school meeting where they were joined by a parent, a head of department, a physiotherapist, and other school representatives, discussing past care and the challenges the patient faced, it dawned on the researcher how many individuals, and what a wide range of professions and organisations can be needed to support the healthcare of just one patient. They realised that the clinical management of children with cancer is a truly team effort, with many different skills being required, as well as the need to collaborate and communicate effectively [42].

3.2. Appropriate Use of Language

From shadowing, the researcher learnt that patient families tended to use more specific medical terms, rather than the word 'cancer', and they often understood (or at least used) medical terminology readily in discussions. Patients and families often become experts in their / child's conditions [43], though presumably they also found these words were far less emotive.

The researcher also learnt that HCPs almost always referred to patients as 'a patient with a brain tumour' rather than a 'brain tumour patient', to avoid identifying a person by their disease or condition. 'Poo' was a term used matter-of-factly by HCPs and families, matching the matter-of-fact tone of many parents for many of these conversations [44].

Shadowing familiarised the researcher somewhat with medical terminology. Though the researcher would not necessarily understand when and why certain terms were necessary, from the way words

were used in discussions, the researcher could deduce, for example, 'Temozolomide' was a medication, and that a 'shunt' was a piece of medical equipment.

The researcher noted that parents seemed to be pre-eminently concerned about the eating habits and the bowel movements of their child. One of the HCPs shadowed commented that food was one of the few things that a parent of a child with cancer could exert control over [39].

3.3. Talking with Children and Young People (CYP) with Serious Health Conditions

Initially, the researcher simply observed during shadowing. However, some of the HCPs strongly persuaded the researcher to have a more interactive role and to talk (and even play) with the patients, arguing that only so much could be learnt from observing and must be learnt through 'doing'—that is, directly conversing with the patients.

When the researcher tried this, they found that, as many HCPs had informed them, 'every child is different'. There was still a lot of 'trial and error' in finding out how to get each young person talking, and the researcher often had to draw on games being played, online videos or DVDs being watched, or nearby branded/themed objects (such as Pokémon or football clothing, toys or paraphernalia in the room) for conversational starting points. They found that there were no real taboo questions in asking an adolescent patient about their illness or treatment, especially when the questions were prefaced by a qualifier such as 'Is it alright if I ask . . . ?' On the contrary, most CYP seemed to find these to be topics that they were comfortable talking about, and had much to say.

Feedback from the HCPs on Shadowing

Though the researcher did not seek feedback on their shadowing, or their ability to build rapport with CYP with serious conditions, some HCPs shadowed offered this. After the researcher had been shadowing a number of youth worker sessions, they were asked by a patient who they were, and 'without thinking', the researcher echoed a response that they'd heard the youth worker say a number of times, and replied "*I'm a stalker*". The patient (and youth worker) laughed and was then more comfortable and relaxed with a stranger observing. The youth worker later congratulated the researcher on how far they'd come; correctly read the patient, their sense of humour, and the situation as one where this 'jokey' comment would be acceptable, be correctly interpreted, and would build rapport.

3.4. Desensitising the Researcher

On one occasion while shadowing, a child aged around 1 was crying for over an hour, as they needed to be almost continually moved to be monitored and have tests in their hospital bed. After listening to this crying for over an hour, in addition to hearing their parent talk about the dozens of operations, procedures and treatments the child had been through, and that the muscles in their legs had wasted away due to having to spend so much time in hospital beds, the researcher was very affected.

The PI viewed this as beneficial, and that after more contact and similar experiences, the likelihood of the researcher becoming distressed hearing about a family's experiences during the course of an interview would be minimized, i.e., they were becoming desensitised [37].

4. Reflections on Benefits from Shadowing

4.1. Hospital Processes and Environment

Shadowing gave the researcher a "*taste of clinical medicine*" [5] (p. 634) and familiarity with the processes and environment, such as medical equipment and the hospital wards.

4.2. Appropriate Use of Language

Prior to shadowing, one of the researcher's greatest concerns in talking with patient families was in saying the 'wrong thing' or asking a question on a taboo topic. Through shadowing, they found that one should not assume what patients, or their families, will find distressing, and that

children were often seemingly unfazed by answering questions on what the researcher considered a 'sensitive' topic. In a similar vein, Solberg (2014) found that children that had experienced or witnessed domestic violence were not necessarily upset discussing it, though they sensed "*uneasiness*" when one participant suspected that they were about to be asked why their mother did not intervene [45] (p. 239). Many parents also seemed to enjoy the experience of talking about this subject to an interested listener. Indeed, other researchers have noticed the 'therapeutic' or cathartic effect that those answering questions for interviews report [46]. The researcher also experienced an interview for the study where the parent did not display any distress when recounting an occasion where they thought that their child would die, though they needed tissues when discussing their child being bullied.

Though interviews often draw more implicitly on the personal experience of the researcher in developing the interview questions and the research design, such as a mother interviewing women about their experiences of pregnancy [47], it is not always the case that a researcher has that level of familiarity with the research setting. When preparing for ethnographic fieldwork (which draws on a range of research methods such as observation, documentary analysis and interviews), a key part of gaining trust and establishing relationships is to learn not only the words used by the group you are observing, but the context in which they are spoken [48]. Understanding this can lead to a new perspective and new insights, though when undertaking a study using interviews alone, this part is omitted.

Though there are benefits of being a member or 'insider' of a group, from long-term or highly implicit understandings that an 'outsider' would most likely miss [38]. A greater benefit is seen from being an outsider, or at least in some ways unfamiliar to the setting. This allows the researcher to 'stand back' and be able to see the interactions or events occurring in front of them as noteworthy, strange, or needing explanation to an outsider. However, in reality, most settings are a mixture of strange and familiar elements (such as a teacher researching in a school that they have never taught in), so it is more a matter of degree rather than a researcher being a complete 'insider' or 'outsider' [47]. Shadowing could be conceived as a useful way to gain access to 'insider knowledge' without having to gain the status of an 'insider'.

4.3. Talking with CYP with Serious Health Conditions

While many qualitative research methods textbooks, and journal articles focussing on methodological issues aver the importance of building rapport with young participants [19,24,48–52] in order to get rich, detailed data,

> "*The rapport that develops between researcher and child is important for encouraging more forthcoming responses*" [48] (p. 166),

very few explain how to go about this beyond "The interviewer asked questions or made comments about the child's personal life, such as family, school, and hobbies" [52] (p. 158), or "small talk about the weather, work, participants' children and how their days had been progressing" [19] (p. 14). The researcher found literature on researching CYP with serious health conditions was quite lacking in specific detail on techniques for building rapport, beyond using their first name and clarifying that they were not a doctor or nurse [53], or maintaining a "flexible and creative atmosphere" [24] (p. 351).

Though in a recent methods book on research with CYP [23], the researcher found reference to starting interviews with "*an easy ice-breaker topic, game or creative method*" (p. 117) and that time invested making CYP "*feel comfortable is time well spent*" (p. 112), as "*the more relaxed the children or young people feel […] with the researchers and with the research, the more honest, open and interactive they will be*" (p. 110). This methods book also explicitly covers 'sensitive topics'—anticipating these, using appropriate methods, and how to respond should CYP become distressed. Conversely, the researcher found that literature on researching sensitive issues tended not to consider CYP [54], and if they did, not to the level of detail of building rapport with them, regardless of a serious health condition [55].

However, there are a few exceptions. Bluebond-Langner's (1978) seminal work 'The Private Worlds of Dying Children' does detail that they introduce themselves, explain their role, then ask children

whether they can join them in colouring, drawing, or whatever the child was currently preoccupied with. (The researcher was even occasionally "*tested*"' to watch TV in silence until the child decides that they are "*OK*" and will answer questions) [53] (p. 247).) However, Bluebond-Langer's (1978) research took place over months, with opportunities for daily contact to build and establish relationships with the CYP [53], which is not available for studies where participants are interviewed once.

Although in the study that the shadowing reported in this paper was undertaken in preparation for, the researcher did arrange a session prior to the interviews where they coloured, drew, talked or played games with the CYP in order to make them more comfortable with the researcher and when speaking with them [14]. The researcher found that engaging and talking with children with serious health conditions requires a more "*practical mastery*", an "*implicit and pre-reflective feel . . . which guides action within social arenas*" [56] (p. 359). 'Practice' of these skills from shadowing can help with their acquisition, increasing ease and comfort when talking to CYP and building rapport.

4.4. Desensitising the Researcher

Although the researcher had been a little 'teary-eyed' watching online videos of children [35] with cancer talking about their experiences in preparation for the study, they had viewed themselves as not that likely to become distressed. They were subsequently surprised that after hearing a parent's account of their child's experiences, they were so much more affected than they expected. (Not unlike the title of an unrelated qualitative study, "*I can't say I wasn't anticipating it, but I didn't see it coming in this magnitude*" [57].)

Regular meetings with the research team for the researcher to debrief—express their emotions in a safe environment—are often recommended after shadowing in a clinical environment [58] or interviewing on a sensitive topic [18,59]. Given that the multidisciplinary team were disparately located, these debriefing sessions were more ad hoc, though after a few shadowing sessions, the researcher did not feel that they needed further debriefing.

5. Limitations

Due to the HCPs' concern for the emotional welfare of families, families were not shadowed when they were in an acutely challenging period, such as having recently being informed of a relapse, or that they were starting palliative care. Therefore, patient families shadowed may differ in certain respects, especially concerning their openness and willingness to talk about the illness and current treatments.

6. Conclusions

In conclusion, shadowing in preparation for sensitive research with children and young people (CYP) can provide a researcher with:

- Familiarity with an unfamiliar hospital environment and processes;
- Familiarity with medical terminology and appropriate language to use around children and young people with serious health conditions;
- Confidence and competence in talking with children with serious health conditions through gathering direct experience of how healthcare professionals (HCPs) interact with patient families within existing healthcare contexts; and
- Emotional desensitisation against upsetting stories from participants during interviews by hearing similar stories in advance.

Shadowing can thus be highly beneficial for researchers undertaking a study in unfamiliar contexts, environments, and populations. The literature on specific techniques to establish rapport when interviewing CYP with serious health conditions was found to be somewhat lacking.

7. Recommendations

Shadowing in healthcare research is recommended in the following situations:

- When researchers are interviewing those with a serious health condition for the first time;
- When researchers are conducting semi- or unstructured interviews with children for the first time; or
- When researchers are interviewing in social contexts that are unfamiliar to them, such as a hospital.

Specific Recommendations when Researching CYP with a Brain Tumour, and Their Families

- Refer to patients with [condition], rather than [condition] patients, to keep you aware that they are a person first, though with a condition.
- Parents will most likely use the specific name of the tumour, rather than 'cancer'. Follow their lead.
- 'Poo' will most likely be discussed, and is not viewed as a childish or 'silly' term
- Do not be afraid to ask for clarification on medical terminology that you do not understand. They will be used to doing so.
- Though you should aim to be tactful and avoid distress when discussing their illness and treatment, be aware that seemingly 'less important', 'less distressing', or 'more everyday' topics may be the ones that they become upset over.
- Occasions to 'practice' speaking and building rapport with children with serious conditions prior to the research will be invaluable. Shadow (or volunteer) at a hospice or hospital, or offer to babysit friends' children with such conditions.

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Concept Paper

Consent for Research on Violence against Children: Dilemmas and Contradictions

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Abstract: The increasing visibility of violence involving children has led to a recognition of the need to research its underlying dynamics. As a result, we now have a better understanding of the complexities involved in this kind of research, associated with children's developmental characteristics and social status, exposure to violence, and compromised parenting of caregivers. This paper discusses the issues raised by parental consent in research on violence against children, specifically the dilemma of children's rights to participation and protection, and proposes changes in research practice in this domain.

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1. The Complexities of Research on Violence against Children

The increasing visibility of violence involving children has led to a recognition of the need to research its underlying dynamics. In 2006, the United Nations Study on Violence against Children (VAC) recommended that states should "develop a national research agenda on VAC across settings where violence occurs, including through interview studies with children and parents, with particular attention to vulnerable groups of girls and boys." [1] (p. 29).

Tackling this challenge has led to a better understanding of the complexities involved in this kind of research, associated with:

(a) Children's social status, their perceived vulnerability and incompetence that, on the one hand, casts doubt on the validity of their accounts and decisions and, on the other, may lead to protective measures that prevent their participation in research [2,3];

(b) Contexts where VAC occur, that are difficult to access given their domestic setting that typically involve private adult-child relationships;

(c) Guardianship of adults, usually parents, responsible for protecting and representing children, within the power relationships between them, and possibly conflicting interests [3,4];

(d) Methodological and ethical difficulties resulting from children's developmental characteristics [5];

(e) Methodological and ethical challenges resulting from children's experience of trauma, such as refusal to participate, lack of accuracy or under-reporting [3];

(f) Cultural values of children's families and the importance given to personal autonomy, and their impact on decision-making regarding participation in research [6,7].

Furthermore, as scholars point out, the few ethical guidelines produced for this area [8] tend to portray children involved in this kind of investigation as a homogenous group, characterized by their age and as victims of violence. Yet, the complexity and variability of this population requires consideration:

- On one hand, research on VAC may be conducted with children who are victims or witnesses or in different roles or conditions that may not always be known in advance. Nevertheless, the common child target populations for research in this domain are deemed to be vulnerable children, within a wide spectrum of children's vulnerability profiles, Children may be considered vulnerable because they belong to families at risk, or because they put themselves at risk. They may also be already involved in child protection interventions that are designed to prevent or to reduce the consequences of child abuse or neglect, or to promote their wellbeing [9].

- On the other hand, the forms of victimization, their intensity, duration and frequency, as well as the age at which they occur, are factors that determine significant differences in their experiences and their impacts. Also important is the meaning that children, who are victims of violence, give to victimization events, as well as to their relationship with the offenders. In this sense, considering the history of child victimization seems to be a fundamental requirement for research in this domain [8].

- Furthermore, when we refer to children, we are referring to a population group aged between 0 and 18 years, with a diverse range of needs, forms of expression and relationships [8]. Research procedures and ethical considerations should reflect these differences, not only from the point of view of language comprehension and forms of involvement appropriate to children's interests, but also taking into account that the impact of violence and the impact of participating in research are likely to vary according to the maturity of the child.

- Lastly, the social and cultural characteristics of children's life contexts add further factors of diversity and complexity [8].

Research on VAC combines three characteristics that make it particularly delicate: it is focused on a *sensitive topic* and it involves *children* who may have been *victims*. Despite all precautions, participants in research on VAC are invited to take part in activities that may be "felt as intrusive, uncomfortable to disclose, and socially undesirable "[10] (p. 2) and, as such, be potentially disruptive, distressing or ultimately harmful [8], particularly for the child victims. In addition, as argued elsewhere [2], the social attributes ascribed to both children and victims are virtually identical, in that both are viewed as vulnerable, powerless and in need of protection. In this sense, the victim's perceived vulnerability reinforces the child's perceived vulnerability. Because of this "convergent negativity (children and victims), social impact of child victimisation is quite significant" [2] (p. 54). The child and the victim are "both voiceless because others speak of them, for them, but usually not to them or because nobody speaks at all about it (violence)" [2] (p. 54).

Therefore, in research on VAC, it must be recognized that to hear from children is not only a research requirement but also an ethical imperative. Either as victims or as witnesses, children are key informants of their lives [11] and experiences; gathering the facts reported by them is as important as understanding their perspectives and the meanings they attach to events. However, it is noteworthy that such research is not neutral or "innocent" [4] (p. 206). It must be conducted with the utmost care, methodological adequacy and ethical integrity, in order "to capture the full account of children's views and perspectives" [4] (p. 206) and not misinterpret their answers and silences. Otherwise, poor quality research practices involving children may paradoxically compromise the value of their participation, eventually resulting "in manipulation, decoration or tokenism." [7] (p. 4) and thus continuing to keep children out of reach [4] in that they are alienated both in and from the research process. These features combine to make research with children on sensitive topics, particularly violence, fraught with challenges [10].

2. Parental Permission for Children's Participation in Research

Parental consent is at the core of the ethical and methodological debate concerning children's participation in research. Giving parental permission is considered simultaneously as a right, a duty, a power and a responsibility of parents.

Adults and, especially, parents are responsible for defending the best interests of their children. Because they usually have a unique relationship with their children, formed by an affective bond, that gives them privileged knowledge, they are key actors in defending their child's well-being [5]. However, as Hagger argues, the assumption that parents are always in the best position to make the most appropriate decisions on behalf of their children is not always true [5]. In fact, parents may not have enough information to make decisions, or may decide according to their own interests and views, disregarding their children's perspective. Furthermore, as Hagger points out, research is a complex process with many implicit aspects that are unpredictable and, as such, may not be anticipated by parents [5]. Ultimately, parents' interests may be in conflict with those of their children.

Parents may not authorize the participation of their children in research on sensitive topics, such as child maltreatment or family violence [12], for a variety of reasons [8]:

- to preserve their family's privacy and thus prevent the child from revealing unintended information, in so far as parents are indirect subjects in VAC research [13];
- to defend what they consider to be their children's best interests, namely to shield them from: (i) experiencing discomfort or being exposed to distressing situations (e.g., experiences of boredom, inconvenience, stress, fear of failure, lowering of self-esteem, guilt, embarrassment) [13]; (ii) suffering potential harmful consequences engendered by the research process such as re-traumatisation or the risk of confidentiality being breached; (iii) being negatively labelled due to their involvement in research (the project, its aim and also the recruitment procedure) [9], even if initially they are not formally identified as victims [4];
- to protect their own interests i.e., to conceal their inadequate or harmful behaviour towards their children and thus avoid the consequences.

As a result of adults' self-interest or their interpretation of children's interests, children are subject to relationships of power and control that are expressed in terms of obligations, expectations and prohibitions that may obstruct their participation in research. Sometimes silencing their voice as victims and at other times denying their testimony as witnesses, in any event, these relationships disregard their perspective. Beyond the ethical issues raised, this may lead to a sample bias that could compromise the validity of research results and the development of knowledge about phenomena of social interest [12]. Underlying these concerns is the dialectic between children's rights to protection and participation and the associated concepts of child autonomy and competence [6,14,15]. As stated by Ruiz-Casares et al., "Whereas sometimes the lack of adult involvement can hinder children's and young people's development and access to resources, overprotection of children and young people can result in their exclusion from processes that affect them at the expense of the children and young people themselves and substantial loss for the communities where they live." [7] (p. 4) This raises the problem of the need for parental consent and its possible limits, especially considering two variables: the age of the child and the legitimacy of the parent.

2.1. The Problem of Child Incompetence

Although varying across countries [16], typically national laws and regulations are based on the legal age of consent, grounded on the concepts of children's immaturity and incompetence. On the other hand, parents are deemed natural and responsible decision makers for their children. Such static and abstract conceptions of children's and adults' capacities are conventional but arbitrary. In fact, both the legitimacy and power of parents to give their children permission to participate in research and children's heteronomy and incompetence are not considered absolute or universal. On the contrary, as Cashmore contends, there is a remarkable range of opinions [12], either based on developmental and neurological evidence [17] or ethical and methodological arguments [18].

What is at stake is that competence is not age-related [15] nor is autonomy. Childhood is a developmental period that involves continuous maturation, learning, and change of behaviours and capabilities. Children's participation in research should reflect this evolution and their social

involvement [7]. Conversely, children's competence also depends on their experience of participation supported by adults (scaffolding) [15]. Autonomy is also relational in nature; Sabatello et al. refer to this concept as *autonomy with others* to designate a "dynamic process of negotiation" between children and parents [6] (p. 2). According to these views, parents are not proxies for children until they reach the age at which they are legally competent and morally autonomous, but they support the development of their children's competencies, enabling their decision-making. Therefore, similar to what Olszewski and Goldkind argue for medical treatments [19], participation of children in research should be the "default position", and each case should be assessed *per se* [6]. Beyond ethical arguments that could support this position, empirical research reveals that, given appropriate information and time, children's decision-making is comparable to adults [17].

2.2. The Limits of Parental Consent

Vulnerable children often find themselves in complex circumstances (e.g., unaccompanied, looked after, runaway or otherwise separated from parents) [8,9] and in situations where families put them at risk and compromise their well-being, as in the case of violence. When parents do not protect their children from harm and, additionally, are a danger to them, these problems are compounded: on the one hand, children are vulnerable due to the risk of harm or to the actual harm suffered; on the other hand, they are also vulnerable as they lack adults that are responsible for representing them and acting as informed mediators.

Violence against children is a situation where there is an acknowledged conflict of interests between parents and children, resulting in a lack of parental protection. Therefore, in obtaining consent for children's participation in research, many authors recognize that parental authorisation is not an unconditional requirement, especially when children have been maltreated [20]. Furthermore, asking for parental consent may place children at risk [8,20], if children are in contact with the violent parent(s) [21].

Some scholars recommend considering the interest of children's involvement in research in terms of the benefit for the individual participant *vs* social benefit. In no circumstances, should the interests of children in general be used to justify the possibility of potential harm to the participating child. Moreover, participants' benefit should prevail over social and scientific interests [20]. However, this cost-benefit analysis should be carefully considered. For children who are victims, participation in research does not always have direct and immediate impact e.g., in terms of reducing the violence they are undergoing or its damaging consequences [22]. Yet, the experience of being listened to, and the opportunities to have their experiences validated and assigned meaning, can have positive effects [22,23] and lead to empowerment [21]. Furthermore, the social impact of research cannot be underestimated. The results of studies can be used to inform policies and professional practices to improve prevention and intervention on VAC that go beyond the immediate participants of the studies themselves, to the benefit of other children [22].

The question that arises under these circumstances is who should give consent for children to participate in research. There is a growing consensus that child protection takes precedence over parental rights [3]. Perry [8] claims that violence and abuse are private matters of social interest. However, according to Koocher & Keith-Spiegel [9], the courts normally only interfere with family relationships long after damage from bad parental decisions has been done.

In view of the obstacles that normally arise in relation to children's participation in research on sensitive topics and particularly on VAC, and given the urgent need for research into these issues, research ethics committees (RECs) play a critical role. Research on VAC requires specialized theoretical and methodological, as well as ethical, knowledge in all stages of the research process, particularly: design, ethical review procedures, informed consent, recruitment, assessment, intervention, and dissemination [24]. RECs are responsible for analysing research projects from the perspective of the rights and risks of the participants involved. Therefore, as Cater and Øverlienb [21] state, RECs should

carefully consider any situation where parents refuse consent for their children's right to participate and thus its potential empowering effects.

Furthermore, it should be noted that informed consent is more than just "a consent form or a legal document", it is "a communication and decision process" [25] (p. 5), with specificities relating to the type of research, its objectives, context and participants. Typically social research involves "a two-way exchange of information between researcher and potential participants" [8] (p. 36); however most research with children implies a "triad" that includes necessary interactions with parents or children's legal representatives [10,26]. Yet, in the case of research on VAC, the informed consent process often involves a dynamic of multiple relationships, usually in a hierarchy of gatekeepers. Though based on ethical standards for children protection, RECs appraisal of research on VAC normally adopts a conventional and legalistic stance; issues related to children's right to participate and be involved in what concerns their own protection and well-being [7,27] are very rarely considered. Following Ruiz-Casares et al., the nature and requirements of effective participation for children and young people in the context of child protection are not resolved and are an on-going area of concern [7].

3. Conclusions

Violence against children is attracting increasing interest from researchers. In consequence, in recent years, a large number of studies on this topic have emerged in the academic community. This sensitive topic, with vulnerable participants, creates new dilemmas and challenges where the scientific value of research and the interests of the participants must be carefully weighed and balanced. This involves going beyond the traditional formal approach circumscribed by ethical and legal guidelines. As Cater and Øverlien argue, "research ethics must not be reduced to a number of principles to be handled routinely" [21] (p. 76). In a similar vein, Isles [28] characterises and questions the informed consent process as often reduced to the collection of a signature on a consent form to guarantee subject's participation.

The conservative model of parents consenting on behalf of their children, followed by children's assent, needs to give way to a joint participatory model where children are included from the beginning, according to their competence, and guided by their parents in the process of decision-making. Whenever necessary, the researcher may triangulate this interaction. In cases where parental consent is difficult or dangerous to obtain, if parents "privilege their own understanding of situations over the child's welfare and rights" [21] (p. 72), the intentional use of limited disclosure by the researcher should be considered within strict limits: (i) to enforce the children's right to participate in research; (ii) when children's participation in research involves no more than minimal risk, with the prospect of direct or indirect benefit to subjects; iii) where the extent of limited disclosure is clearly defined [29].

Research on VAC requires the adoption of an attitude of responsibility, vigilance and reflexivity throughout the research process [30]. Moreover, it necessitates a new paradigm of communication between RECs, researchers and research participants; closer, continuous and more horizontal communication will allow researchers to better understand children's perspectives and to be sensitive to their needs [21]. This new paradigm of communication, more flexible and fluid, encompasses *ongoing consent* as suggested by Flewitt [31], involving close attention and response by the researcher to children's reactions, and the relationship of *ethical symmetry* proposed by Christensen and Prout [30], which involves giving children and adults the same status as research participants.

Research projects on VAC ought to provide evidence that they are necessary, valid and ethical. Therefore, compliance with ethical principles and guidelines is a key requirement. However, the role of RECs should not be limited to checking compliance with ethical requirements at the inception of research projects. RECs need to become more closely-coupled to the researchers and continue to monitor the development of research projects and their processes e.g., communication between researchers and participants. This would result in an enhanced understanding of the needs and experiences of researchers [32], the participants' characteristics, and the sociocultural context where research is being conducted. We believe that ongoing ethical deliberation, informed by concrete

knowledge of the research as it develops, will allow for the relevant ethical and methodological issues to be addressed, as necessary, at the various stages of the research process.

Assessment and management of risk of harm for research participants is part of high quality research. Considering that vulnerability is context-dependent [27] and individual competence and autonomy are an expression of meaningful relationships of individuals with contexts, people and processes, quality research does not constitute a risk factor for harm to participants deemed vulnerable [33]. Therefore, instead of adopting a paternalistic approach, concerned with making access to children difficult [33], RECs should work with research teams to enable robust and adaptive research programmes. Only the adoption of a dynamic, contextual and personalized approach guarantees that the children's involvement in research is appropriate. This is necessary for accessing and for understanding the experience of the key informants (and beneficiaries) of this domain. By doing so, we give children the opportunity to contribute to the research agenda, to improve our research processes, and, indirectly, to influence socio-political changes based on research evidence [25] that have the potential for positive impacts on child victimisation and interpersonal violence [22].

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Concept Paper

Reinforcing and Reproducing Stereotypes? Ethical Considerations When Doing Research on Stereotypes and Stereotyped Reasoning

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Abstract: Many social scientists are interested in studying stereotypes and stereotyped reasoning. This interest often comes from a wish to contribute to creating a more just and equal society. However, when we as scholars study stereotypes and stereotyped reasoning, we risk reproducing and maybe even reinforcing these processes, and thereby harming individuals or groups of individuals. The debates of this ethical issue mainly take the form of general discussions of research ethics and of weighing the aim of the research against potential harm to participants. While these reflections are extremely important, there is a need for discussing how this ethical issue can be handled in practice. The aim of this article is to develop a set of practical guidelines for managing this ethical issue, based on the examination of ethically delicate moments experienced during an ethnographic study of the construction of health and risk identities among seventh-graders in Denmark. Three guiding principles are proposed: Develop an ethical sensibility in order to identify ethically delicate moments; consider ethics as well as methods when constructing and posing questions; more specifically, briefings and debriefings can be used to address ethical issues; and, finally, make participants reflect upon their opinions and answers.

Keywords: research ethics; ethical sensibility; reflexivity; stereotypes; stereotyped reasoning; research with children; qualitative research; focus groups

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1. Introduction

When we as scholars design and carry out studies, we are occupied with conducting efficient research in accordance with research criteria. We continuously encounter methodological hurdles, which we have to overcome to advance our research in the most efficient manner. However, sometimes we find ourselves in situations where conducting efficient research may conflict with ethical considerations or principles. Research projects examining stereotypes and stereotyped reasoning may very likely fall within this category. When scholars try to uncover how participants employ stereotypes in their categorization and identification of themselves and others, they risk reproducing and reinforcing stereotyped reasoning by drawing attention to or probing participants to employ specific categories or classifications when answering questions [1–3]. A researcher may be interested in uncovering class stereotypes and hence ask a respondent to assign specific characteristics to people from different social classes. Likewise, a scholar interested in uncovering gender stereotypes may ask participants to describe what they perceive as truly feminine and masculine. However, by doing so, the researcher invites respondents to engage in stereotyped reasoning. This constitutes a dilemma for the researcher: The concern about obtaining data and the ethical concern of not reinforcing processes of stereotyped reasoning and thereby potentially violating the principle of beneficence [4]. According to this principle, which is also referred to as the "do no harm" imperative of research, the potential benefits of research should outweigh the potential harms of participating for human subjects [4]. However, weighing potential harms and benefits is a task associated with a high degree of uncertainty

since it is difficult to predict potential harms and benefits of research. Ethical review boards and codes of ethics are there to support and guide researchers in these ethical questions and to uphold the standard for ethical research. However, procedural ethics are not sufficient to address this ethical issue. Weighing potential harms and benefits requires significant knowledge about the research topic, the research setting and context as well as the methodological approach adopted in the concrete study, which ethical review boards may not always have, and which general ethical codes cannot take into account [5,6]. Moreover, since potential harms and benefits are difficult to predict, unexpected ethical issues can arise after approval by an ethical review board [5–7]. This calls for a focus on situated and contextualized ethics as well as ethics in practice. In other words, we have to discuss how we can minimize the risk of violating the principle of beneficence in practice in specific research situations.

The risk of reproducing stereotypes when doing research on stereotypes applies to a wide range of social science studies and is not unique to specific methodological approaches. However, few scholars have addressed this issue, and most discussions of the dilemma do not provide practical guidelines and substantial advice for scholars. The aim of this article is to develop a set of strategies that researchers can use, particularly in interview studies, to address the risk of reproducing or reinforcing stereotypes and stereotyped reasoning properly. The article is based on experiences from an ethnographic study of the construction of health and risk identities in the seventh grade in a Danish public school [8] as well as insights from the literature on these types of ethical concerns. Three guiding principles are derived from the examination of the empirical material as well as the engagement with the literature. First, scholars should seek to foster an ethical sensibility to be able to identify potential ethically delicate moments in the research process. Second, researchers should pay particular attention to the ethical dimension when they develop their questions. Third, they could ask participants to reflect upon their opinions and answers, for example, during interviews.

The article starts with a brief overview of how stereotypes and stereotyped reasoning have been studied in different literatures, what constitutes the ethical problem, and how scholars have sought to overcome it. Afterwards, the methodological approach and the study that forms the empirical base of the article are presented. The article then proceeds to the three guiding principles that could be helpful to scholars facing this ethical issue.

2. Studying Stereotypes and the Risk of Reproducing Stereotypes: The Dilemma in the Literature

Stereotypes and stereotyped reasoning are studied in various literatures based on a wide range of methodological approaches and methods. For example, experimental vignette studies are often used in the literature on stereotypes and discrimination in street-level bureaucracy [9–13]. Street-level bureaucrats such as caseworkers or teachers are presented with vignettes (case descriptions of a client) and asked to indicate how they would treat the client, for example whether they would impose sanctions, grant benefits, etc. By changing the name of the client (to an ethnic minority name) or some characteristics of the client (educational background, job), it becomes possible to study whether the client's ethnicity or social class affects how the street-level bureaucrat acts. This approach is often used in survey experiments, but can also be adopted in qualitative interviews [12,13].

Another approach to studying racial and social class stereotypes can be found in educational research in the form of statement questions in survey questionnaires. Respondents are presented with statements that represent prevailing stereotypes of race and class (for example: "Asians are better pupils than English pupils") and asked to agree or disagree. This approach has been criticized from an ethical point of view for encouraging and legitimizing the use of racial or ethnic stereotypes as frames of reference [3].

In gender studies, gender stereotypes are examined by, for example, asking participants what they associate with proper femininity and masculinity [14] as well as using the gender essentialism scale [15]. Within psychological research, a common way to study stereotypes (gender, racial, etc.) is through the implicit association test, which measures the strength of association between concepts (for example women and men) and evaluations (clever and caring) [16,17].

Which methodological approach to adopt depends on the subject of study and the scope of the research, for example whether the researcher is interested in implicit biases (for example the implicit bias approach) or more conscious stereotypes and opinions (as in the case of statement questions). However, I would argue that all approaches entail a risk of reproducing or reinforcing stereotypes and stereotyped reasoning. Research on stereotypes and stereotyped reasoning shows how creating an in-group and an out-group in itself results in discrimination of the out-group [18,19]. This is what makes research on stereotypes and categorization important and relevant. However, this should also make researchers aware that drawing attention to distinctions between groups or categories of people in research situations may have consequences.

While the risk of reproducing and reinforcing processes of stereotyped reasoning is inherent to studying these phenomena, few scholars actually address and problematize the ethical implications of this when presenting their research. This ethical issue is mainly debated on more abstract levels in general discussions of research ethics that center on the importance of reflecting on these issues, on considering the purpose of our research and "whose side we are on" and on weighing the aim and scope of the research against potential harm [1,20]. While these contributions are extremely important, I would argue that researchers would benefit from a stronger linkage between these ethical considerations and their everyday research practice.

Some scholars have discussed how to accommodate the ethical dilemma on a more practical level. In her study on identity formation among ethnic minority children in the Danish public school, Gilliam discusses how she tried, during interviews with the children, to uncover the use of ethnic categories among the children and how this process increased the children's focus on ethnicity [2]. This may have reinforced specific identities and stereotype understandings among the children. Gilliam describes how she tried to question the boundaries the children drew during the interview in order to counter this side effect of the research process [2], but she does not provide evidence for whether this strategy was effective. Other scholars have argued that asking open-ended questions instead of statement questions, such as "Asians are better pupils than English pupils" and inviting respondents to agree or disagree, is a way to avoid reproducing and legitimizing specific stereotypes [3]. However, whether this is a more ethically appropriate strategy can be questioned, since asking statement questions may actually force respondents to reflect explicitly on the stereotype presented, whereas open-ended questions may allow respondents to answer based on implicit and unquestioned stereotypes. Which approach to choose is thus more a question of methodology than of ethics since changing the way of asking questions may also alter what the researcher is actually capturing or measuring.

The aim of this article is to advance and specify these insights from the literature by examining ethically delicate moments in a research project I recently conducted and to derive some practical strategies to accommodate the ethical concern of reproducing and reinforcing stereotypes and stereotyped reasoning. In the following section, I present the methodological approach adopted in this article as well as the study that forms the empirical basis of the article.

3. Materials and Methods

The aim of this article is to provide a set of guiding principles for how to address the risk of reproducing and reinforcing stereotypes and stereotyped reasoning in research on these issues. As mentioned, the article builds on discussions in the existing literature and experiences from an ethnographic study on the construction and enactment of health and risk identities in the seventh grade in Danish a public school [8].

I develop three guidelines that scholars should pay attention to and incorporate in their research in order to manage the risk of reproducing and reinforcing stereotypes. The guiding principles are derived by drawing on discussions in the literature and by examining ethically delicate moments in the empirical material. My approach can thus be characterized as abductive; I have moved back and forth between theory and empirical observations, building claims through this iterative process [21,22]. In the following, I present the research design and methodology of the study.

The study took the form of an interpretive ethnography [23,24] on the topic of health risk prevention in schools conducted in four seventh-grade classes at two Danish public schools. More specifically, the project focused on how the meaning of health and risk as well as health and risk identities were constructed and transformed in the interaction between students, their peers and their teachers. The study asked the following questions: How are health and health risks defined in policies, among teachers and among students? How do policies, teachers and students categorize healthy schoolchildren and schoolchildren at health risk? How are identities as healthy and at risk performed in the school setting? The study thus examines categorization and classification processes as well as potential processes of stigmatization of individual students and groups of students. Since health is a potentially very sensitive topic related to stigma, this was a probable risk. Moreover, since the research was situated in the natural environment of the students (peers from school), the potential reinforcing effect of stigmatization has direct consequences for them (something they may experience in their daily lives at school).

The data was generated through a combination of participant observation (more than 500 h), focus groups with students, semi-structured interviews with teachers, focus group interviews with teachers and collection of policy documents. In this article, I mainly draw on experiences from the focus groups with the schoolchildren and observations. The observational data consists of observations of interactions between students and between teachers and students that somehow concerned situations where health risk behavior or state were at play, for example interactions where students discussed eating habits, health education, physical education classes, etc. The observational data consists of field notes on participant observation [24,25]. This entailed taking short notes in a notebook—a condensed description—during fieldwork and later re-writing the notes and filling in the gaps with details, thereby turning them into an expanded account [25].

I chose to conduct focus group interviews with the students because this allowed me to observe how the students negotiated the meaning of health and risk, as well as how they constructed health identities in interaction with each other [26,27]. Hence, focus groups were an appropriate technique to generate the type of data I needed to shed light on my subject of study. Furthermore, I was dealing with schoolchildren—a group of participants many researchers consider vulnerable. Research participants may have different needs and interests as well as varying degrees of power to pursue these interests and protect themselves, and accordingly some participants are in some situations vulnerable [1]. Schoolchildren may have less power to pursue their interests and protect themselves. Moreover, the relationship between adults and children entails an imbalanced power and information structure, which is not solely a result of the interview and research situation, but a general condition resulting from the fact that adults appear as authorities in every aspect of the child's life [28–32]. While it can be argued that the literature sometimes neglects the situational and dynamic nature of power relations among individuals and accordingly overestimates the imbalanced power structure between the adult researcher and children, doing research with children inevitably involves some methodological challenges. It is likely that it is more difficult to construct questions in a manner that makes them immediately understandable to the respondents, depending on their age. It may also make it more complicated to get answers since children may mistake the research situation for a teaching situation and wish to please the researcher by giving the right answers, or what they believe the researcher thinks are the right answers [2]. The imbalanced power structure cannot be eliminated, but it can be minimized by adopting "varied and imaginative research methods" [32]. One way is to make use of focus groups, which resemble a situation that schoolchildren are familiar with, namely interacting and talking with their peers. The focus group may have a more informal atmosphere and soften the asymmetrical power structure between the (adult) researcher and the (child) respondent [2]. Schoolchildren may feel more in control of the situation than in a single-person interview with a researcher. This way, respondents are empowered, which is essential in order to reduce the power differential between adult researcher and child respondent [28].

Since I was interested in collective negotiation and construction of meaning and identities, I made sure to address the children as a collective and encouraged them to discuss the questions collectively. A way to foster discussions and negotiations in a focus is to make use of exercises [33]. Exercises give members of a focus group a common task to solve, a common point of departure for discussion, and it allows the researcher to facilitate rather than lead the research situation. During the focus groups, I thus made use of various exercises. First, before the interview, I asked the pupils to make a short photo diary from their everyday life with pictures of situations, activities, habits, etc. that they associate with being healthy and unhealthy. This exercise was inspired by the technique photovoice, which is used in community-based participatory research [34–37]. The pupils sent their photos to me via email or text, and I printed them and brought them to the focus group. These photo diaries then formed the basis of discussions in the focus group. Among other things, I asked the children to classify the photos from the photo diaries and to categorize and classify themselves and their peers in relation to friendship groups and health behavior and state. The classification exercises combined with photo material proved a good tool for this specific kind of research, because having photo material and exercises made it easier for the young participants to express their views on an abstract and intangible phenomenon such as health. Moreover, it made the focus group situation interesting and increased the participants' attention span. Finally, the fact that the schoolchildren took and brought their own photos seemed to empower them by letting them express their understandings and opinions without the researcher having to ask a lot of questions and taking the lead in the focus group. The interview guide is attached in full length in the Appendix A.

I had many methodological considerations and arguments for choosing this approach. However, studying health categorization through this specific approach and dealing with vulnerable participants (young teenagers) in their natural environment created an ethically delicate situation. In Denmark, there is no tradition for having ethical review boards that approve research projects in the humanities and social sciences. Research projects with human subjects in the natural and medical sciences do need to be approved by the national research ethics committee, which is an independent authority under the ministry of health [38]. Recently, some Danish universities have begun to establish local institutional review boards [39]. The purpose of these institutional review boards is to review research projects with human participants in the social sciences and humanities in cases where the researchers need the approval for example in order to publish in particular journals or obtain a grant. At the point where I conducted my research these institutional review boards had not yet been established, therefore my research proposal could not be approved by such an authority. Instead, I discussed potential ethical challenges and how to address them with colleagues, and I obtained informed consent from the school principals, teachers and parents. However, I still encountered ethical challenges during my research. Based on these experiences and reflections on discussions in the literature, the following section seeks to develop a set of guidelines for managing these kinds of ethically delicate moments.

4. Addressing the Dilemma

Studying stereotypes and stereotyped reasoning will most often involve drawing participants' attention to stereotypes or inviting participants to engage in stereotyped reasoning. Moreover, when researchers ask participants such questions, they may perceive it as a legitimization of the stereotypes in question. This last point may be more pronounced in qualitative research, such as interview studies, where the researcher's courtesy and responsiveness could be interpreted as a declaration of agreement. Studying categorization and stereotyped reasoning will thus inherently involve some risk of reinforcing or reproducing those processes. This is the case for this type of research independently of research design and specific methods used. This article focusses on how to address the dilemma in qualitative research, particularly ethnographic studies and interview studies, but I would argue that the guidelines could be useful for scholars working with, for example, survey questionnaires.

Even though research on human subjects will always influence the participants and the social world surrounding them to some extent—and potentially inflict some degree of harm to individuals—we

should not, of course, refrain from doing research. Shedding light on stereotypes and stereotyped reasoning is highly relevant and important for society, but we should not neglect these ethical issues related to our research. Even though I do not believe it is possible to eliminate the risk of reinforcing these processes, I will argue that there are ways of minimizing it. The practical guidelines for minimizing this risk proposed below are by no means a substitute for procedural ethics such as general ethical codes and ethical review boards. They are suggestions for how researchers can manage ethically delicate moments in practice, which is rarely a topic in the literature.

4.1. Cultivating an Ethical Sensibility

Scholars have argued that ethical research behavior requires more than ethical knowledge and cognitive choices, namely that researchers are able to identify ethical issues and feel a responsibility to act in a morally appropriate manner [40]. Reflexivity has been stressed as a way to ensure ethical research by several scholars [7,41–43]. It is argued that researchers should not just be reflexive regarding the process of knowledge production for example concerning their positionality (methodological issues), but also in relation to how their research might affect research participants and how they as researchers should act in potential delicate situations (ethical issues) [7]. This kind of ethical reflexivity entails:

> *"[A]n acknowledgment of microethics, that is, of the ethical dimensions of ordinary, everyday research practice; second, sensitivity to what we call the "ethically important moments" in research practice, in all their particularities; and third, having or being able to develop a means of addressing and responding to ethical concerns if and when they arise in the research (which might well include a way of preempting potential ethical problems before they take hold)"* [7].

This section seeks to elaborate on the second point, the sensitivity towards ethically important moments. These moments are difficult to predict, but manifest themselves during the research process for example when the researcher interacts with participants and through the process of gaining knowledge about the lifeworld of participants [7,44]. The following example illustrates the difficulty in identifying and anticipating an ethically delicate moment.

Caroline: "I kind of think it goes here."

(Caroline takes her lasagna photo and puts it with the healthy food)

Clara: "I don't know. I'm not sure, I think this one goes. I don't know."

(Clara removes Caroline's lasagna photo from the healthy food.

Caroline knits her brows, pushes her bottom lip outwards and looks at Clara)

Iben: "Uh uh, Caroline! Killer face."

Clara: "No, but I don't think so. I don't know, I'm sorry."

Iben: "But that stuff that's also healthy."

(Iben points to the lasagna photo)

Caroline: "Yeah, I think so too."

Clara: "It's just that cheese is not like super healthy."

Caroline: "No, but ... "

(Focus group with Clara, Caroline, Iben and Filippa)

The quote is from a focus group with four 13-year-old girls, Clara, Caroline, Iben and Filippa. At the time of the focus group, the girls were good friends and described themselves as a "squad". In the excerpt, they are discussing their photo diaries and sorting their pictures into different piles, one of them with "healthy food". As the quote shows, Clara expressed the view that Caroline's photo of lasagna does not belong in the healthy category. After this episode, Caroline withdrew from the conversation and barely said anything for the rest of the focus group. During the recess after the interview, she avoided her friends and hung out with another group of girls. The teacher had not been present during the focus group and was not there during recess to observe Caroline's reaction, and I debated whether I should intervene. On the one hand, I felt it was a bit silly. It was, after all, "just a lasagna", and quarreling with your friends is a part of growing up. On the other hand, I felt that my research had somehow hurt Caroline's feelings. I had seen Caroline crying at school on some occasions, and the teacher had told me "she had issues" and "was a sensitive girl". I thus had the sense that the exercise had reinforced unpleasant feelings and sparked tension between the girls. I knew that it was not just about the lasagna, but a question of friendship, status and identity. In this situation, I chose not to intervene, mainly because I did not know what to do, and I hoped the girls would quickly make up, so the risk of long-term harm would not be great. Instead, I could have followed up with Caroline when I sensed that she was sad after the interview. I could have approached her and inquired into what she was feeling to get more information on how the focus group had influenced her and to assess the potential harm. It is not always possible to follow up with participants, and another strategy I could have chosen was to immediately act on the signs of unease I were sensing and tried to facilitate reflection and reconciliation between the girls during the focus group, which will further be elaborated in Section 4.3. It is difficult to decide on what to do, but I believe a strategy of reflexivity—reflecting critically on the potential problems and responses from the outset of the research—could have helped me respond to this situation in a more suitable way.

A prerequisite for being able to act ethically, is the ability to sense when ethics are at play, and what I want to show with this episode is that it is sometimes difficult for the researcher to anticipate what makes a situation become delicate. I knew that the focus group and the questions could potentially result in uncomfortable conversations, but I had no idea that a discussion on whether lasagna was healthy food could cause so much conflict. The example thus highlights how making sure your research is ethically justifiable is not solely a task you deal with beforehand through procedural ethics, but a process that continues throughout data collection, data management, publication, etc. Doing ethical research thus also involves making decisions about what is appropriate in a specific situation in a specific context, and we need to pay attention to not only procedural ethics, but also to situated and applied ethics [6]. As mentioned, a prerequisite for making appropriate decisions in concrete situations is sensitivity to identifying ethically delicate moments [40]. The question is how this sensitivity can be cultivated. Pader uses the terminology "ethnographic sensibility" [45] to denote awareness of details with orientation towards the meanings of these details in this particular context that characterizes ethnographic research. Ethnographic sensibility thus entails that the researcher sharpens and uses all her senses when doing research. Similarly, I would argue that the sensitivity to identify ethical issues in research can be developed by activating the senses and directing them at identifying ethical issues. This "ethical sensibility" is about awareness of details (for example the tone of Clara's voice, Caroline's facial and bodily expressions) and awareness of the meaning of what is happening in terms of research ethics, i.e., harm to participants. Ethical sensibility thus entails attention to research ethics in the process of conducting research as well as an ability to sense when research ethics come into play.

4.2. Constructing and Posing Questions

As scholars, we spend a lot of time on methodological discussions about how to construct questions. Reflections on how to construct and pose questions in order to address ethical issues are a way to minimize the risk of reproducing or reinforcing stereotypes and stereotyped reasoning. I believe one of the most important parts of asking questions (in interviews and questionnaires) for this

purpose is briefing and debriefing to make sure our research lives up to ethical standards. When we formulate briefings and debriefings, we are often concerned with procedural ethics such as informed consent. However, briefings and debriefings can also be used to manage the risk of reproducing and reinforcing stereotypes. For example, in the study I conducted, I started out by establishing some ground rules for the interview by making a statement, such as:

> In this group, it is also very important that you respect what others say, and that you do not repeat it to classmates, teachers, or others afterwards. You can tell what we discussed, but you cannot say that it was X who said it. Do we agree?

Moreover, I finished off the focus group with schoolchildren by asking them questions such as, "How has it been talking about your class and the groups in it?" in order to get a sense of how sensitive it had been for the students to talk about these issues.

Some scholars argue that we should ask open-ended questions instead of statement questions to avoid priming and legitimizing the use of particular stereotypes. As mentioned, whether this is a more ethical strategy is debatable. In my research, I adopted this approach and asked open questions like, "How do you think these photos fit together?", "Which photos or piles of photos do you think best describe the pupils/your peers?" I thus left it to the participants to construct the categories. However, in order not to leave these categories unquestioned, I combined the open-ended questions with making the participants reflect on these categories, which I discuss further in the following section.

Moreover, during interviews with the schoolchildren, I tried to legitimize behavior that was often perceived as "less healthy" or "unhealthy" by using myself as an example:

> You know how some people care a lot about their health and do a lot of things to stay healthy, and others maybe care more about other things? For instance, I don't always think that much about being healthy. I like chocolate a lot, and I really like to watch series on TV, and I sit in front of my computer for hours at work every day.

This meant that if there were children participating in the focus group who belonged to the group of "less healthy" students, there was at least one other person present in the room (me) who also belonged to that group, hopefully making the situation more comfortable.

4.3. Facilitating Reflections

Me: "So how do you feel about this? Do you think it is okay or fair that it is this way?"

Karla: "It doesn't have to be different."

Carl: "I think it is fine."

Karla: "I also think it is fine."

Marius: "Yeah."

Mette: "Yeah."

Carl: "I think that maybe sometimes we could hang out with some of the others also."

Karla: "Yes, for example Lise. Sometimes she is left out and that annoys her."

Mette: "When you look at these cards, it kind of makes you think that there are a couple of people that you don't really know like where they belong."

Karla: "Yeah you don't . . . "

Mette: "know what to do with them . . . "

Karla: "yeah"

Mette: "Because they don't really … yeah … "

(Focus group with Karla, Marius, Carl and Mette)

This excerpt is from a focus group with four 13-year-olds (two boys and two girls) who belonged to the group of popular children in the school. The quote is from the part in the interview where they had just categorized themselves and their peers in "friendship groups", showing me with small nametags the hierarchy of the school class. At the end of the interview, I encouraged them to reflect upon their classifications by asking whether they thought it was okay and fair that it was this way. As the quote shows, they started out by agreeing that it was fine, but during the conversation, they actually discussed the problems in the class. This illustrates that by making participants explain and discuss their reasoning (for example in a focus group), it is possible that the research situation can challenge existing hierarchies, which becomes clear in the statement made by the girl, Mette, "when you look at these cards". Doing the exercises and answering the questions, which potentially reproduce and reinforce stereotypes and stigmas, allow reflection and challenging of stereotyped reasoning and stigmatization. Another strategy for researchers could thus be to facilitate reflections; encourage participants to reflect critically upon their answers.

5. Conclusions

This paper discusses how ethical challenges can arise when we study categorization and stigmatization. More specifically, how we can avoid reinforcing such processes while still conducting efficient research. This problem, I argue, is seldom addressed comprehensively in the literature. While it may not be possible to eliminate the risk of reinforcing these processes, I argue that there are steps one could take to try to minimize it. First, scholars should use reflexivity not just as a strategy to ensure the quality of the knowledge claims that they make, but also in relation to ethical issues. This includes developing an ethical sensibility. A pre-requisite for making ethically appropriate choices is that researchers pay attention to and are able to identify ethically delicate moments, which may not always be straightforward. How the research process plays out—especially in qualitative research—is not easy to anticipate and what can turn out to be an ethically delicate moment in a particular research context is thus to a large extent unpredictable. Thus, the researcher should attune her senses to the ethical. Furthermore, the researcher should not only think about methods, but also ethics when constructing and posing questions, for example by using briefings and debriefings to not only secure procedural ethics, but also to inquire into how the participants experience the interview and thereby facilitating the researcher's critical reflections on his or her research practice. A final strategy is to make participants reflect upon their opinions and answers. After all, it is possible that the research situation will actually challenge stereotyped reasoning among participants. Ethical reflexivity and ethical sensibility are important for conducting ethical research. While this article has focused on the individual researcher, I would argue that a crucial part of developing self-reflexive strategies is deliberation within the research community about research ethics.

Conflicts of Interest: No conflict of interest to declare.

Appendix A

Table A1. Interview guide 1: Social categories and identities in the classroom.

Phenomenon	Research Questions	Questions
Briefing	Presentation and warm-up questions	(1) To begin with, I would like you to state your name and your age, so that it will be on the tape Before we begin the interview, I would just like to say that whatever you say here is confidential. This means that I will not repeat what you say to your teacher, to the other children from your class, or to your parents. I will use it in my paper, but no one will know that you were the ones who said it. In this group, it is also very important that you respect what others say, and that you do not repeat it to classmates, teachers, or others afterwards. You can tell what we discussed, but you cannot say that it was X who said it. Do we agree? (2) Can you tell me a bit about how it is like in your class?

Introduction to activity based questions: "pile sorting"/"card-sorting-task" (joint task)
A pile of name tags with all the names the pupils from class is spread across the table

Phenomenon	Research questions	Questions
Groups in the class Mapping of the social landscape (Group level) Underlying categories and principles of differentiations	Who belongs with whom? Who does not belong with whom? What do the pupils in the different groups have in common? How do they resemble each other? Are there some points where they differentiate? Which? How do the pupils in the different groups separate themselves from each other? Are there some points where they resemble each other? How are the groups' mutual relations?	Here are a bunch of name tags with the names of the pupils in your class. Sometimes there are some who hang out more often in a class. Well, some groups of people who hang out and talk more than they do with others. That happens at my work too. For example, I talk a lot with a guy called Jonas because we share an office. That does not mean that you do not like other people. There might just be somebody you hang out with more often. (2) How is it like in your class? If you had to group the people in your class together the way they belong, how would you do so? You can decide how big the groups should be. They do not need to be of equal size, and some can be alone. That is up to you. There is not a correct way or a wrong way of doing it. You are the ones who decide. (3) What do the pupils in the groups have in common? (3b) How are they different from each other? (3d) Why do you think that these pupils *hang out*? (3e) It is always like this? Are there different groups during class, during recess, or outside school? (3f) How are the pupils in the various groups different from each other? (3g) Are there some points where they resemble each other? (agreement?) (4) How do you think it would look like if your teacher had made the groups?
Self-identification (disidentification) (individual level)	Which group of pupils does the individual pupil associate himself/herself with? Which pupils do they distance themselves from? Why? Which groups do they associate/distance themselves with/from?	I can see that you have placed yourselves there. (5) Which groups do you think you fit minimally into? (5a) For example, if you were going camping, and the teacher decided whose tent you slept in/which cooking team you were on, and you ended up in group X. How would you feel about that?
Debriefing		It is completely normal that you sometimes hang out with some people in class more so than with others. That does not mean that you do not like other people. (6) How has it been talking about your class and the groups in it? (6a) Do you sometimes talk about it in class? For example, during form time? (6b) Do you sometimes talk about it with your classmates? For example, in your spare time?

Table A2. Interview guide 2: Health categories and identities in the classroom.

Phenomenon	Research Questions	Questions
Introduction	Presentation of the participants in the focus group	(1) Like last time, we are going to start the round with you stating your names, so it will be recorded on the tape
		Activity-based questions: Photo diaries (individual task)
Sense of health and categories (individual)	What is healthy? What is unhealthy? According to the pupils, when are they being healthy/unhealthy? How does health appear in their day-to-day life?	You have sent me some pictures that show healthy and unhealthy things, activities, times, etc. in your everyday life. (2) Would you mind giving a brief account of your pictures? Let us take a round … (2a) On picture X, is that something you often do/experiences/eat in your everyday life? (2b) Do you think what is on picture X is healthy/unhealthy? Why? (2c) When does it happen? (2d) Who are you with when it happens? Where are you? (2e) Do you think about if it is healthy/unhealthy when you do/eat what is on picture X? Why/Why not? (2f) Do you talk about how healthy/unhealthy it is when you do it?
		Activity-based questions: joint task—"Picture sorting" with health pictures(joint task)
Health categories (joint)	What is healthy/unhealthy? Which differences and similarities of the perception of what is healthy and unhealthy are there between the pupils? How is that reflected?	(3) We have looked at your pictures. If you had to group your pictures the way they fit together, how would you do it? Please go ahead. There does not necessarily need to be a pile with what is healthy and another one with what is unhealthy. You can make multiple piles and think about it. *Probes* *(3a) All right, can you tell me something about the piles you have made?* *(3b) Why have you chosen to divide them into these piles?* *(3c) Do you all agree, or are there some of the pictures or the piles you disagree with? How would you like them to look?*
Activity-based questions: "Picture sorting" with health pictures and name tags		
Health identities and categories	How do they understand the other pupils' health? Who is healthy/unhealthy? Who is like each other in regard to their health? Why? How do the pupils understand their own health? With what do the pupils associate themselves? From what do they distance themselves? With whom do they associate themselves? From whom do they distance themselves?	I have these name tags from last time. Now, it is normal that some people care deeply about their health and want to do a lot to stay healthy while others care about other things . For example, I do not always care if I am healthy (I really like chocolate, and I also like watching shows on the television). I would probably place myself there. *(they get their own name tag)* (4) If you had to place yourselves in one of the piles with the pictures, where would that be? Why? (4a) If you had to place the others from that class, how would you do it? Why? *(agreement?)*
Health promotion		(5) Do you sometimes talk about what is healthy and unhealthy with each other? (5a) When for example? (5b) Do you listen to what your classmates say about health? (5c) For example, if one of your classmates began to eat healthier or started exercising, would you do the same? (6) Do you also talk about health with your teachers at school? (6a) Is health something you learn about at school? Something that is in the curriculum? (6b) What do you talk about then? (6c) What do you do? (6c) Do you like it when you learn about health, or when you move around? (6d) Do you listen to what your teachers (or the health visitors) say about health? (7) Do you sometimes talk about what is healthy or unhealthy with your parents? (7a) What do your parents say? (7b) How you respond? (7c) Do you listen to what your parents say about health? (8) Who do you listen to the most?

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Article

Ethics in Categorizing Ethnicity and Disability in Research with Children

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Abstract: The use of categories is a contested subject in social sciences. The use of social categories allows researchers to explore similarities, differences, and inequalities between groups of people. However, by using social categories, researchers run the risk of essentializing differences. The aim of this article is to problematize the procedural and relational ethics of using categories in research with children. Based on two research projects studying inclusion and exclusion in physical education, we examine the ongoing ethical dilemmas of categorizing children in terms of disability and ethnic background. The reflections are grounded in intersectional and relational ethical perspectives with a focus on how power is manifested in practices and structures throughout the research process. The data consist of field notes, transcripts of interviews with children and their parents, and the authors' reflective accounts. The results are organized into three main themes: (1) How categories frame the research in its initial phases (informed consent and voluntary participation), (2) power relationships in context (navigating meanings of categories in the interviews and the relational ethics of generational ordering in combined interviews with children and their parents), and (3) (re)constructing stories and ensuring anonymity. In the discussion, we reflect on how singling out groups of children framed the research, how categories and power relations were negotiated and navigated in interviews and fieldwork, and how, in the reporting of the results, understandings of the children and their experiences were constructed. We argue that by not reflecting on the ethics of categorizing children in research, researchers are in danger of reproducing rather than challenging social inequality and discrimination.

Keywords: categorization; children; disability; ethnicity; intersectionality; relational ethics

1. Introduction

The use of categories and the act of categorizing human beings in research is highly contested [1,2]. The underlying dilemma is what Gunaratnam [3] (p. 31) referred to as the "treacherous bind" of categories, in which researchers need social categories to address issues of inequality and discrimination, but at the same time, researchers need to critically de- and reconstruct these "discursively entangled" concepts. Several scholars have called attention to how categories such as children at risk, vulnerable children, disabled children, and ethnic minority children form ideological thought and political action [2]. Categories do not neutrally describe concepts, but rather contain political guidelines and can lead to stigmatization and hierarchization among people if left unexamined [3,4]. For example, scholars have pointed out the tendency of presenting people belonging to ethnic and cultural minorities in research literature only when they negatively deviate from what is considered normal/mainstream [5–7]. In disability research, diagnosis and categorization of children into disability groups is often objectively reported by portraying the disability as an inherent feature of the child rather than a constructed category. Within such research, the category and label of disability often connote marginality and stigma [8]. Hence, the use of categories in empirical research calls for ethical consideration.

The issue of categorization is particularly relevant in areas related to health, physical activity, and physical education [9,10]. While categorization of race and ethnicity in epidemiological research is considered important in order to generate knowledge to support public health initiatives [11], scholars have questioned how people are forced into broad categories that do not account for increasingly diverse populations and, furthermore, how studies often fail to recognize differences *within* groups of people [11,12]. Furthermore, scholars have pointed out how research regarding ethnicity in Western societies tends to center on the experiences of the *minoritized other* and is undermined by colorblind approaches [13]. As such, white researchers in the area of physical education have started to examine the ways in which the taken-for-granted nature of whiteness shape their professional identities and the research they engage in [13,14]. Scholars have also illuminated how children from minority backgrounds or with disabilities are often placed within homogenous and fixed categories and treated within *deficit discourse* [15–19]. Within this discourse, children of minority backgrounds or with disabilities are seen as lacking the skills, values, and norms to be recognized as good and competent students in physical education [20]. Scholars have suggested that research has contributed to (re)producing categorical thinking and *othering* by focusing on how children's characteristics, such as cultural background or ability, act as barriers to participation rather than examining how the subject in Western countries is racialized, white-centric, and embedded in thoughts of Eurocentrism and ableism [19,21–23]. Furthermore, scholars have critiqued how many studies are based in a *single issue* approach (i.e., focused on disability, gender, or ethnicity alone), which runs the risk of missing how experiences are influenced by multiple aspects of individual lives or the marginalization and exclusion experienced by children who fall outside the scope of the category of focus [12,23,24]. To counter this, there has been a growing body of research applying intersectional frameworks to investigate the ways in which students' multiple identities are relevant to their physical education experiences [12,23].

While our reliance upon social categories in social research can reproduce dominant conceptions of the category in question, categories can also be used to mobilize political action and transformation [3]. As emphasized by feminist scholars in the field of physical education and health, this requires scholars to engage in critical reflections regarding the complex issues of power entailed in research relying on categories of difference [5,10]. The implementation of intersectional frameworks has been illuminated as important to address categorization and power relations in socially just ways [2,16,25–27]. Intersectionality provides tools to understand the complex, dynamic, and contextual character of categories and how they are experienced in individual lives and in interactions [2,5]. Yet, the call (and responsibility) to challenge stereotypes and bring forward diversity within an intersectional framework raises ethical issues that are less discussed in the literature.

A large body of research drew attention to the issue of categorization in regard to how it is represented and implemented in official measurements and procedural ethics [11,28], however, there is still a need for more researchers to provide insight into how these challenges are navigated in specific research situations, contexts, and social relations [3,10,29–31]. Based on two research projects studying inclusion and exclusion in physical education in schools among children with disabilities and of diverse ethnic backgrounds, we reflected upon the behind-the-scenes messiness of using social categories in research [32]. In the article, we problematized the procedural and relational ethics of using categories in research with children and reflected upon the relational encounters between children, parents, teachers, and researchers in the two projects. The aim was to contribute to the discussion of how categories framed the knowledge produced and the power relationships between the researcher and the participants. More precisely, the questions asked were: How does singling out minority groups of children frame our research? How are categories and power relations negotiated and navigated in our research? How are children and their experiences reconstructed in writing?

In this article, we build on the writings of Carolyn Ellis [30,33] to understand the relational ethics of categorizing children in research. Ellis stated that ethical research means more than getting a project approved by the ethics committee (procedural ethics) and replacing names with pseudonyms. Relational ethics "requires researchers to act from our hearts and minds, to acknowledge our interpersonal

bonds to others, and initiate and maintain conversations" [30] (p. 4). The ethics of engaging children in research are widely discussed in childhood sociology literature [34–37]. While unequal power relationships are present in all research with human beings, research involving children is influenced to a greater extent by perceptions of their competence and vulnerability—particularly for children categorized as disabled or from an ethnic minority background [38]. Research centered on children's rights to be listened to and to take an active role in research that directly affects them requires a redistribution of power in the research relationship [5]. Yet, the redistribution of power in research is difficult to facilitate. Berry Mayall [27] argued that the asymmetrical power relationship of childhood versus adulthood is constructed as a principle of social categorization and generational organization that all researchers attempting to conduct research with children need to reflect upon. Ethical research practices with children require that we recognize children's inherent vulnerability while questioning their structurally constructed vulnerability [34–36]. Inherent vulnerability is a consequence of biological immaturity. Structural vulnerability, in contrast, arises as a consequence of, and is reinforced by, social and political structures that produce powerlessness in children. Intersectional and relational ethical perspectives allow researchers to consider ethics beyond their official rights and responsibilities, and instead base them on thoughtful/caring relationships, thus providing tools to balance power relationships in research situations [5,27].

2. Materials and Methods

The current article was based on two research projects exploring issues regarding inclusion and exclusion in the context of physical education in Norway. The Norwegian Social Science Data Services (NSD) approved the projects (Project A: 35845, Project B: 39074). Data collection for the projects took place from 2014 to 2015. Both projects conceptualized inclusion within the agenda of education for all, which emphasizes equity and respect for diversity as important principles guiding policies and practices [39]. However, the projects differed in terms of research design, the (non-)use of predefined categories, and how categories were used in terms of the selected analytical perspectives used to provide insight into inclusion/exclusion [24]. By exploring the two linked, yet distinct projects, we aimed to contribute the methodological literature regarding performing ethical research with children. As Cecchini [29] (this issue) argued, the risk of reproducing the stereotypic and marginalizing understandings that research seeks to challenge apply to all kinds of methodological approaches. In line with Ellis [30], we argue that investigating how we navigate these shared challenges will strengthen knowledge regarding how to construct socially just research. The following sections describe the two projects, the data, and the analytical approach used for this article.

2.1. Project A

The first project addressed students' experiences of inclusion and exclusion in multiethnic physical education classes. The aim of the project was to explore, from an intersectional perspective, the diversity of stories among students from diverse backgrounds [10,12]. In order to capture the complexity of lives in context [26], an ethnographic design using participant observation and semi-structured interviews was chosen. Data consisted of field notes from participant observations of 56 physical education lessons and interviews with 17 students. At the end of the fieldwork, students were selected for interviews according to a generic purposive sampling technique [40]. In order to sample a diverse group of students, the participants were selected based on gender, ethnic background, social groupings, visible skills, and attitudes expressed toward the subject. The interview guide was designed to complement the field notes and generate rich accounts of experiences regarding welfare, learning outcomes, and perceived learning environments within physical education and in school in general. Based on an intersectional perspective, the interview guide also contained questions about family background, leisure-time activities and interests, and social relationships in order to understand the students' stories in a larger context.

About one-third of the students in the classes were bilingual, having backgrounds from countries in South Asia, the Middle East, West and East Africa, and North America. All students except one were born and raised in Norway. The first author—a female, white, non-disabled, ethnic Norwegian PhD student—conducted the fieldwork and interviews. The observed lessons were spread over three semesters for the two classes. During the study period, two male and two female, white, ethnic Norwegian teachers were involved. The school, a public school located in the Oslo area, was contacted through the physical education teacher, and permission to conduct the research was obtained from the school management. In terms of procedural ethics, written informed consent was obtained from teachers and parents and oral consent from the students interviewed. Consent stated that all data would be handled with confidentiality, and interviewees were informed of the possibility of withdrawing at any time.

Because of its attention to context and recognition of individual agency, applying intersectional frameworks is viewed by many scholars in the field as one solution to address categorization and power relationships in the research process [5,10,16]. Viewing identities as multiple, fluid, and shifting, I decided to enter the field with an inclusive approach, not focusing on a special group of children and not knowing anything about how students might be categorized according to official measures of ethnicity. In order to identify classes where students had diverse ethnic and cultural backgrounds, the school chose classes for the fieldwork based on number of bilingual students present (approximately 40%). However, in the initial phases of the fieldwork, I was not familiar with which students were bilingual or not. This approach allowed me to explore how, when and which differences mattered, as well as how students negotiated different positions in the class. By applying an intersectional perspective crosscutting social division, such as gender and social class, individual differences and their opportunities and constraints could be recognized [12]. However, working with ethnicity in research requires specific ethical considerations, particularly in research where the illumination of individual experiences related to ethnicity is central [1,7]. Not knowing the ethnic backgrounds of the students also raised issues around power relationships between the researcher and the children. Blurring the lines of ethnicity challenged me to reflect critically upon the ways in which my own background informed the questions and observations [41]. However, it possibly made it more difficult to reveal how issues related to ethnicity often work in subtle ways [42].

While the project aimed at deconstructing essentialist and racialist images of the *ethnic other*, social categories were considered important in order to reveal power structures, exclusion, and social injustice [3,10]. One of the strategies for this was the application of an intersectional lens in combination with a thematic narrative analysis of the ethnographic data [43]. Children's stories can provide insight into the structural and contextual processes that produce inequality and exclusion. This insight can be gained by considering the processes of positioning and identification in relation to categories of difference (i.e., by paying attention to how the students identify themselves and others in terms of ethnicity, being fit and sporty, or physical appearance) [22]. The thematic narrative was important, as it stressed that interviews were analyzed separately and that extracts were not separated from the interview when interpreting the sequences of text. Extracts were first interpreted in light of the data, i.e., the interview as a whole, interviews with peers, and field notes. Secondly, the data were interpreted in light of the national and political contexts and previous research in the field of physical and general education.

2.2. Project B

The second project (Project B) was a multimethod research project that addressed inclusion in physical education as experienced by children with disabilities and their parents [44]. The understanding of inclusion in this project was directed toward children's rights to "participate in regular physical education with their peers while receiving the supplementary aid and support services needed to take full advantage of the curriculum and the social, physical and academic benefits it aims to provide" [45] (p. 3). Although the selection of participants proceeded from a medical categorization of individual

characteristics of physical, mental, or emotional functioning, disability in this project was understood within an interactional approach [18,46]. The interactional approach to disability recognizes that disability is not experienced or lived in the same way by all individuals; rather, it is understood as contextual, situational, and individually dependent [46]. The aim was to better understand the interactions between these personal and environmental elements and what supported or hindered inclusion in physical education. Overall, Project B consisted of one survey study and one interview study with children and parents. The data for this article were limited to the interview study.

Purposeful criteria-based sampling was used to recruit participants in the interview study. The main criteria were that the child was identified to have a disability and attended general school. Participants were recruited at a rehabilitation center specialized in physical activity for children with disabilities. In the study, 15 children with disabilities (nine boys and six girls) and 26 parents (10 fathers and 16 mothers) were included. Seven children were diagnosed with cerebral palsy (CP), five with Down syndrome, four with physical disabilities, three with learning disabilities, two with Asperger spectrum disorder (ASD), and four with other disabilities, such as visual impairment or an unspecified diagnosis.

The interviews were conducted while the families attended a three-week stay at a rehabilitation center. The overall themes in the semi-structured interview guide were: (a) Children's placement in physical education, (b) children's experiences with the activities and organization of physical education, (c) social relationships with peers and teachers, and (d) experiences with the learning climate. The interviews were recorded and transcribed verbatim. The exceptions were two interviews in which I wrote notes to log the conversation because the child preferred not to use a recorder. The interviews were conducted as combined interviews with the child and the parent together or as individual interviews, depending on the participants' preferences (12 interviews with children and parent(s) together, three interviews with the child alone, and 13 interviews with the parent alone). The second author—a female, white, non-disabled, ethnic Norwegian PhD student—conducted the interviews. Written informed consent was obtained from children and parents.

2.3. Data and Analytical Approach

Throughout the two projects, the authors wrote reflexive accounts to raise awareness and reflect on how their backgrounds and experiences might have influenced the questions asked and the understandings constructed [47]. Field notes, transcripts of interviews, and the reflective accounts written throughout the two projects formed the basis of the discussion in this article. We first discussed the ethical dilemmas we experienced while working with social categories in the projects. From the discussion we developed the aforementioned research questions. Based on the research questions—which incorporate ethical challenges from the initiation of projects to the write up of the results—we reread our field notes, the interview transcripts, and our reflective accounts to better understand the relational ethics of navigation and negotiating social categories in our project. The selected extracts and narrations problematize our research in terms of negotiating social categorization, power and generational ordering, and our relationships with the participants. The narrations take the reader backstage of the research and offer confessional tales regarding the relational ethics of performing research with children categorized in terms of disability or ethnic belonging [32]. All names of participants in the extracts are pseudonyms to maintain anonymity.

3. Results

This section presents the procedural and relational ethical dilemmas of using categories and the categorization the we experienced in our research, from initiating the project to the final phase of reporting the knowledge constructed. The results are organized according to the research topics: (1) How categories framed the research in its initial phases, (2) power relationships in context, and (3) (re)constructing stories and ensuring anonymity, which are related to the ethical dilemmas involved in

reconstructing the children and their experiences in this article. We each bring in our own voice to reflect upon our projects, A and B.

3.1. How Categories Framed the Research in its Initial Phases

The following section explores how categories built into the definition of the projects influenced the approaches used to recruit participants. In both studies, the analyses of the data illuminated several ethical issues and communicative challenges regarding the navigation of generational ordering in research with children. In the initial phases, Project B encountered ethical issues regarding informed consent, while in Project A the challenges were related to ensuring voluntary participation.

3.1.1. Informed Consent

In Project B, the processes of recruitment and securing children's informed consent presented several ethical challenges. The Norwegian ethical guidelines recommend consulting parents before engaging children under the age of 15 in research, thereby allowing parents to act as gatekeepers. However, children also have the right to receive enough information about the project to make an informed decision on whether or not they want to participate in the research [34–36]. In the initial stages, I often felt a sense of powerlessness by this dependency on the goodwill of parents and how parents described the research to their child [36].

As participants have the right to opt in or out of research without having to explain why, it is often difficult to know why people refuse to participate [34,36]. In the communication with parents for Project B (i.e., before the interviews), parents voluntary offered some reasons why they refused to partake. Some parents refused to take part fearing that the research would stigmatize the child and construct differentness. Several children in the project had previously experienced a school system in which inclusion was just a rhetorical ornament, while in practice they experienced exclusion and marginalization. One parent explained that she did not want her daughter to take part in the research because of the value-loaded term *inclusion*. According to the mother, the daughter was tired of always feeling different and in need of adaptation. By refusing to inform the daughter of the project, she was protecting her from yet another place where she was singled out because of her impairment.

The ethical challenge of informed consent was also apparent in the interviews. In some of the interviews, it appeared to be the parent wanting to take part in the project to learn more about the physical education setting, while the child took part because their parent had strongly encouraged them to do so. In such cases, ethical regulations and guidelines designed to protect children can also construct children's vulnerability in research. In the case above, the parent and the researcher both constructed this situation. These situations required that the researcher pay attention to what was going on, recognize and see both the parent and the child, read the relational cues, and (re)act in the best interest of the child [33]. In some situations, the interviews were cut short because I could see that the child was tired, bored, or uncomfortable.

3.1.2. Voluntary Participation

At the beginning of Project A, seven of the students did not give their consent for participation. The NSD guidelines stated that the project could be initiated, however, that these students should not be included in the data. Yet, entering a field where not everyone had given their consent provided several ethical dilemmas. For example, how could children be removed from the social interplay among peers in a class? Was there any way that non-participating children could be part of the data without violating their decision not to be part of the project? At the beginning of the fieldwork, I decided to note the non-participating children in terms of only their gender in the field notes. As the fieldwork unfolded, I gained a rapport with some of the students who did not participate, and four of the seven later decided to join the project. At this point, I was more familiar with the students and could go back to the earlier field notes to write the students into some of the accounts.

There are ethical concerns regarding entering a setting where some people have not given their consent for participation [1]. Why, then, was entering this particular field and finding ways to include the non-participating children so important that the researcher decided to challenge one of the cornerstones of research ethics? At the beginning of the fieldwork, a number of the non-participating children were identified by one of the physical education teachers as bilingual and having an ethnic minority background. As the purpose of the project was to generate stories of children with ethnic minority backgrounds and to investigate the inter-ethnic relations between students of minority and majority backgrounds [12,41], the non-participating students constituted an important target group. Issues related to recruitment and consent are particularly urgent in research relying on certain categories as the starting point [10].

In Project A, the children had the opportunity to gain insight into the project before consenting. Because consent to research is conceptualized as a process, the fieldwork design allowed me to build trusting relationships with the not-yet participants to familiarize them with the project before they made a decision [30]. Building trust in research takes times and requires fieldwork.

3.2. Power Relations in Context

In both projects, we experienced asymmetrical power relationships in the interviews with the children. Some of these could be sensed during the interviews and were recorded in the reflective accounts, while others became more evident when reading through the transcripts.

In Project A, power relationships became particularly evident in relation to some of the questions in the interview guide. For example, all of the interviews started with the researcher asking the child the open question: "Could you just start by telling a bit about yourself?" Daniel responded: "I'm 16 years old from Nigeria, and I have lived here [in Norway] my whole life, I was born here...and I play soccer in my spare time." The students were informed of my interest in how students of diverse backgrounds experienced physical education. The majority of the children included sports-related leisure activities and their relationship to exercising in response to the question. However, while none of the ethnic Norwegian students mentioned their ethnicity, all but one of the students with minority backgrounds included information about their ethnic background at the beginning of the interview. As in the extract from the interview with Daniel, it became evident how the students with minority backgrounds experienced being targeted for their background in a way that majority children did not. Also, in relation to questions directly involving ethnic background, unequal power relationships between un/privileged positions appeared. Two extracts illustrate how social categories were negotiated in the interview:

> Interviewer: Do you think ethnic background has any influence on who hangs out together in your class or at school?
>
> Navid [Boy, Persian]: What do you mean? If we are treated any different? [Alert in his voice]
>
> Interviewer: No, no, just, you know, who hangs out together in your class.
>
> Navid: [Interrupts] You mean like good friends and such?
>
> Interviewer: Yes, for example.
>
> Navid: Eehm when I chose...or friends and stuff like that I do not think about whether he has a different background, however, most of my friends have a non-ethnic Norwegian background.

The second extract was drawn from an interview with Maya, a 15-year-old girl living with her father who emigrated from Iran 20 years prior. To my question about whether she considered herself Norwegian or Persian, she answered:

Norwegian! Obviously! Not...no. If you think that I am Persian, then for sure you think "Ooh she is probably used to such Persian stuff and things like that," but no, I am Norwegian, Norwegian, Norwegian!

In different ways, the extracts illustrate the asymmetrical power relations in the interview and how categories are often connected to stereotypic images of minority ethnic groups as *other* [15]. Though I sought to ask children to openly reflect upon ethnicity, bringing up ethnicity as a topic appeared to have different meanings for the children. For some children, their ethnicity was related to experiences of being treated differently (to an unarticulated Norwegian standard). In the interview situations, these different meanings became evident through the children's use of binaries, such as we/you or us/them. In retrospect, considering multiple interpretations of the interviewer–interviewee relationship and how the students navigated power structures in the interview situation provided insight into their contextualized meaning-making in a larger societal context. For example, in the case of Maya, one interpretation is that her statement was a response to how she perceived the researcher's ability, as a representative of the majority culture, to define her. Her response can also be interpreted as a resistance to power if she expected the researcher to devalue Persian culture in comparison to Norwegian. Maya's response reveals how the question evoked associations toward power relationships in a larger societal context, in which the meaning of the binary categories of Norwegian and Persian are locked and ranked. Additionally, in the interview with both Maya and Navid, the students addressed the researcher with "What do you mean?" and "If you think..." This direct confrontation alerted me of the ways in which participants could resist and challenge power structures by questioning the content of social categories.

Navigating the Generational Ordering in Interviews

In Project B, navigating the generational ordering in the interviews posed different challenges depending on whether the child was alone or with their parent. In the combined interviews, I had to navigate the triangle of communication patterns and negotiations between the child, parent, and myself. In these interviews, my attempts to structure the communication were complicated by the need to develop rapport with the child and the parent, while simultaneously, communicative negotiations were in play between the parent and the child. A less successful example is from an interview with Annabelle and her father:

Father: Every year that went by, the distance between them [referring to Annabelle and her peers] grew and grew. She is barely in contact with them now. It's healthy for the class that there is someone a bit different—that everybody doesn't look alike. But sometimes it gets a bit rough.

Interviewer: What do you mean?

Father: Not everybody accepts [the father pauses] or. Annabelle doesn't have empathy. She doesn't know when enough is enough, and the guys, they punch when they think it's enough you know.

Annabelle: [Interjects] I'm going to the pizza place tomorrow.

Interviewer: [To Annabelle] Are you really?

Father: [Interjects] We will have to see.

Annabelle: Mom is coming.

Interviewer: That's nice! Are you looking forward to her visit?

Annabelle: [Nods]

Interviewer: [To Annabelle] What activities have you done today?

Father: We started today with [pauses and refers to Annabelle]. What did we start with today?

Annabelle: Climbing.

In the field notes written directly after this interview I wrote down feeling uncomfortable in the interview and inadequate as an interviewer. Annabelle was playful in the interview and was not particularly interested in follow the line of questions introduced. My concerns were that Annabelle, who was in a situation in which she had little control, experienced that we talked about her more than with her, and that the way we talked about her constructed her experiences of bullying and exclusion within a personal tragedy model of understanding disability. In this interview, I was left with a feeling that I had co-constructed yet another disempowering arena for Annabelle.

In the interviews, parents also added to the child's story if they believed that the child struggled to answer. Silence in interviews could be both powerful and painful. While the researcher often interpreted the children's silence as a thinking pause, parents seemed to interpret it as the child being uncertain of what to answer. This occasionally led parents to answer on behalf of their child. In some situation, parents even took control of the communication by acting as an interviewer as well as answering the questions directed at the child. The following example with Timothy and his father particularly illuminates several of the issues discussed:

Interviewer: [To Timothy] Maybe you could start by telling me a little bit about the school you go to?

Father: [To Timothy] You're enrolled in [name of the school]. You can continue to talk about the school now Timothy.

Timothy: Tell what?

Father: Talk about the physical education lessons. When the doctors ask you at the medical examination what you like best at school, you usually answer physical education.

Timothy: Yes.

Father: And you can talk about why you find physical education interesting.

Timothy: I like to be physically active and things like that.

Interviewer: Yes? What do you like best in physical education?

Timothy: Ehhh ball games and dodgeball and games like that.

This interview demonstrates a situation in which the father took control over the communication and steered his son's story toward a narrative they had shared several times before. Some of the children and their parents had attended numerous medical/treatment interviews previously. Because of the familiarity with medical interviews, I had to work to get beyond the medical narratives that the families had told several times, while also honoring and supporting the stories shared in the interview [33].

Another challenge was the participants' avoidance of the topic of peer relationships in school. One case was an interview with a young girl and her mother. During the interview, the conversation ran smoothly, and both the child and her mother shared their stories of marginalization and exclusion in physical education. However, during the interview, I could sense that there was more to the story than what was told. Both the mother and the child were reluctant to share stories of peer relationships and friendships. The interview was cut short by the girl leaving to attend a physical activity session, and the mother and I continued the interview alone. After the daughter left, I introduced questions around

peer relationships and social exclusion, and the mother narrated a maternal story of seeing her child being more and more socially excluded within her peer group. Analyzing the data, the researcher noted several contextual factors that could have influenced the situation. Identity projections are always socially situated, and what a person says is contextually bound. Discussing the diverse experiences of being a parent when the child is present might encourage enactment of two different and even conflicting socially situated identities. Enactment of conflicting identities could explain why, in some interviews, the children and their parents avoided speaking directly about peer relationships when both the child and parent were present. As with the parents, the children also protected their parents from sensitive information during the interviews. Sensing this protectiveness, I was reluctant to contribute to a conflicting situation for the parent and child by asking them to reflect further on the child's difficulties while they were present when it was clear that the child struggled socially at school.

I knew prior to the interviews that the setting would pose various challenges. However, by analyzing the data with relational ethics of categorization in mind, it become clear that not enough reflection was given to the implications of relationships and communication in the interviews. Foreseeing some of these challenges might have helped me to prepare and navigate the generational ordering better or to construct a caring environment that allowed for more detailed descriptions from both parents and children.

3.3. (Re)constructing the Stories—Ensuring Anonymity

Contextualizing individual experiences is essential in intersectional research, as is seeking to understand the complex ways in which multiple identities shape opportunities and constraints in interactions with others [26]. However, retelling the rich stories of lives in context challenges researchers in terms of ensuring anonymity. This is especially the case in ethnographic work [48]. In Project A, emphasizing diversity in order to break with stereotypes and homogenous narratives regarding physical education and ethnicity was central to the purpose of the project. However, in research conducted in a defined environment or institution, chances are high that participants recognize both themselves and others, making it "difficult to ensure that data are totally unattributable" [49] (p. 341). Changing a name is not enough. In Project A, there was also the risk that other students and teachers would recognize participants in the project, as there were few teachers involved and only two school classes in the sample. Furthermore, there was the risk that recognizability might extend beyond the institution (e.g., that individual students would be recognized by parents or within a community). For example, the Pakistani community in Norway is portrayed as an interconnected social network [50].

From an intersectional perspective, children's disabilities and backgrounds, such as ethnicity, culture, and religion, are important for research. However, these characteristics also make the participants more vulnerable. How can researchers meet the requirements of anonymity while simultaneously highlighting the different aspects of the participants? Reflecting upon their own research on why so few students pursue degrees in physical education teacher education, Flintoff and Webb [10] discussed how a small sample made it necessary to stick to broad generalizing categories for their participants, leaving out any individual viewpoints their participants held regarding identity. They reflected: "These decisions are compromises and are very much at odds with our theorizing of identities as multiple, fluid and shifting" [10] (p. 580).

In Project A, one of the ways the researcher dealt with the challenge of ensuring anonymity within a framework of intersectionality was through applying a thematic narrative analysis of the data, as this allowed the researcher to maintain the truthfulness and nuance of the children's stories throughout the analysis [43]. While analyzing the data, the researcher (re)constructed the stories as close to the lives of the children as possible to maintain their rich detail [30]. However, in preparing narratives for publication, the researcher went through the stories and chose to leave out some details or rewrite certain aspects (e.g., writing the occupation of parents in more general terms or changing the gender and/or number of siblings). The researcher also made thorough reflections regarding parts of the research where it was more important to safeguard anonymity than others (e.g., if it was conceivable that

publication could have direct negative consequences for the participant in question) [30]. One example in the data was a child from a religious minority in Norway. Talking about the importance of religion in the family, the child stated that their parents held a liberal view on religion and that a sibling was an atheist. At the end of the interview, the child brought up this topic again, expressing the importance of this information not being connected to the family. In such cases, it is essential to be aware that some pieces of data cannot be published [30].

4. Discussion and Concluding Remarks

Although social categories are essential for the generation of knowledge regarding social inequality and marginalization [3], the use of categories in research is a highly contested practice and calls for researchers to engage in ethical reflection [1,2]. The current study provided examples of how researching diversity and inclusion creates situations requiring ethical considerations that cannot be solved through official guidelines. The article explored how singling out minority groups of children framed the research, how categories and power relationships were negotiated and navigated in interviews and fieldwork, and how, in the writing of this paper, categories were negotiated at the cross-road of intersectionality, relational ethics, and the procedural ethics of ensuring anonymity. These issues are particularly urgent within research related to health, the body, and physical education [9,10,17,19]. Previous research regarding peoples' experiences and beliefs related to health and physical activity has largely failed to consider the heterogeneity within certain groups of people [10–12,19]. Measured against implicit standards embedded in Eurocentrism and ableism, certain bodies or groups of children have been objects of stigmatization, marginalization, and exclusion due to their backgrounds or (dis)abilities [12–16]. As such, there has been a call for more research that challenges deficit discourses and negative stereotypes and explores the variety of stories among students of diverse backgrounds [12,19]. Yet, this call (and responsibility) raises ethical challenges.

Both of the projects presented in this paper involved challenges regarding the recruitment of children and ensuring their right to make their own informed decisions regarding participation. In Project B, these challenges related to how parents acted as gatekeepers. Participation in research exploring inclusion and exclusion of specific groups of children depended on participants' inclinations toward collective action to improve knowledge within that specific field. This again depended upon identification with the wider group in focus [51]. Some parents tried to limit the focus on their child's disability, thus resulting in them not discussing the disability with their child. One reason could be that the parents sought to reduce the social stigma coming with a disability label [8]. Another reason might be that the parents did not identify with that label of their child. Similarly, some children may have refused to take part if they felt singled out because of their impairment or if they themselves did not identify with the disability label [15]. Recognizing some of the reasons why parents might refrain from allowing their child to participate could help researchers to attentively design the study and inform parents about the intentions with the research, which in this case was to illuminate some of the concerns the parents expressed.

In Project A, the researcher experienced ethical dilemmas of entering a field where not all children gave consent for participation. Scholars have raised concerns regarding how negative representation in research might be reinforced as a result of some groups not wanting to take part in studies they perceive as reinforcing their otherness, that are on the premises of the majority population, and in which they do not recognize themselves [1,8,52]. In regard to Project A, it could then be asked if participation should always be voluntary as a starting point [1]. According to Ellis [24], researchers must ask themselves what the greater purpose of their research is and consider whether it justifies the potential risk to others. As defenders of social justice, researchers have a responsibility to challenge marginalizing discourses, such as bodies at risk, or normalized absence/pathologized presence [7,10,15]. As such, the authors agree with Boddy [1] that there is no single best approach; rather, from a relational ethics perspective, it might be necessary to challenge how researchers consider voluntary participation in

some situations. However, it is important that in such cases, researchers spend time building trusting relationships with participants and practice consent as a process [30].

In addition to providing researchers with tools to improve their sensitivity toward how children's everyday life experiences are situated in relationships of power, intersectionality can also inform how relationships of power are negotiated in interview situations [5]. Relational and mindful ethics advocate that researchers consider the complex stories of the people in their studies, as these stories and lives are important to understand the relationship in the interview [33]. In both studies, the authors experienced how social categories framed the stories of the participants, how stories were "clustered around some hegemonic constructions of boundaries between 'self' and 'other' and between 'us' and 'them,'" and that these relationships were "closely related to political processes" [50] (p. 2). Researchers and participants need to continuously attempt to resolve misunderstandings that might appear during interviews [31,33]. Reading emotions and relational cues in interviews and acting upon them might mean that researchers cannot push through with certain questions, even though the answers would be valuable to illuminate the research question at hand [33]. Furthermore, intersectionality rejects the binary thinking that one is only or always included or excluded. Applying multiple interpretations within an intersectional framework can redirect the researcher's focus toward children as active agents and how they resist and negotiate power relationships while still recognizing their vulnerability.

Scholars in the field of physical education have called for more research regarding inclusion that extends beyond single issue approaches and illuminates the richness of children's stories, however, this creates great challenges in regard to anonymity. To navigate this challenge, it is crucial that researchers base their studies around ethics of care. Researchers should seek to handle data in ways that keep stories nuanced and truthful. However, while it may be appropriate to write the stories, not all aspects of data can or should be published [30].

Scholars have a responsibility to challenge homogenous and essentialist understandings of categories [10] and how these understandings influence people's lives. As Gunaratnam [3] stated, there is a need to work both with and against social categories [3]. Discussing racism and ableism necessitates categories, yet categories (re)produce lines of difference. By negotiating and navigating the use of categories in this research, the authors experienced the power relationships entangled within categories and how categories can be used for political means. While procedural ethics might lull researchers into thinking that their studies are ethical, working within a relational ethic perspective calls attention to the need for self-reflection on the researchers' roles, motives, and feelings [33]. At the heart of these reflections regarding the ethical dilemma of categorization was the fear that this research would reproduce rather than confront and challenge marginalization and social inequality. Our article contributes to the literature on ethics in qualitative research. The study has limitations in that it was constructed after the initiation of the two projects; as such we did not generate data specifically for the questions raised in the article. Yet, seeking to make the right choices, we agree with Ellis [30] that researchers need to engage with each other's stories from the field. By sharing stories from research projects, these collective experiences might help researchers to reflect critically on how to use categories ethically in their studies.

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The Problematics of Assessing Trans Identity in Survey Research: A Modest Proposal for Improving Question Design

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Abstract: One of the central issues facing the trans community today is not only to be counted, but also how to be properly counted. If and how trans people are counted has a huge impact on what we know, or what we think we know, about the trans community. When trans people are not counted, we know nothing, but when trans people are counted incorrectly, the results can be even worse. The question addressed in this paper, therefore, is how to develop a question(s) that will more accurately account for the trans population on national surveys. By drawing on cognitive interviews testing a gender identity and sexual identity question for a national official health survey, an argument is made for an improved method of understanding trans measurement on surveys.

1. The Problematics of Assessing Trans Identity in Survey Research: A Modest Proposal for Improving Question Design

The terminology used to capture what is commonly referred to as the transgender community is still under construction and negotiation [1]. Following Ryan [2], the term "trans" will be used throughout this paper "as an imperfect shorthand to refer to individuals whose current gender identity does not match the social expectations of their medically assigned sex at birth. This group could include, but is not limited to, those who identify as transgender, transsexual, genderqueer, third gender, or gender non-binary, among many other possible identities that would be seen as gender non-conforming." Existing research has shown that the trans population is particularly vulnerable to social and legal exclusion, economic vulnerability, and violence. Significant further research is needed to improve our understanding of the full range of issues facing the trans community and this paper suggests one way in which that research might be improved.

One of the central issues facing the trans community today is not only to be counted, but also how to be properly counted. If and how trans people are counted has a huge impact on what we know, or what we think we know, about the trans community. When trans people are not counted, we know nothing, but when trans people are counted incorrectly, the results can be even worse. Many studies, mostly needs-assessment and behavioral risk surveys, have shown the negative social and health differences suffered by trans people with issues related to HIV/AIDS [3,4], self-harm and suicide [5,6], homelessness [7,8], and a variety of other negative health outcomes. Although many contest this data, including how it was collected, few contest the actual construction of the question used to collect the data. Thus, an improved understanding of question design could potentially reshape the ways in which we view current survey dependent knowledge of the trans community [9–11].

One of the principle problems facing those trying to capture an accurate picture of the trans community through surveys is that many trans people themselves do not want to be counted as such [12]. In many ways, doing so would defeat what many have tried to achieve. For many, being

transgender is more of a process, a means to an end, than it is an end goal. It is not that they want to be trans but that they want to transition to another sex and/or gender (For a more elaborate discussion on this, see Roen 2002 [13]). That said, there are still arguably a bedrock of common issues faced by trans people as a "community" that warrant some kind of official count so that these issues can be more properly understood. The question then becomes—how can we develop a question(s) that will more accurately account for the trans population on national surveys? This paper will suggest an important first step toward answering that question.

Perhaps the most common situation where questions (or response options) related to trans identity appear on national surveys is in the context of either a gender or a sexual identity question. Although significant research has been done on the ways in which trans people make sense of their gender and/or sexual identity (see, for example, discussions in Stryker and Whittle, 2006 [14]), there are still research gaps on how trans people make sense of their gender and/or sexual identity on official surveys [11]. This is an important question, as data from official statistics has important political and policy consequences. In this paper, an examination will be made of cognitive interviews conducted with twenty-one trans-identified respondents to both a gender as well as a sexual identity question in order to get a better understanding of how respondents made sense of these questions, and particularly of how they made sense of their own status as a trans person on an official survey.

2. Current State of Trans Identity Measurement on Surveys

Previous research has primarily utilized two different methodologies to study the trans population: needs assessment studies conducted on a local and regional level and surveys conducted through non-probability sampling to target the national population, largely done using the internet.

A number of needs assessment surveys have been conducted in order to gain insights about health patterns among trans individuals. These studies tend to focus on accessible trans populations, such as sex workers or clinical samples. Relying on specific segments within the trans population to make inferences about the larger trans population can have a number of negative consequences, such as over-representing certain health conditions, particularly when tied to particular demographics [3]. While these needs assessment studies are helpful in understanding the respondents included, due to the sampling methods, we cannot use the results found in these types of studies to make inferences about the trans population as a whole or even of the trans population in that community.

Researchers have also turned to online surveys in order to learn about the trans population at large. These surveys have the advantage of capturing respondents who do not openly identify as trans; however, there is currently no method to randomly sample online, and thus researchers rely on gathering large samples in an attempt to compensate for this limitation. The largest of these surveys, The National Transgender Discrimination Survey (NTDS), interviewed 6456 respondents who identified as transgender or gender non-conforming, using a web survey that was augmented with paper questionnaires for difficult to reach populations [15]. Ultimately, the survey received responses from respondents in all fifty states in the United States of America plus the District of Columbia, Puerto Rico, Guam, and the US Virgin Islands. Survey respondents reported lower incomes and higher unemployment rates compared to the rates reported by the Bureau of Labor Statistics for the general United States population. Respondents were also more likely to be younger and to be white. Additionally, while a large number of studies have focused on trans individuals who are sex workers, only eleven percent of respondents to the NTDS reported ever having exchanged sexual services for financial compensation. The survey also found that respondent sexual identities varied greatly. Despite the large number of responses and the regional diversity of the responses, we cannot assume that these results are representative of the national trans population. In surveys of the United States population at large, we could compare the reported demographics of the survey to known population totals from the Census; however, in this case, there are no known population estimates for trans-identified people to use for comparison. Ultimately, while surveys like the NTDS take a large

first step in conducting surveys of the trans community, its results are only representative of those who responded to the survey.

The needs of trans people are often not represented on official surveys largely because we do not yet have an accurate way to measure trans identity [11]. Typically, transgender respondents have been identified on surveys with three different approaches. The first approach is to ask two separate questions—one on birth sex and the other on current gender identity (as used by Rosser et al., 2007 [16]). An "inconsistency" between the two answers leads to a classification of the respondent as trans. Although this option is less likely to put off non-transgender respondents, it also suffers a number of drawbacks. It is an indirect way of assessing transgender status and, therefore, relies on analyst interpretation rather than respondent identification as a trans person. It is also often contested by large surveys who do not wish to add an additional question to what are, quite often, already lengthy assessment surveys.

The second approach is to simply ask directly if a respondent is trans or not (as used, for example, in the Massachusetts Behavioral Risk Factor Surveillance System, 2007 [17]). This approach has the benefit of being more direct and relying exclusively on respondent identification. A drawback of this approach, however, is that there are many individuals who researchers might classify as trans but who do not themselves identify as such. In other words, respondents who are born male and transition to female now consider themselves to be simply female rather than trans.

A third approach is to add a trans response option to an existing gender and/or sexual identity measure (as, for example, in research by Conron, Scout, and Austin, 2008 [18]). This approach has the benefit of not increasing survey burden with additional questions and also not asking respondents if they are transgender in a limited context. The addition of a response option for trans identity, especially when situated among other response options, has the benefit of allowing respondents to select this option within the context of other gender options.

3. Methods and Data Analysis

The first step to developing any good survey question is to understand how respondents interpret and comprehend the question. According to Tourangeau, Rips, and Rasinski's model [19], respondents must comprehend the question, retrieve relevant memories, integrate all of the relevant memories or facts, and finally map this information onto the provided response options. Each of these tasks presents an opportunity for error. As a qualitative method of pre-testing survey questions, cognitive interviewing allows researchers to follow the steps taken by the respondent to arrive at their final answer. Additionally, cognitive interviewing allows researchers to note different interpretations of the question and response options across respondents [20]. Cognitive interviewing is currently the primary method of testing utilized by federal statistical agencies in the United States. Ultimately, cognitive interviewing provides rich narratives that can be used to better understand patterns of interpretation across respondents and demographic groups, which can ultimately be used to ensure that the survey question performs as intended [21].

Data for this analysis comes from 21 cognitive interviews conducted with respondents in the United States who self-identified as transgender, transsexual, or genderqueer. Although there is some debate as to the sample size necessary to obtain valid results from a cognitive interviewing study [22,23], there is relative consensus that the goal of cognitive interviewing is to saturate patterns of interpretation, not to make generalizable population estimates. Thus, the true measure of a successful cognitive interviewing study is one of pattern saturation rather than a question of the number of respondents.

The respondents in this study reflect a wide range of backgrounds. Eleven interviews were conducted in English, while ten were conducted in Spanish. All Spanish translations were conducted by the author and are shown in English below. Two respondents had an elementary school education, two had attended high school but did not obtain their diploma, four respondents had a high school diploma or General Education Diploma (GED), three had an Associate's Degree, five had a Bachelor's Degree, and one had a Master's Degree. Respondents ranged in age between 21 and 51 years old,

with the majority of respondents being in their thirties. Additionally, six respondents identified as White, four identified as Black or African-American, three respondents identified as multiracial, and the remainder identified as "some other race" (this occurred primarily with Spanish-speaking respondents as Hispanic and Latino were listed as ethnicities, not races, on the tested questionnaire).

The interviews were conducted as part of a larger project testing a revised sexual identity question for the National Health Interview Survey (NHIS). Interviewers from the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) conducted the interviews in July and August of 2011 [24]. All interviews were conducted in a major metropolitan area in the United States. As is common with cognitive interviewing, respondents for this project were selected using purposive sampling. Respondents were recruited through email by a number of organizations serving the Lesbian, Gay, Bisexual, and Transgender (LGBT) communities as well as by word of mouth.

Respondents were scheduled for specific interview times (with the exception of a few "drop-ins") and reported to a set location for their interview. Interviews lasted between 30 and 60 min, with the typical interview lasting from 45–60 min. While all interviews were conducted anonymously, respondents were asked to consent to the audio recording before the interview and again once the interview began. At the conclusion of the interview, all respondents were given $50 as remuneration. Interviewing for the project continued until theoretical saturation was reached—that is, interviewing was continued until no new patterns of interpretation were detected. The number of interviews required to achieve saturation can vary greatly; for example, a recent empirical study found that saturation was achieved in as few as twelve interviews [22]. For this project, a total of 139 cognitive interviews were conducted and 21 of the interviews were conducted with transgender, transsexual, or genderqueer-identified respondents before researchers felt confident that saturation had been reached.

The questionnaire for this project was administered using an audio-computer-assisted self-interview (ACASI) instrument, which has been shown to improve data quality in potentially sensitive questions such as sexual identity [25]. Respondents were asked to answer a number of demographic questions using the ACASI system without assistance from the interviewer.

At the conclusion of the questionnaire, respondents were asked each item and were then asked to explain their answer. Typical follow-up questions included, "Why did you answer in this way?", "What do you mean by that?", and "What does term X mean to you?". If a respondent's answer seemed vague or unclear, the interviewer asked questions such as: "Can you give an example to describe what you are talking about?" Specifically, for the sexual identity question, respondents were also asked how they typically referred to themselves and were also asked about other words that did not appear in the question. The culminating text from the interview related how respondents understood or interpreted each question and also outlined the types of experiences and behaviors respondents considered in providing an answer.

Interview data was analyzed using the constant comparative method as described by Ridolfo and Schoua-Glusberg [26]. The constant comparative method is an inductive method of analysis that relies upon systematic coding of interview responses along with analysis of the interview data to develop theories. Once the interview was completed, the interviewer's notes along with the audio recording of the interview were entered into a qualitative data analysis program designed especially for the analysis of cognitive interviews. As data was entered into the program, the interviewer's notes were reviewed by analysts to ascertain how the respondent interpreted the question and to determine what information the respondent used to explain why they answered the way they did. After all interviews were completed, the patterns that emerged during the initial round of analysis were refined and developed into categories and themes that were then applied to group the applicable interviews (for more on data analysis of cognitive interviews, see Miller, et al. [27]). As a final step, interviewers were compared by themes of race, education level, and language of the interview to determine whether there were any similarities or differences between these groups.

4. Understanding Trans Identity through Response Options

An examination of the patterns of interpretation of trans respondents to both a gender as well as a sexual identity question will be conducted in order to better understand how trans identities might be better captured on official surveys. A further examination of trans respondents' responses to a gender identity question as well as to a sexual identity question individually will be conducted and then a comparison will be made between the two response sets to look for overlapping patterns. It should be noted that in both questions, trans-related identities appeared as a sub-option—that is, as a follow-up option—to one of the primary response options.

4.1. Transgender Identities Reflected through a Gender Identity Question

All respondents were asked the gender identity question below. This question appeared as the first question on the survey and was written with the goal of providing trans respondents a response option outside of the traditional dichotomous male and female response options.

English: Do you consider yourself to be ... Male, Female, or It is more complicated (Go to 1a)?
Spanish: Usted se considera ser ... Hombre, Mujer, o Es más complicado (Go to 1a)?
English Followup: [If it is complicated is selected] By answering it's complicated, do you mean that ...

Male, assigned female at birth
Female, assigned male at birth
Masculine, assigned female at birth
Feminine, assigned male at birth
Transgender or genderqueer, assigned female at birth
Transgender or genderqueer, assigned male at birth
Something else
I didn't mean to choose this option
Spanish Followup: [If it is more complicated is selected] Cuando dice es más complicado, quiere decir que ...

Hombre, al nacer asignado como mujer
Mujer, al nacer asignado como hombre
Masculino, al nacer asignado como mujer
Femenina, al nacer asignado como hombre
Transgénero o géneroqueer, al nacer asignado como hombre
Transgénero o géneroqueer, al nacer asignado como hombre
Algo diferente
No quise elegir esta opción

Responses from trans respondents varied greatly and ultimately reflected the diversity of their backgrounds. Table 1 summarizes trans respondents' responses to the tested gender question.

Table 1. Responses to Gender Identity Question.

Responses	Frequency
Male	5
Female	9
It is more complicated	7
Transgender or genderqueer, assigned male (3)	
Transgender or genderqueer, assigned female (2)	
Masculine, assigned female (1)	
Feminine, assigned male (1)	
Total	21

The differing responses to this question are likely a reflection of the fact that respondents were at differing points in the process of identifying as trans. Respondents who selected male or female tended to be further along in the transition and/or self-identity process, while those who had not yet begun or were at the very beginning of the process tended to gravitate more towards the 'it is more complicated' response option. One respondent who had completed their transition explained why they did not select 'it is more complicated' by saying, "I felt the wording to be . . . not a comfortable fit for me, the wording was . . . awkward is not necessarily what I would describe it as. I don't find it to be complicated because I know what it is. Trying to articulate it is a different matter. I don't want the perception be that it is more complicated." Another respondent who completed his transition to a male explained that he liked seeing the third option (that is, something other than 'male' and 'female') available and even considered selecting this option but said, "But I chose male because whenever I fill out any paperwork and whenever I self-identify its male."

One consistent finding among trans respondents is that they liked having a third option available when discussing their gender. However, they found the current wording to have a negative connotation. Twelve trans respondents indicated that they either didn't like the wording of 'it is more complicated' or said that the option was "not for them". Respondents stated that the 'it is more complicated' response option was for people who were still questioning their gender or people transitioning genders. Additionally, three respondents stated that they did not view their gender as being complicated and, therefore, they did not feel that this response option was right for them. One respondent said, "I don't see it as being complicated, just different." Another respondent asked, "Why is it complicated that I'm neither [male or female]?" While another respondent went so far as to say that he felt that the phrase "it is more complicated" made it sound like he "had issues" because of his trans status.

Additionally, trans respondents described their gender as being socially constructed. Interviews were coded as "gender as socially constructed" if the respondent mentioned their behavior, actions, appearance, clothing choices, or hobbies in explaining their gender. Overall, seventy percent of trans respondents described their gender as being socially constructed. In explaining what defines them as a female, one trans respondent said, "[Its] Not so much biological, but mental . . . In my mind I more associate with the female gender." Responses similar to this were very common in interviews with trans respondents.

Another issue arose with the 'it is more complicated' follow-up question. Four respondents in Spanish interviews noted that they found the response options under the 'it is more complicated' follow-up question to be confusing. Many respondents noted that they were confused about the differences between the response options. This problem did not arise in English interviews, indicating that Spanish-speaking trans individuals might use different terminology than English-speaking trans individuals or that there are some problems in the translation of the terminology from English. The higher than average education levels of the English-speaking trans respondents might also explain why none of them found the response sub-options for the 'it is more complicated' follow-up to be confusing.

4.2. Transgender Identities Reflected through a Sexual Identity Question

All respondents were asked the following sexual identity question:
English: Do you think of yourself as:
[For men:] Gay
[For women:] Lesbian or gay
[For men:] Straight—that is, not gay
[For women:] Straight—that is, not lesbian or gay
Bisexual
Something Else (Go to A)
Don't Know (Go to B)
Spanish: Usted piensa en sí mismo como . . .

[For men:] Gay
[For women:] Lesbiana o gay
[For men:] Heterosexual, o sea no gay
[For women:] Heterosexual, o sea no lesbiana o gay
Bisexual
Otra cosa *(Go to A)*
No sabe (Go to B)

A. English: [If 'something else' is selected] By <u>something else</u>*, do you mean that . . .*

You are not straight, but identify with another label such as queer, trisexual, omnisexual or pan-sexual
You are transgender, transsexual or gender variant
You have not figured out your sexuality or are in the process of figuring it out
You do not think of yourself as having sexuality
You do not use labels to identify yourself
You made a mistake and did not mean to pick this answer
You mean something else *(Go to C)*

Spanish: Cuando dice <u>Otra Cosa</u>*, quiere decir que . . .*

Usted es gay o lesbiana, pero se identifica más con otras clasificaciones como queer, multisexual, o trisexual
Usted es transgénero o transexual
Usted no sabe o está en el proceso de descubrir su sexualidad
Usted no piensa en sí mismo como teniendo una sexualidad
Rechaza personalmente todas las etiquetas para describir a su persona
Usted se equivoco y no quiso escoger esta respuesta
Usted quiere decir otra cosa [Go to 6c]

A. English: You did not enter an answer for the question. That is because you:

You don't understand the words
You understand the words, but you have not figured out your sexuality or are in the process of figuring it out
You mean something else

Spanish: Cuando dice <u>No Sabe</u>*, quiere decir que . . .*

Usted no entiende las palabras
Usted entiende las palabras, pero no sabe o está en el proceso de descubrir su sexualidad
Quiere decir otra cosa

C. English: [If 'you mean something else' is selected]

What do you mean by something else? Please type in your answer
_____

Spanish: ¿Que quiere decir por <u>otra cosa</u>?
Por favor escriba su respuesta:
_____

The sexual identity question tested by the QDRL demonstrated an overall marked improvement over questions that had been previously tested [24]. The goal was to develop a question that would not only reduce the rates of missing and 'don't know' responses, but also help those who were answering to answer "more correctly"—that is, to reduce misclassified responses as well as reduce missing responses. To that end, three meaningful design principles were used: 1) use labels that respondents

use to refer to themselves, 2) do not use labels that some respondents do not understand, particularly if those terms are not required by any other group of respondents, and 3) use follow-up questions to meaningfully categorize those respondents answering 'something else' or 'don't know'. These revisions were shown to be largely successful as the vast majority of respondents were able to select the category that best reflected their sexual identity. Of most import to the topic of this paper, the presence of the 'something else' category, and the subsequent follow-up options, was successful at helping transgender respondents more accurately identify themselves.

As shown in Table 2, trans respondents fell across the spectrum of identifying as gay or lesbian, not gay or lesbian (and thus, straight or heterosexual depending on the language in which they took the survey), and something else (followed most typically by the response sub-option of 'you are transgender, transsexual, or gender variant'). This complexity of response options from a single demographic is not viewed as problematic, however, as the question is intended to capture self-reported identity.

Table 2. Responses to Sexual Identity Question.

Sexual Identity Category *	Frequency
Gay or Lesbian	5
Straight—that is, not gay	3
Bisexual	1
Something Else	12
Total	21

Note: * These are the English language translations.

Many trans respondents referred to the gay community in broader, more encompassing terms than LGB or heterosexual respondents. Thus, a number of trans respondents conceived of the term "gay" as both an individual identity as well as an umbrella term for a larger community of sexual minorities (the exact composition of that community varied among respondents). One trans respondent said that although gay can specifically refer to a man who is masculine it can also be used to refer to "the whole community". Another trans respondent wanted to choose the term transgender but since it was not available in the list of primary options, he chose gay because he felt that this was the closest option for him since it would include him in the LGBT community. Another trans respondent said that she thinks of the term 'gay' as being in the middle of a big circle of other terms like bisexual and transsexual and that gay is the word used to describe all of these things. She said that gay is the generic word used to describe all of these other terms but that it is not specific enough and she would not identify this way. Instead, she identifies specifically as transsexual.

Several interesting demographic themes emerged from the interviews as varying patterns of interpretation were found based not only along the lines of gender identification (discussed in depth below), but also along lines of education, age, and language of survey. There was a clear relationship between years of education and propensity to select 'something else' with those with a high school education or less being far more likely to identify as 'something else' than those with more than a high school education. It is also interesting to note that the only two respondents to identify as bisexual were both college-educated, identified their gender as male, and spoke English. Overall, younger respondents (under 40) were more likely to identify as 'something else' or 'gay or lesbian' while older respondents (over 40) were more likely to identify as 'bisexual' or 'straight—that is not gay'. The improving climate for 'something else' identified people in pop and political culture in the United States today might help make sense of this trend.

4.3. Non-Trans Interpretation of Trans

One of the guiding principles behind the testing of this question was not to include words that would confuse other populations if they were not specifically needed by another population. This was

not found to be a problem with the trans response options on either the gender or the sexual identity question. In neither case did a non-trans respondent inadvertently select one of those options.

Some respondents, especially those who did not identify as 'something else' had varying initial conceptions of what the 'something else' category could possibly mean or simply had no idea what it might imply. A heterosexual female, for example, said that something else made no sense to her because either you are straight or you are not. Another heterosexual respondent thought that "maybe they like dogs." Another female respondent said that something else could be a hermaphrodite. She said that she knew a couple of hermaphrodites and that these are people born "with both sexes, both organs," and then their parents decide if they want to raise them as a boy or a girl. Another respondent said it was for someone who does not know whether they like men or women and is the same as the 'don't know' option. The most common understanding of the 'something else' category, however, was that it implied some variation of an understanding of transgender. One respondent, for example, said that something else is for those people who do not know what they want to be—male or female—and that they have not found their sexuality yet. Another respondent felt that maybe it was for people who did not want to openly identify as gay or who were transgender or "lost" and do not really know what they are. Others noted that it was a category for people who are not a lesbian or a homosexual. A gay male respondent said that "there are so many letters now" and so it gives people a chance to pick something different. Perhaps the most important finding of non-trans understandings of the something else category is that its presence did not increase response error. That is, these respondents did not choose this option because they understand that it was not for them. On the other hand, many trans respondents did choose this option, thus increasing response accuracy.

5. Intersection of Gender and Sexual Identity

One of the interesting, and perhaps most insightful, findings of this study was the relationship between how trans people identified on the gender question compared to how they identified on the sexual identity question. In general, results indicate that trans respondents made a stronger, but less clear, distinction between their gender and sexual identity than non-trans respondents. It should be re-emphasized that this data is not from a representative sample and, therefore, cannot be used to deduce larger population trends. It can, however, be used to help better understand patterns of interpretation among respondents.

Gender identity was shown to be a particularly prominent component of sexual identity for trans respondents. Several of the trans respondents noted that the first thing they looked for was a 'transgender' response option. This was certainly not the case for all trans respondents, as some chose 'gay or lesbian' or 'straight—that is not gay' without debate or hesitation. However, when failing to find this option, these respondents then chose 'something else' assuming that that is what it meant. This association might have been heightened by the fact that the gender question also asks if someone is male, female, or it is more complicated. Even several non-trans respondents felt that 'something else' was connected with the 'it is more complicated' category on the gender question. In both cases, the non-normative response was given a somewhat generic, catch-all heading. This might also help to explain why trans respondents saw a stronger association between their gender identity and their sexual identity.

While respondents did understand the differences between gender identity and sexual identity, more respondents identified as transgender in the sexual identity question than the gender identity question. Ultimately, this study highlights the complexity of these issues among individuals. The complexity is summarized well by a respondent who currently identifies as genderqueer but is considering a switch to identifying as transgender. She said, "If I were to transition into male there are some people who consider me straight but I don't feel like I would fit into the cissexual identity [Note: 'Cissexual' is a term used to describe those who feel that their current gender identity matches that of the social expectations of their medically assigned sex at birth] of straight. So I guess I would go towards something else and have a very complicated sexual identity."

As Table 3 indicates, those who identified as 'it is more complicated' on the gender identity question were most likely to identify as 'something else' on the sexual identity question. Those who identified as male were least likely to identify as something else with those who identify as female falling somewhere in between. This suggests that a respondent who identifies outside of the gender binary is also more likely to identify outside of hegemonic sexual identity categories as well. It is also noteworthy that the only 'bisexual' response came from a respondent who identifies as male and the only 'straight—that is, not gay' responses came from those who identify as female. Those who identified as 'it is more complicated' on the gender question only selected either 'something else' or 'gay or lesbian'.

Table 3. Gender Identity by Sexual Identity.

		Sexual Identity				
		Gay or Lesbian	Straight—That is, Not Gay	Bisexual	Something Else	(Totals)
Gender Identity	Male	2	–	1	2	5
	Female	2	3	–	4	9
	It is more complicated	1	–	–	6	7
	(totals)	5	3	1	12	21

One of the advantages of cognitive interviewing and follow up probing is that it allows researchers to gain deeper insight not only into the *what* of the response, but also into the *why*. Further probing revealed that at least four of the respondents would have chosen a trans option but because they did not see it (it was not in the original set of options but rather only as a sub-option under 'something else') and so they chose another option. Two of these respondents ended up identifying as 'straight—that is, not gay' and two of them as 'lesbian or gay'.

One of the respondents who chose 'straight—that is, not gay' did so only after a long hesitation. He said that although he knows other people probably think of trans as more gay than straight, he does not identify as gay and so ended up not choosing it. Another respondent who also chose 'straight—that is, not gay' said she did so because she identifies as female and is attracted to men so that makes her straight. She said that if she had seen the trans option, however, she would have chosen that. She noted that she would never have gotten to that sub-option because she was very put off by the connotation of 'something else' and so she would likely not be identified as trans if that is how it is listed.

One of the respondents who chose 'lesbian or gay' said they would have picked trans right away but as it was not on the list, they did not feel that they had that option. Another respondent who chose 'lesbian or gay' said they use the term 'transsexual' to describe themselves "and nothing else". She never uses the term gay to describe herself but as she did not see a trans option she felt that gay was the option with which she most closely identified.

Aside from the above misclassifications, there were also a number of other respondents who, although they did end up in the "right" category, said it would have been much easier for them if trans had been in the original list of options. One respondent noted that their "first instinct" was to choose trans. When they did not see this option, they ended up selecting 'something else' and then the trans sub-option.

Several of the respondents held a strong disassociation with the gay and lesbian community. Like many of the straight-identified respondents, their most salient sexual identity was not a direct association, but rather a "not-me" identity—that is, they defined themselves more by what they were not than by what they were [28]. Several trans respondents, for example, explicitly identified as "not gay" emphasizing that just because they are trans does not mean that they are gay. One respondent when asked to identify a trans identity stated that it is a transition from being a man to being a woman or vice versa but that this does not imply that you are gay or lesbian. It simply implies that you are

trans. Another respondent said, "I cannot identify myself as either lesbian or gay because . . . because I am not a woman to say that I am a lesbian. And I also don't want to say that I am gay because for me it's a word that only pertains to homosexual behavior. So, I thought that I could find a word that would better pertain to how I more identify." Another respondent explained, "I don't consider myself to be gay because I feel like the term gay is intended for like gay men. And straight is I guess if you consider me to be female then the kind of guys I like I mean and they are guys are like straight guys that I've ever been with so . . . [. . .] . . . once next year is over [when she gets her surgery] I probably would say straight." If the option for 'something else' had not been there, she said would have selected straight.

Building on the above, there are also many within the trans community who still more closely associate with the conventional dichotomy of gay and straight. A clear theme among many of these respondents was that whether or not they identified this way was directly related to where they were in their transitioning process. It is interesting to note that this transitioning process was defined as a physical one rather than a mental, emotional, or social one. One Spanish-speaking respondent, for example, said that they identified as gay because "I have not made changes to much of my body. So, I am gay". Another Spanish-speaking respondent said that she does not identify as a lesbian because that is a term for women who like women, and as she does not like women, and so she cannot be a lesbian. She also does not identify with the word gay because that is a term for men who like other men and although she likes other men, she is no longer a man. She also said that she does not identify as transgender because she is not yet a transgender—who she defines as having made the full cross-over from one sex to another—but rather is in the process of transitioning genders. Indeed, for these respondents, unlike for many other trans respondents, their identity as trans was more about *trans*itioning than about a stable identity. They see their current identities as transitional rather than fixed and permanent.

6. Conclusions

One of the advantages of cognitive interviewing is that it allows researchers to gain insight into the thought processes of respondents and thus they can take analysis beyond a cursory understanding of the statistical data. In this case, probing on the gender identity and sexual identity questions proved particularly useful to gain a better understanding of why certain respondents answered the way they did and to a noteworthy extent enabled a richer understanding of the data.

Overall, findings indicate that the response option for 'something else' was well understood by those who identified as such. The 'something else' option was the one most frequently chosen by trans respondents, who then most frequently selected the trans sub-option in the follow-up question. Overall, the data indicates that the presence of a trans category in the list of primary response options, however, would likely have a significant effect on how members of the trans community identify both their gender identity and especially their sexual identity on official surveys.

The findings from this study cannot help produce the perfect survey question to capture the trans population. Given the shifting, flexible, complex nature of trans identity, that is a goal that will be difficult to achieve. Until there is a nationally representative, random sample survey of, or including, the trans population, we will only have qualitative inferences. These findings can, however, move us several steps closer to understanding how to not only improve survey methodology related to the trans population and, therefore, to obtain "better" results, but also how to better interpret those results. An improved survey methodology and, more importantly, an improved means of making sense of that methodology are important first steps toward improving our understanding of the various issues facing the trans population today.

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"I Don't Have the Nerve to Tell These People That I Cannot Help Them!": Vulnerability, Ethnography, and Good Intentions

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Abstract: The nonprofit organization where this ethnography took place, driven by the maxim "lending a hand", was forced to reduce its efforts to what it considered essential, at a time when austerity was beginning to take shape in Portugal. The analysis of the logics employed to distribute food to the neediest proved to be critical to the understanding of the consequences of apparent beneficial actions in this context. The concept of "vulnerable" is, therefore, discussed considering how it was produced by a legal instrument and how it was reproduced by a local institution, what were the consequences for the subjects involved in this research and also for the vulnerable ethnographer. This investigation was based on several months of intense fieldwork where different ethnographic methodologies were employed in order to grasp the complexities of vulnerability and good intentions, such as participants' observations and semi-directive interviews. Although this paper focuses on the analysis of the distribution of food support during a later visit to the fieldwork site, it is not the purpose of this paper to discuss issues of food shortage, but to contribute to the debate of care in the context of deprivation and precariousness, anchored in an ethnography where these concepts intertwine with real situations.

Keywords: medical anthropology; social housing; vulnerability; social suffering; good intentions; austerity

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1. Introduction

Six months after finishing my doctoral research, I went back to the Health and Development Promotors (HDP)[1]. This nonprofit organization, founded in 2000, was celebrating its eleventh anniversary. Following a pilot project initiated at the now defunct Quinta do Mocho in Loures, one of the largest informally built neighbourhoods that had grown clandestinely between the 1970s and the 1990s mostly due to the arrival of immigrants from the former Portuguese colonies in Africa, cultural mediators were hired among the residents of this neighbourhood to act upon and improve the health of the local population. When the official implementation period of this project ended, these same promotors saw the need to continue the work. The desire to provide ongoing, rather than timely and exceptional services that addressed what they considered to be the most pressing issues motivated the official creation of an institution that later established itself in the new neighbourhood where residents were also relocated.

For eleven months, I undertook an intensive ethnography with this nonprofit organization that I returned to sometime after the fieldwork period was completed. Following Martins and Mendes,

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[1] The institution referred to in this article is protected by anonymity, as are all actors, who are therefore identified by pseudonyms. Formal consent of all participants was obtained during fieldwork and before each of the interviews. The methodology employed was approved by the Anthropology Department of ISCTE-IUL.

when discussing the conditions under which ethnographers conduct fieldwork, "we return in order to understand time and again, always with the renewed hope of knowing something new, of being taught something new"[2] [1] (p. 35), I decided to return for a day to the neighbourhood of Terraços da Ponte. This late visit is narrated in this article along with historical considerations about how vulnerability was produced in this territory and the ethnographic quandaries that emerge when researching populations considered vulnerable.

2. The Production and Reproduction of Vulnerability in the Margins of Lisbon

At the beginning of the 1990s, over 150,000 residents lived in shacks in the metropolitan areas of Porto and Lisbon. Portugal had joined the European Union in 1986 and international events were being planned for the capital city, such as Lisbon European Capital of Culture in 1994 and the 1998 World Exposition. At the same time, structural urban renewal projects were projected to redesign the metropolitan landscape. Following external and internal pressures, the government, consequently, decided to launch the Special Rehousing Program (PER, or *Programa Especial de Realojamento*, in Portuguese) to eradicate all shacks, rehouse the slum-dwellers in municipal houses, and upgrade the country's image.

Published on 7 May 1993 with a Decree-Law [2], and implemented during the subsequent two decades, the PER was launched by the XII Constitutional Government of Portugal. When it was enacted, the program was already an outdated housing program due to its inability to provide a thorough strategy of urban and regional development [3,4] and the sanitary discourse adopted regarding the rehoused population [5].

In order to operationalize the program, the government provided some of the necessary funds and ordered each municipality to complete a census and categorize the slum residents. The survey, employed during the summer of 1993, worked as a population technology [6], intended to classify and make the undistinguishable mass of occupants visible for bureaucratic purposes. It also defined and mapped formal and informal areas of the city for intervention purposes.

These rigid bureaucratic procedures and the top-down mechanisms of implementation, as well as the lack of social support during rehousing, transformed the PER, a mere financial instrument, into a social program with serious, albeit variable, territorial, social and political implications. Implementation depended on the efforts employed by each municipality and different results were achieved [7], which in some cases led to a replication of a culture of poverty [5,8] based on a broad definition of vulnerable populations living in shanties that justified political and social intervention [9]. The decree overlooked household needs and focused on a specific typology that demanded elimination, i.e., the "barracas" or shacks, despite the existence of a multitude of informal architectural expressions and social arrangements in the different neighbourhoods.

The program focused on the construction of new infrastructures rather than urban regeneration and mainly aimed to construct housing projects in peripheral urban areas marked by poor infrastructure. When the municipalities did not disperse the original slums, these communities were physically and socially isolated in the ghettos. One of these neighbourhoods was Quinta do Mocho in Loures, located in the periphery of Lisbon.

The Quinta do Mocho's restructuring project involved the demolition of the informal houses and the construction of Urbanização Terraços da Ponte, a rent-controlled neighbourhood where the former 4000 residents had been transferred by the municipal council in 2001. After almost three decades, the abandoned residential project in Quinta do Mocho, occupied and creatively refurbished by the newcomers, was demolished. These residents, who had inhabited the four abandoned towers and for years invested in their "homes", were rehoused by the municipality of Loures in Terraços da Ponte. Because the material conditions surrounding them were assumed to be conducive to crime

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2 All subsequent translations from Portuguese, unless otherwise stated, are my own.

and underdevelopment, the top-down analysis of their lifestyle was conducted by applying housing policies regardless of local specificities or prior consultation with the population. At the same time, ad hoc initiatives that were designed to deal with urgent problems were adopted and implemented, such as organizing a group of cultural mediators chosen among the residents to tackle urgent health problems of the population. The evolution of this group into a nonprofit organization concerned with empowering a vulnerable population is considered in the next section of this paper.

3. "What Is That Word They Like Us to Use? Oh Yes, Empowerment!"[3]

The official objective of eradicating slums in the metropolitan areas of Lisbon and Porto has been defined by its legislation as "a still-open scourge in our social fabric" [2], therefore simplified social exclusion through access to decent housing based on the stigmatization of life and sociocultural conditions of the residents living in the informal neighbourhoods [5]. These sites were characterized by their "advanced marginality" [9]. The neighbourhoods where clandestine construction proliferated described as perishing territories in need of intervention and socio-political reintegration policies. Vernacular and informal architecture was equated with a lack of moral and social adjustment. The unofficial and concealed goal of PER became the adjustment of the slum residents to a normalized and recognized lifestyle [5] and the inhabitants of Quinta do Mocho were rehoused in Terraços da Ponte under these assumptions.

As some anthropologists have noted, the margins of the state [10–12] function as natural peripheries or containers for individuals considered not sufficiently socialized within the law. The technologies adopted by programs targeting [13] populations deemed "vulnerable" living in these socially and spatially marginalized territories, ended up producing consequences similar to the ones these programs were ideally combating. The existence of power is, thus, paradoxically based on the need to constantly produce this marginal condition where many individuals find themselves [14], making them simultaneously victims and perpetrators [15–17]. These dynamics wind up perpetuating the binomial compassion and repression, which is engulfed in good intentions and is materialized by programs developed by state and non-state entities established locally when dealing with "vulnerable communities".

The increasing pathologization of behaviors based on precarious housing conditions and the belief that changing them would also discipline the lives of those targeted by these same programs, has led to a proliferation of local initiatives and institutions which direct and indirectly exert control over citizens' bodies and behaviors [18,19]. These projects frequently focus on health as the ideal governing technology, which has been "used as a shorthand for the capacity of the modern self to be transformed through the deployment of various rational practices of self" [16] (p. 45). This type of action [20], which decontextualizes the historical, political, and social production of suffering and vulnerability [21], is often well intended, but provokes unplanned consequences [22]. As Sliwinski stated when discussing the contradictions of international donations after an earthquake in El Salvador, "explaining vulnerability warrants considering the development history of a country. At the very least, it needs to take into account the accumulated effects of economics, political, and social factors that influence people's livelihoods and their environments" [23] (p. 20).

At the same time as these initiatives erupted, in places such as Quinta do Mocho, the subliminal goal of the PER Law Decree of acting upon the political subjectivity of residents following neoliberal demands [24], motivated each resident to incorporate and embody "policies, discourses, and practices that would 'free' an individual to govern (oneself)" [25] (p. 52). Unrestrained from their previous housing conditions, these individuals were meant to inhabit the new municipal houses and to upgrade

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[3] Taken from my field notes, this quote refers to an episode I observed and registered at HDP headquarters. Dona Angelina, the non-profit's president, whilst filling out a form to apply for funding for a psychosocial support project the institution intended to implement in the neighbourhood, was trying to find the right words in order to ensure its financing.

their political and social subjectivity in order to feel empowered by their new living conditions [26]. For those unable to fulfil this goal, the nonprofit organizations, funded by private and public funders, acted like the neoliberal arms of the state [27] and took the responsibility for uplifting the population they served via projects and psychosocial programs.

In such cases, the use of a specific language appears as an essential condition in the relationship between organizations that depend on external funding and can be a determining factor in obtaining the capital needed for projects. During the course of my fieldwork, I had the opportunity to see the embarrassment of waiting for a new tranche from the private or state funders of HDP, which would allow them to pay salaries or top up the diesel tank of the nonprofit organization's van used to transport patients to the hospital or to meetings with official authorities. Throughout my eleven months of fieldwork, and due to my involvement as a volunteer ethnographer [28], I was constantly asked to assist the nonprofit managers who were applying for funding, but I was also involved in different activities and tasks for the organization which they could not afford to hire more help. Thus, the adoption of Anglo-Saxon terms and neologisms could distinguish successful financing from the total loss of funds for the following year, which would also imply firing or not hiring qualified workers, and thus deliver poorer service.

For Cruikshank [26], however, the democratic values of citizenship and self-regulation have been presented as the ideal solution for poverty, crime, and other social problems, acting as a government strategy aiming at transforming individuals into liberal citizens. The good intentions deployed in programs responsible for helping people to help themselves and which, in turn, unfold into citizenship technologies (speeches, programs, etc.), ensure that subjects are politically active and rationally self-governing. The author states, inspired by Foucault [29] and Rose [24], that citizens are not born politically inclined and motivated to work on themselves; they are "made" according to the power relations that simultaneously enable and constrain their subjectivity. However, these depend on the subjects' voluntary compliance, which does not mean that they are not coercive and do not interfere in various social dimensions. Subject citizens are free, but their freedom is a condition for power to operate over them.

Cruikshank also analyzes how the concept of empowerment reached relevance in the second half of the twentieth century, both for individuals and institutions. This universal appeal that brought together the interests of feminists, civil rights activists, environmentalists, among many others, has become a citizenship technology, that is, "a method for turning individuals into citizens and maximizing their political participation" (p. 67). The upsurge and dissemination of the buzz word "empowerment' was market inspired and promised not only self-governing but the autonomy of individuals. In order to act on the interests and desires of others to drive their actions to an appropriate end, power works through, and not against, the subjectivities of individuals and demands the subject's ability to adjust themselves to new social realities [25,30]. Maximizing the capacities of the powerless makes the poor self-reliant, active, productive, and participatory, i. e., citizens, which makes the use of concepts such as "empowerment and self-esteem almost mandatory in goal statements when nongovernmental organizations apply for funding" [26] (p. 94).

For the author, this movement is based on a war on the poor, who are isolated and targeted by state intervention. Their capacities are circumscribed, calculated, and engraved in policies that aim to remove them from a predefined situation and to justify specific intervention upon them. Social reformers emerge and their actors multiply on the ground. This modeling of the poor, which is based on their own involvement and investment, is based on the production of a leveling and standardizing class, duly known, adequately formulated in statistics, and supported by psychosocial disciplines [24]. The characteristics of the various groups that make up the new category of the poor share a culture of poverty, lack of power, civic participation, and motivation to solve their own problems. This ideology was established with the desire to empower those who are deprived of these qualities, based upon the assumption of the common good.

In the field, institutions, such as HDP, implement and develop these ideas on the population they are trying to serve. The real intentions of governing and regulating bodies has made psychologists, social workers, and even the leaders of organizations on the ground feel that they know what is best for the communities they serve, even more than themselves. Furthermore, the dependence of external financiers, make these institutions closer to the mentality of the donors, of which they are usually unaware of, than that of the vulnerable communities, acting as state replacements or liaisons on a local level [31,32], unexpectedly popular in neoliberal or austerity contexts. This compassion that moves them to lend a hand [33], to label their clients as "vulnerable", and to use the jargon that makes them worthy competitors in the funding race, corresponds to a practice of doing good that is hardly criticized [15].

HDP was fueled by the need to reduce the suffering of needy, vulnerable, and marginalized individuals, as these subjects had been characterized by a Law Decree, in 1993, which motivated the creation of one of its pioneering projects, "Lending a Hand" in 2006. This project was oriented towards personal and social upgrading, as well as to the promotion of recreational activities to combat the isolation and social exclusion of some of Terraços da Ponte inhabitants who were previously living in Quinta do Mocho, but also individuals who had come to Portugal from the former African colonies with scarce means to undergo medical treatment and lived in the neighbourhood. The focus was gradually shifted to illegal immigrants, to other residents, and to similar neighbourhoods that were considered to be in need of support as well. "Lending a Hand" has received and was dependent on the financial support from different public and private entities and its continuation demanded a thorough compliance with bureaucratic procedures.

However, what was the result when the empowerment of these communities and individuals was yet to be completed when funds ran out? The next chapters explore how a nonprofit organization in an informal and rehousing neighbourhood tackled the vulnerability of the population it served after a national financial crisis shattered the country's already declining welfare system. But first, we need to consider the role of the ethnographer when investigating" vulnerable communities".

4. Materials and Methods: Becoming Vulnerable in the Field

Contrary to what was said of anthropology for years, the objective of ethnography is not to confront what is said with what is done, but rather to integrate discursive formulations [34]. Anthropology drives us to find similarities rather than differences. It is not a search for the "other", more sensitive or more vulnerable, but rather a quest for the commonality between two distant worlds, whether in different hemispheres or at the end of a main road uniting different experiences of people living in a European capital, as I came to find out during my PhD fieldwork.

Given the impossibility of being able to grasp exactly "what those who hear us understand about what we say, because their referential worlds will always be different from ours" [35] (pp. 113–114), the recognition of similarity makes it possible to apply a principle of coherence based on shared facts, or mutuality. In the incessant search for the perception of what "being human" means, anthropologists seek to understand the differences by following paths common to both the researcher and the interlocutor, however distant their reference worlds may be.

Anthropological knowledge can only be produced through a condition of mutuality. It is this condition that allows us to situate ourselves in relation to the context of observation. Mutuality is always constitutive of the place where the anthropologist positions himself. In the sense that mutuality implies "being with", "being in the company of", this condition is therefore co-constitutive of the other, neither anterior nor external [36] (p. 592).

According to Mapril and Matos Viegas [34], due to the very conditions of reciprocity that are established in the field and that require a constant negotiation and adjustment of the methods, the construction of the research object is not linear. The need to explain the hypotheses and exact methodologies to explore it, which is a common practice in other scientific disciplines, is not easily

replicated in an ethnographic setting and somehow makes the physical presence and pertinence of the researcher more vulnerable, frail, and in need of constant negotiation.

However, if anthropologists assume that the process of knowledge construction is based on a constant transformation that takes place in the networks of social relations that make up the ethnographic terrains, this intersubjectivity that develops on the basis of shared revelations allows for the constant formulation of the categories themselves. By intersubjectivity, however, Mapril and Matos Viegas did not understand a way of knowing what others retain trapped inside their minds or participating in their activities without becoming them, a general assumption in traditional monographies [37], but to conceive the conditions of knowledge production linked to the social relations that produce them. The intersubjective experience inherent in ethnographic research makes it not a means to an end, but a way of producing knowledge itself and to "arrive at a range of humbler concepts through the labour of ethnographic description" [38] (p. 339). This dimension of ethnography allows for the adjustment and the redefinition of posture and methods in the field and in the face of unexpected situations." In other words, it is the ethnographer's imperfection and inadequacy that reveal the differences, as well as their constant effort of correction and approximation" [39]. This type of permeability and contamination, that exposes both interlocutor and investigator to vulnerability [40], are both integral and fertile to ethnography, and therefore need to be taken into consideration in the knowledge production process [39].

As Berg [41] realized while conducting a multi-situated research in Spain and Cuba on political memories among expatriated Cubans, contrary to what classical ethnographies point to as the norm, her fieldwork immersion was not gradual until it reached enviable levels of proximity to the interlocutors. Berg travelled a much more winding path, approaching and distancing herself from her object and interlocutors on several occasions, constantly negotiating her role within the relations established with Cubans in various diasporic contexts. Her effort constituted a successive investment in the construction of her research ground so that it would not escape her, a burden most ethnographers carry with them while conducting research and, particularly, when investigating sensitive or vulnerable subjects and topics.

During the course of my research I have repeatedly felt the same obstacles. The difficulties in delimiting the terrain, along with numerous impediments, were partly overcome by a physical proximity to the institution and a continuous and a laborious participant observation exercise. Sometimes the nonprofit organization that sheltered me was the root of the obstacles in my fieldwork, because I was inevitably confused as one of the trainees when volunteering for the institution, a mandatory condition to guarantee access to patients and the daily life of the institution. Detaching myself from this label was sometimes complicated and counterproductive to my own research. There were interlocutors that I approached more closely, and others with whom I had to negotiate proximity at different times. I frequently felt that defining my position was a strenuous and continuous task, and each conversation, each observation, motivated new ways of sharing, new understandings, and new research perspectives. Albeit demanding, being there and reflecting upon the fieldnotes these negotiations produced [42], resulted in a better understanding of the paradoxical work of both the institution and the trainees, with whom I was frequently mistaken for.

Similar to Berg, I also began my research following a snowball technique, which mimicked the social relations in this context [43]. I first asked the NGO president about the type of support given and the residents who were under their care who were classified as mentally ill. I proceeded with interviews and informal conversations with these individuals, the NGO, and the municipal workers operating in the field. The already sullen theme of mental health, often associated with issues of these immigrants without legal documents, dependent on subsidies, and social support, complicated the already labyrinthine issues surrounding any ethnographic endeavour, and forced me to a continuous task of field making, justifying Mapril's [44] assertion, that "the field is never chosen, but produced" (p. 56).

As a result of this mutual aid agreement between the nonprofit organization and myself, as both a volunteer and an ethnographer, I conducted several research exercises, such as observations of the interactions between the psychologist and the social worker interns and the community they were trying to help. I accompanied residents to doctors' appointments and to interviews with social workers monitoring their cases. I was present in several meetings with state and non-state entities, such as the Portuguese Immigration and Borders Service, the municipal immigration department, and the International Organization for Migration with whom the NGO had active protocols. I also helped with small tasks, such as visiting a resident suffering from depression or helping to fill in an application for a job, just to list a few. These activities were all part of the endless list of tasks the interns were supposed to perform daily. I helped them as much as I could and observed how they conducted their relationships with the residents.

As Davies stated [45], this kind of reflexivity is particularly relevant in social sciences, but mostly in ethnography where intersubjectivity, mutuality, and empathy become integral to the comprehension of the context in which knowledge is produced. Although emotionally demanding [28], the ethnographer's availability to find a shared and common ground during fieldwork adopted during visceral, sensorial, and sensitive ethnographic immersion permits to capture the plasticity of subjectivities and the incongruences of lived experience, in order to better understand and construct experience-laden concepts such as vulnerability [38] in its multidimensional interpretations, involving interlocutors and ethnographers in the field.

We are therefore not talking about "becoming like the other" or projecting or attributing our emotional state to others, but learning or understanding the unknown through analogy or resonance with our experiences, in constant tension between ourselves and the other in a dialogical process through which the anthropologist and his interlocutor reveal, illuminate and transform their personal identities in an attempt to create a common referential universe [39] (p. 48).

I also realized that participation in the association's dynamics simultaneously fostered approach and withdrawal experiences that also conditioned my selection of research methods. Sometimes, if participant observation was welcomed, as when there was no one available to drive a resident to an appointment at the hospital, I took this as an opportunity to ask the patient some questions relevant to my research. If it was necessary for someone to accompany one of the nonprofit managers to a meeting, it provided another opportunity to attend and participate. As well, in other cases, I chose to observe and annotate the daily interactions inside the nonprofit organization between users and interns. On other occasions I was invited to attend meetings with official authorities, where relevant discussions were being held and the presence of an HDP representative was mandatory.

The continuous presence in the field provided me with a broader and more constant display of the conversations, verbal and nonverbal communications, incongruities and contradictions, continuities and ruptures, to record daily life and the ordinary in my fieldwork notebook [42], but also to strategically select the next step of analysis and methodology to employ. Participant observation allowed me to be there, to live the reality of HDP for several months, and to consolidate my knowledge. The semi-directive script [46] with the key questions to address, which allowed my interlocutors to feel free to give relevance to topics that would be important to them and that would compel me to reassess the guidelines of my research, was reviewed several times, but also set aside whenever the discourse of my interlocutors was more relevant than my incipient concerns.

There were several and constant negotiations regarding my role at the nonprofit organization with the users who resourced its aid when caught in several political, domestic, and health entanglements, and the interns who made that territory their daily workplace. Added to these were the demands placed upon myself by virtue of my willingness to volunteer which demanded an almost total availability on my part to support the organization constantly struggling with financial and technical problems, a dual and ambiguous role where anthropologists researching NGOs constantly find themselves [27,47].

5. Results and Discussion: Homecoming

In December 2011, when I returned to Terraços da Ponte, Portugal was under a new bailout, similar to what had happened in 1977 and 1983. Five years in power, the socialist government was facing international pressures driven by alarming socioeconomic indicators, a sovereign debt crisis, an excessive deficit, and a rampant unemployment rate. This led to a formal request for financial assistance. The third bailout finally came to Portugal through the hands of three entities, the European Commission, the European Central Bank, and the International Monetary Fund, which was implemented by the XIX Constitutional Government elected on the 21 June 2011, composed of a new coalition between center right parties. The critical financial situation and the measures taken to overcome it paved the way for substantial changes to the welfare state [48], which were accompanied by a reconceptualization of the support provided to those who deserved to benefit from social support [49].

On the day I revisited the nonprofit organization, it seemed like it had entered a pre-apocalyptic state, as if the news from the newspapers that warned us every day of further austerity measures had suddenly materialized in front of me. Although the institution was never a place of great abundance, where two trainees struggled daily to solve as they could, and without great means, the various problems that entered through the door, the escalating scarcity of recent months had not prepared me for the scenario I encountered. Upon arrival, there was only Mariana, the psychologist, in sight, who was busy managing and distributing goods from the Food Bank. The day ahead was anticipated to be particularly hectic with the organization of bags to be delivered and the arrival of the users, who were waiting for their turn, after confirming that they were registered and that they would be entitled to food aid.

The association's entrance was now divided into two zones separated by screens. The space, formerly centered on psychosocial support, had been reorganized into what seemed to me to be currently HDP's main activity: distribution of food to the needy. On the left side, duly protected from outsiders' eyes, were shelves of various food items from the Food Bank with which the HDP now had an active protocol. Cereal boxes, pasta, rice, sausages, tuna, and olive oil could be found scattered around the place or already displayed on the newly installed shelves. The interior of the fridge, where our lunches were previously stored, was filled with yogurt pots and other perishable items. The freezer bulged with sliced bread, sausages, butter, and cheese. In addition to these goods, crates filled with bananas, tomatoes, pears, turnips, bread, and spinach could be found everywhere. There were also vanilla desserts, cookies, saltine crackers, and milk packets waiting to be properly packaged in bags assigned to the homes of all who had duly justified their need for food support.

Mariana kept some assets for certain families whose needs were already known because they had young children, for health reasons or even considering their already proclaimed preferences. In the case of a mother who had to leave her children early in the nursery in order to get to work on time, Mariana was careful to prepare two large bags reinforced with fresh products for the children's soup, fruit, yogurt, and their preferred breakfast cereals. To ensure that she received the long-awaited goods, Mariana arrived at the nonprofit organization about an hour early, solely for this mother, who only at the end of her long working day could lift up the second bag. In addition to arriving early, Mariana also left later due to the demanding schedule of this woman, who once attended the job search workshop held at the nonprofit organization and was now working full time. She represented the epitome of the caring mother, the fulfilling client, the citizen whose example was referred to others [26]. Therefore, she deserved special treatment, even at the expense of Mariana's sleep.

They also told me that since Senhor Ramiro, the association's president, had suffered a car accident, destroying the van previously used to collect Food Bank goods and take patients to doctor appointments, several changes had taken place. First, both the psychologist and the social worker interns were fired. Although their internship had terminated in June, the institution was able to keep them working full time, but with the accident they were forced to let them go due to lack of funds. Now they supported the distribution of food only on a voluntary basis and moved by compassion for the poor, who they once helped on a different basis, namely, with psychological and social support [50–52].

When the partnership was established with the Food Bank, the registrations collected indiscriminately by Dona Angelina practically with all the residents of the neighbourhood were cancelled and the process underwent a more rigorous scrutiny in accordance with the rules imposed by the giving institution, deferring several applications which did not fulfil the specified criteria. I asked Mariana what they were looking for during the home visits ordered by the Food Bank and she told me that they saw the conditions in which people lived, what foods they had, if they were name-branded or generic, although this was a dubious standard since the applicant could still have food items from previous visits to the Food Bank. Although the research methods were not perfect, they were nevertheless applied by the former interns to guarantee the support's fittingness.

Mariana, while organizing the deliveries, took the opportunity to explain to me how she managed the operation as required by the Food Bank. They found that some people owed two euros for transportation, an amount charged by HDP to each family to fund the nonprofit's workers visit to the Food Bank warehouse after the van accident. The psychologist affirmed that taking that step had been enough to distinguish those who "really needed" from those who abused this service, because of the ridiculous and symbolic value asked in order to receive a "free" bag of food. In Mariana's words, the situation was solved using a simple calculation: "They decided that they would donate monthly to transportation. They said that their contribution was barely enough to buy a bottle of olive oil at the supermarket and that if they backed the transportation, they would have access to two bags of goods, so it was a more advantageous situation."

Although definite rules had been established about what each person was entitled to receive, not only to comply with the requirements of the Food Bank's protocol, the interns, according to what they already knew from each family, followed a more "subjective" or "intuitive" approach in choosing what was deposited in each bag. I noticed on this visit that Mariana (I later checked with Carla, the social worker, when she arrived) had already gained a greater complicity with the residents of the neighbourhood since my last visit. She knew them by name, she had already visited their homes, she was acquainted with their needs and preferences. She had listened to them listing their burdens and sorrows and she had become one of the guardians of the neighbourhood Food Bank refrigerator and pantry. I also noticed that she had some "pampering' reserved for certain people, as was the case of a woman who returned late in the afternoon asking, in a low voice, if Mariana could give her some extra items in case there were some remaining, to which Mariana replied to, in the same tone, that "Yes, maybe it could be arranged". The interns had, thus, become receptors of the narratives of suffering presented by the users and responded with compassion, actively participating in the moral economies at stake [15].

These compassionate efforts employed by the former interns, which involved staying until very late on Food Bank days and taking on the heavy work of loading and unloading, without any help, the van rented only for this purpose, was coincident with the logic of "lending a hand" [33] prevalent when they worked officially for the nonprofit organization. The compassion, the moral imperative that was above any other narrative was now the only one that subsisted when everything else at HDP seemed to crumble in the face of financial collapse. However, this abandonment was all the more necessary during austerity times. Touched by the community's needs and suffering, they had become infected by the communicable vulnerability [30] present in their complaints, moving them to act, to do something, to lend a hand. They did so in the name of a common humanity, which they justified as a universal imperative [53] and impelled them to work even without pay, in the name of the welfare of others and to alleviate their suffering [50,52]. This narrative, which established a hierarchy of priorities in which the hunger of the users of the association for which they used to work outweighed their personal needs, became dominant.

Provided the community deficiencies were properly marked and the vulnerability of this neighbourhood was once again defined by formal instruments such as the Food Bank inquiries and mandatory home visits, the goods were delivered and on the scheduled day the residents lined up at the nonprofit's door to collect their two bags full of "free food". They also did so as long as people

complied with their part of the agreement, i.e., that the refrigerators in their homes remained devoid of essential food, that they were visible on the poverty lists, and that they managed to pay the two euros. Stronger compassionate forces would, if necessary, be activated by a mother struggling to get to her job on time. These same forces allowed for a "little treat" to be kept for others, but they also stratified and hierarchized who "really deserved" and who was not sufficiently compliant to receive support, which was made available to the detriment of the life of the former workers. It did not solve the problem in its genesis and did not allow for any kind of counterargument because, as is well known, compassion knows no enemies [15,16]. Similar to what Bornstein [54] found in her ethnography with Christian ONGs in Africa, the attitude of Mariana and Carla allows us to understand how an economy of care and ethics operates, and under which moral imperatives the possibilities for help are determined [55].

However, in practical terms, HDP struggled to reward all this effort. One of the managers, Dona Angelina, confided to me that, unfortunately, it did not seem that the readmission of the former interns would happen any time soon, because "nobody gives us money" and "there are cuts everywhere". By the end of 2011, the austerity discourse was widespread and structural cuts to the welfare state and its subsidiaries were deemed indispensable [48,49].

However, this dedication and self-sacrifice deployed by the former trainees to the residents of Terraços da Ponte was not overlooked by its inhabitants. One member of the HDP board regretted the departure of the interns and told them that in the neighbourhood everyone called them their "mulatto mothers". The effort had been rewarded, because of their atonement, shared vulnerability, and recognition of the helpless conditions lived by the residents of the neighbourhood, both Mariana and Carla were now considered honorary members of Terraços da Ponte.

When, at the end of the day, Senhor Ramiro and Dona Angelina arrived at HDP, Mariana confronted them with the arrival of many individuals requesting Food Bank assistance and the impossibility of HDP helping them all. She asked if she had to refuse the new applications submitted during the day. "I don't have the nerve to tell these people that I cannot help them!", she confided to me later. Senhor Ramiro accepted the newly arrived inscriptions but added that these would be the last.

When Dona Angelina arrived, she also shared with me that Adelaide, a former resident who I had met during fieldwork, was finally working as a housemaid, but no longer lived in the neighbourhood. This information had already been transmitted to me by Mariana, namely that Adelaide had left her daughter with her father and moved in with her sister somewhere far from Terraços da Ponte, something that both the psychologist and the social worker disapproved of and viewed as child abandonment. Sometimes Adelaide would return to the nonprofit organization, always telling a different story. The cycle continued and renewed, while interns and institution assisted passively without being able to lend a compassionate hand to Adelaide.

6. Conclusions

This paper explains how the vulnerability of a community was produced by the enactment of a special rehousing program in the 1990s and reproduced by the local institutions operating in the field. The objective of this paper is to critically and ethnographically discuss how, in the face of strenuous financial constraints, the moral economy of compassion was reorganized by a nonprofit organization focussed on helping a population considered "vulnerable". It also presents the figure of the ethnographer, both vulnerable and viscerally engaged with the field, for whom fieldwork is more than a rite of passage, it is a mandatory condition for the production of anthropological knowledge.

Returning to HDP after several months of absence, allowed me to conclude that ensuring the physical survival of the residents, rather than addressing the socioeconomic reasons that caused them suffering, had become the norm. It was necessary to help, not to waste time questioning what instigated it. The urgent matters that had directed the constitution of a group of cultural meditators in the 1990s were again the main driving forces behind their work with the community.

In order to prevent fraud and encourage appropriate civic participation, the morally charged discourse disseminated by nonprofit organizations working with the poor distorts the economic

responsibilities that generate poverty. This is equated with a behavioral deviation, pathologized and instituted as an object of expert intervention, in which helping those who were" made' as those who need it most, ultimately divert attention away from socioeconomic inequalities. They fail to recognize the historical and political conditions that promote suffering, as well as the actions they employ that ultimately increase it rather than decrease it [21]. By not addressing vulnerability correctly, they make even more complex the situations of the individuals to whom they try to" lend a hand". It legitimizes and perpetuates structural imbalances and permits the survival of individuals in extreme situations without these causes being addressed or discussed [47]. These forms of "governing for health" [16] (p. 48) lead to the creation of new forms of subjectivity in which the structures of institutions are absorbed by individuals, creating a sense of individual failure [56] and expanding the power of the state in original ways when, in neoliberal times, it seems to be retracting.

Institutional responses tend to fragment these problems into differentiated smaller pieces which then become the subject of highly particularised technical policies and program, increasingly ones that last for short periods of time and then are replaced by yet others which further rearrange and fracture these problems [57] (p. 29).

But what were the real motivations behind the work of HDP, only humanitarian? Where did the desire or even the need to help come from? Where to allocate needs and vulnerability, I wondered, only on the side of the recipient of aid? Considering the "contingencies and playful' creativity or aesthetic self-construction to represent individual lives, to which the image of the victim often seems inadequate, partial at most, and humiliating" [58] (p. 9), the concepts of agency and resistance punctured my ethnography, forcing me to rethink such broad concepts. The data collected prevented me from understanding individuals as mere victims, benefactors as the sole disinterested active agents, or the government of the former as the equivalent of a serial production of amorphous and passive subjects.

Similar to Malkki [59], who criticized Fassin and Rechtman's [60] stance on humanitarianism, which focused mostly on the lack of satisfaction of the other's basic needs as a key factor in the decision to help, the reality present in the nonprofit organization directed the interpretation of the ethnographic data to a realm where precariousness and vulnerability intertwined daily [38]. The pursuit of a more fulfilling life, more satisfying levels of sociability than those found in his or her homeland, or the need to belong to something that transcended them existentially, were some of the reasons Malkki found in the course of her research that pushed not only caring for others, but also caring for oneself among Red Cross volunteers [29].

HDP interns also expressed a desire to help the residents of the neighbourhood, particularly those with whom they most easily identified. Although they stated that they did so to address the precarious or fragile situation in which they found these individuals, there was also an active quest to fill gaps on their side, to help them make sense of their work and daily life at the nonprofit organization. Like the nuns helping after the earthquake, in 2001, that devasted El Salvador, the former interns interiorized their humanitarian work as a "gift of self" [23] (p. 69). Citizenship technologies [24,26] were being deployed on both side of the "help barricades".

These ambiguities and paradoxes registered during intensive periods of fieldwork in omnipresent ethnographic notebooks enable the thorough analysis of institutions and the hazy modalities of care managed during austerity times, which some authors have noted that in the Portuguese case were responsible for the survival of some deprived families at the expense of a comprehension of the scope of scarcity these same individuals had to endure [47].

Because "NGOs are not simply monoliths carrying out the latent agendas of their partners, but a 'bundle of contradictions', a site of 'dynamic cooperation and conflict among its partners' and, arguably, within themselves" [32] (p. 262), in order to make sense of the inherent contradictions present in their work and the type of care they deliver to the populations they serve, ethnography obliges us to discuss their" vulnerability". This vulnerability, which is also shared with the ethnographer and the workers involved in psychosocial aid, attests to the original ways in which it intertwines with the lives of individuals. The help deployed is not perfect, it does not exempt the state of its responsibilities and

rests on "ways to care for one another in a context where their very relations, and the very struggle to maintain the everyday, are at stake. Of course, they often fail, and tragically so. But they keep trying to the very end" [56] (p. 203).

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Multiple Vulnerabilities in Medical Settings: Invisible Suffering of Doctors

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Abstract: While there is a substantive amount of literature on vulnerability of different kinds of patients in different settings, medical professionals are usually considered as the ones who possess power and gain a privileged position. In this paper, we aim to demonstrate that in a certain context physicians—a social group which is usually referred to as "powerful"—consider themselves vulnerable, and this positioning may influence patients in turn. This perspective highlights the complexity of interactions within medical organizations and contributes to the studies of sensitive topics and vulnerable groups. We conceptualize vulnerability of doctors and discuss what can be problematic in powerful doctors' position. We describe some features of the post-Soviet context of Russian healthcare system and maternity care, both of which can be conceptualized as a hybrid of legacy of Soviet paternalism and new neoliberal reforms, managerialism and marketization. Empirical research is based on the ethnographic evidence from the study of a Russian perinatal center. In this article, we explore specific "existential" and "moral" vulnerabilities of medical professionals who routinely have to cope with multiple challenges, such as complicated clinical tasks, rigid control of different state bodies and emotional responses of suffering patients. We argue that there is a bond between the vulnerability of doctors and that of patients, whose position becomes more problematic as professionals become more vulnerable. At the end, we discuss methodological and theoretical implications of our research.

Keywords: vulnerability; maternity care; healthcare; doctors; perinatal center; suffering

1. Introduction

The goal of this paper is to examine an invisible vulnerability of doctors, whose power is usually taken for granted by social researchers. We examine their vulnerability in the context of perinatal center—one of specialized high-tech maternity care units in Russia. Vulnerability in social sciences is frequently interpreted as a one-sided process within binary relationships: since doctors have a ruling position, professional knowledge and agency, it is patients who are powerless and suffering. The vulnerability of medical professionals is rarely discussed in studies of vulnerable groups and sensitive experiences.

The term "vulnerable" is a concept that sometimes is used interchangeably with such terms as "sensitive", "hard to reach" and "hidden populations" [1] (p. 3). Vulnerability is defined as a lack of autonomy and independence, bodily and psychological insecurity, marginalized or deviant status, lack of acknowledgement within the society [1]. This term refers to individuals and social groups, as well as to certain situations and topics. Researchers have been studying vulnerability in connection to taboo topics that are emotionally overwhelming [2] (p. 6)—the ones concerning intimate, discrediting or incriminating experience [2], such as death, grief, violence, AIDS, drugs and homelessness. Vulnerable groups are exposed to discrimination, intolerant attitude, subordination. In particular, they include people who have certain health-related conditions, such as terminally ill or mentally ill [3].

Doctors are rarely characterized as a vulnerable group, but within certain circumstances, they can be recognized as "vulnerable". However, based on analysis of the post-Soviet maternity care and inductive analysis of empirical data, we argue that Russian doctors could systematically experience vulnerability and that different kinds of vulnerabilities of doctors and patients are interwoven. Our analysis deals with social and institutional (rather than psychological) dimensions of doctors' vulnerabilities. Sociological discussion on vulnerability in medical settings is the starting point of our research. Vulnerability is usually seen as an inherent quality of certain social groups (but not others), while in our approach it has many dimensions and might be attributed to relatively "powerful" groups.

Our research is aimed at examining social arrangements of interactions in medical organization, feelings of its participants and barriers for patient-centered approach to maternity care in Russia. Doctors in Russia have to satisfy contradictory clinical, bureaucratic and social requirements. The social position of medical professionals is characterized by lack of autonomy and high level of subordination. Their positioning is contextualized by such processes as hybridization of market, contemporary managerial reforms and the legacy of soviet paternalism. 'Unjust' (from doctors' point of view) demands from patients, management and authorities; routine collisions with severe clinical conditions; emotional situations and absence of various resources makes doctors vulnerable in special ways, which we define as "existential vulnerability" and "moral vulnerability".

The structure of this article is as follows. First, we describe data and method. After that, in background section, we conceptualize vulnerability of doctors and discuss certain problematic issues related to doctors' powerful position. Then, we describe some features of the post-Soviet context of Russian healthcare system and maternity care in particular. Perinatal center is considered as a special case. Following empirical sections are based on the ethnographic evidence from the study of a perinatal center. We introduce the analytical terms "existential vulnerability" and "moral vulnerability", which were inductively constructed to explore multiple challenges which medical professionals routinely have to cope with. Then, we argue that there is a connection between vulnerability of doctors and that of patients, whose position becomes more problematic as professionals become more vulnerable. In the end we discuss methodological and theoretical implications of our research, concerning (1) the subject of vulnerability, (2) meaning of the context in exploring vulnerabilities or vulnerable groups, (3) interconnections between vulnerabilities of doctors and those of patients and (4) the position and actions of the researcher in the empirical field when dealing with multiple vulnerabilities.

2. Materials and Methods

The aim of this project is to explore various attitudes of medical professionals, patients, and other actors in medical environment in order to identify potential tensions, conflicts and complaints in medical settings and determine the ways to cope with them. We focus on the interactions between medical professionals and patients, as well as between the staff members and different departments of perinatal center.

The research has been built on fundamentals of institutional ethnography developed by Dorothy Smith [4]. According to it, communication (a transmission of information and the ways actors implement it to their work) links local practices with the broader institutional context [4] (p. 169). Adapting the logic of the "extended case method", this methodology allows us to study the connections between macro-structural changes and practices at the micro-level [5,6].

This methodology provides opportunities to observe practices and understand the social meanings and structures, which stand behind them. A comprehensive study of different social perspectives allows us to identify organizational tensions in the Perinatal Center and explain what challenges and at what levels (organizational, interactional) are systematically reproduced.

The empirical base of the study (2019) consists of:

1. 33 sessions of ethnographic observations (including field conversations, field interviews, analysis of material environment and documents) in one of the Russian perinatal centers. The collective of

three field researchers conducted 249 hours of observations, which were recorded as 391 pages of field notes.

2. Observation at medical events (including conferences, seminars, trainings) at the research site and in the other medical organizations.

3. Analysis of written complaints by patients.

The results of the current research have also been triangulated with the previously gathered data. We did not include this data into analysis and do not refer to it in this article (as it does not address its main questions and goals), but it contributes to our understanding of the social processes within healthcare system in Russia:

1. Analysis of documents (State laws, orders and projects; online reviews (n = 35) (2018); posts of flashmob "violence in delivery" (#nasilie_v_rodah) (n = 50) (2018))

2. Interviews with patients (n = 10) and healthcare professionals of perinatal center (n = 20) (2018).

3. 16 sessions of non-systematic observations at perinatal center (2018);

In the text we use the term "professionals" interchangeably with 'medical practitioners' to denote doctors of different specializations, nurses and midwifes working in various departments. We mostly focus on doctors—obstetricians, neonatologists, anesthesiologists, pediatricians and others. On one hand, they are the ones who make decisions and take responsibility (both in front of controlling bodies and patients) for negative effects of treatment, birth traumas, lethal outcomes, etc. On the other hand, both in theoretical debate and empirically, they are more associated with power, high status and emotional neutrality in medical institutions than nurses and midwives, who are less powerful and more associated with care and involvement. In this article, we want to show that due to these reasons "powerful" doctors are becoming vulnerable in a very specific way. At the same time, we recognize the significance of nursing staff, who do a lot of emotional labor and faces different challenges, and consider them as vulnerable too.

The research was authorized by the administration of the perinatal center and was approved by the ethical committee of Saint-Petersburg Association of Sociologists (SPAS). All of the participants were informed about the study and were guaranteed confidentiality and anonymity.

3. Background Section

3.1. Multiple Vulnerabilities in Healthcare

Despite the radical transformations of healthcare within the last decades globally, doctor–patient relationships have been conventionally characterized by asymmetry in terms of power, agency, knowledge and control. This asymmetry goes back both to a normative paternalistic model described by Parsons (1951) [7] and to medical power and medicalization in Foucault's terms [8] and their numerous progenies. It implies a type of doctor–patient relationships, in which the patient seeking medical help performs a "sick role", which undermines his dependence on a doctor, vulnerability, incompetence, and helplessness. While Parsons explained such distribution of power as a functional and mutually beneficial cooperation, his concept has been widely criticized by scholars, who interpreted such relationships rather as conflicting and problematic. As healthcare systems were changing, the social positions of doctors and patients within them were changing too. The critical view of social scientists also shifted from social roles and norms towards interactions, practices and structural limitations. However, the idea of power as a part of medical professions was still a cross-cutting issue for many scholars. One of the classics of sociology of medicine, Eliot Freidson, proposed a conceptual model, in which an attempt to gain control over laymen (as well as to cure them) characterizes medical professionals and their interactions with patients, which means that medical experts' authority and patients' autonomy have been in conflict [9]. References to Foucault are important for interpretation not only of patients as constructed though medicalization, normalizing medical gaze and power [8]

but for understanding of both patients' and doctors' subjectivities as constructed in medical settings and depending on each other [8].

At the moment, one of the most facilitated concepts both in public health and scholarly research is a patient-centered model of medical care, which aims to establish egalitarian relationships between patients and healthcare providers. However, the concept itself is still being discussed [10], and practice, framed by this principle, has to deal with different limitations. Despite certain organizational steps towards patient-centeredness in Russia, basic elements of asymmetry in patient–doctor relationships remain the same as in the paternalistic model. Power and knowledge are still exclusively attributed to professionals, and patients are still positioned in interactions as objects of medical manipulations. Particularly, in the sphere of obstetrics and maternity care, which tends to be the frontier of patient-centered change in a global context, in Russia the notion "doctor knows best" is still quite relevant. According to sociologists and clinicians, women are mostly deprived of the possibility to act, make decisions, withstand the aggressive manipulations from medical personnel [11]. In many researches, a patient turns out to be a powerless and suffering figure.

Vulnerability of patients is evident not only due to their physical suffering but also due to their subordinate social positions and respective emotional experiences. Loss of self is among the main indicators. According to the study conducted by Kathy Charmaz [12], the main suffering of chronically ill people could be described as the "loss of self" [12] (p. 168). As Ian Wilkinson and Arthur Kleinman put it, "The most terrible and disabling events of suffering tend to involve us in the experience of losing our roles and identities" [13] (p. 9). There are multiple ways of overcoming the position of powerlessness for patents discussed in literature. Their subjectivity changes as they receive voice, became storytellers, consumers, citizens [14–16]. Alongside with the fact that patient gets agency through getting voice, neoliberal transformations in healthcare (both globally and in Russia) also contribute to changes of a patient, who becomes not just a passive suffering sick person but an active consumer, who has resources to make choices, to decide and to get actively involved into the process of cure. In maternity care women make choices and become demanding consumers [17].

By including patients' perspective, voice and emotions into its scope, medicine takes a step away from biomedical paternalistic model towards more egalitarian notions of medical profession and principles of doctor–patient interaction. The relationships between doctors and patients are changing as patients get more recognition, resources and power. The asymmetry of power and knowledge in doctor–patient relations still persists, but the healthcare systems are changing. Moreover, within the context of these changes, doctors become the ones who struggle for power, authority and professional acknowledgement but, as we suppose, frequently appear to be vulnerable, lose their agency, get existentially affected, feel injustice and suffering.

We assume that social scholars pay little attention to doctors' experiences because of the binary approaches towards understanding of suffering and vulnerability: since doctors have (rather) powerful ruling position, knowledge and resources, it is patients who are perceived as powerless, vulnerable and suffering.

Nevertheless, the vulnerability of medical professionals is frequently discussed in studies dedicated to dealing with complicated clinical tasks, vulnerable groups and sensitive experiences, for instance, in the case of disciplinary processes following patients' complains [18], due to distress and professional burnout, or as a result of being traumatized due to negative patient outcomes [19]. Vulnerability of medical professionals also has class, gender and specialization dimensions. For instance, young female doctors, as well as nurses and midwives can experience more pressure due to their subordinate gendered position. Some studies show that there is a connection between the vulnerability of doctors and that of patients. Within the discipline of psychology, scholars describe the phenomenon of countertransference [20] when doctor's own problems or emotional responses are translated to patients. In the opposite direction, patients' responses and complaints can go beyond the certain situation and negatively affect the professional identity of doctors [21]. Doctors can also be seen as "second

victims" of some adverse patient events, which happened due to a medical error or to patient's condition [19,22,23].

There is evidence (mostly from psychological disciplines) that medical professionals experience psychological difficulties while providing the end of life care (especially for children), dealing with loss (for example, reproductive loss) or telling the "bad news" (e.g., [20,24]). Vulnerability of some groups of professionals depends on workload, stress and possibilities for coping with it [25,26]. However routine emotions of medical professionals and their structural reasons have gained little analytical interest within social sciences (one of the examples is [27]).

In this article we want to consider the situations, in which doctors in a Russian high-technology perinatal center become vulnerable. These vulnerabilities are hard to determine as such a priori, but they rather demand careful observation of practices and situations. We conceptualize vulnerability of doctors as associated with a lack of professional autonomy, lack of trust and authority, institutional complexity, the inconsistency of regulation and the ambiguity of rules. Vulnerabilities are expressed in "existential" and "moral" modes. The vulnerability of doctors (and other healthcare providers) usually remains invisible for both patients and public. We want to make it visible; for this, we will try to overcome the duality of the patient–doctor relationship concept and show that both sides of this interaction may be interpreted as powerful and vulnerable, and that these relationships are not binary but more complex. Power is more diffusive as determined by numerous structural limitations in concrete contexts.

Scholars of the Neo-Weberian approach in sociology of professions define professional power of a doctor as that consisting of clinical autonomy, particular knowledge and competence in medical diagnosing and curing, high social status and professionals' closure [9,28,29]. However, in different social contexts, the autonomy and powerful position of medical professionals can be challenged in multiple ways by the marketization and managerialism. In Russia, beside marketization and managerialism, we can also observe the effects of governmental paternalism [30], which systematically restricts professional power and ability to make decisions but still assigns them the main responsibility for healthcare provision. At the same time there is an extension of the scope of doctors' professional roles and obligations—they are expected to provide psychological, emotional, administrative support of patients—which they are not always able to implement. In further section we will describe the institutional context of Russian maternity care system, in which dominating managerial regulation in combination with the new market mechanisms in healthcare, considerably restrict professional power of doctors.

3.2. Institutional Arrangement and Change of Maternity Care in Russia Causing Professional Vulnerability

This section addresses the wider context of changing health and maternity care in post-Soviet Russia and emphasizes how changes predetermine the emergence of multiple vulnerabilities in terms of institutional complexity, the inconsistency of regulation and the ambiguity of rules. The tendency of considerable transformation of the healthcare sector and professional work in it is a world-wide phenomenon [31]. The neoliberal policy, which fosters the dominance of managerialism and market principles of regulation and financing, can be considered to be a common trend in healthcare worldwide [32] (p. 378). However, different social contexts constitute various configurations of the maternity care and challenges, shaped by neoliberal policies. That of Post-Soviet Russia, which is characterized by the quite limited professional autonomy of doctors, midwifes and nurses [33], represents the case of the appreciable challenges emerging for professional work.

In general, maternity care in Russia mostly consists of state-funded and facility-based services, which in many respects inherit the organizational arrangement and regulatory paternalistic framework from the Soviet period [34–36]. As the whole system of Soviet healthcare, maternity care used to be centrally regulated and highly standardized in terms of both the way of material provision and medical practices.

Social researches analyze health care in Soviet times and later in post-Soviet Russia as historically one of the most rigid bureaucratized systems [33,37]. Being overregulated and centralized, following the state interests and goals, the system of healthcare (and maternity care in particular) leaves little space for professional autonomy and institutionally remains insensitive to the needs and circumstances of a concrete organization, professionals and patients. We add to this investigation how some features of the institutional arrangement of maternity care in Russia set multiple vulnerability of health care practitioners.

We will analyze further how professionals became vulnerable in their routine working interactions. Our main argument is the following. Clinical power of professionals in Russian maternity care is limited not only by biomedical conditions but also by volatile non-flexible contradictory managerial-paternalist state rules and norms from one side and growth of patient demands from the other. Professionals often could not fulfill contradictory state's rules or follow consumers' numerous demands, and they became vulnerable facing moral and legal injustice from both sides—state bodies and patients. We will look shortly on legislative and institutional conditions, pronatalist state concerns, volatility and paternalism of the health care as the main structural conditions influencing on doctors' position.

Legislative contradictions can be considered one of the key features of institutional and organizational settings of health services in Russia. Perpetual change of the formal rules and regulations aggravates the conditions of systematic uncertainties. As a result, healthcare practitioners' work consists of not only professional (clinical) responsibilities and managerial tasks but also includes a lot of special structurally invisible efforts for coordination of routine activities in order to bridge institutional and organizational gaps and manage uncertainties.

Institutional conditions, which advance professionals' vulnerability, consist of the multiplicity of the controlling bodies and ongoing strengthening of the State's control over the sector of healthcare and all the activities related to childbirth. Every medical organization is an object of intent attention of the Ministry of Health, the Russian healthcare control and Russian consumer control bodies (Roszdravnadzor and Rospotrebnadzor), fire inspection, etc., and, in case of negative outcome, of the law enforcement officials.

With the statist turn in welfare policy of the Russian state [38], pronatalism has become a core part of the state's political agenda. Maternity care appears to be even more controlled and inspected sphere, as it directly relates to the National priority of demography and growth of population [30] and, hence, represents a particular concern of both the Federal and regional authorities and a particular site of control. In particular, the rates of maternal and infant mortality serve as one of the key indicators of the regional governors' performance and efficiency. Hence, each case of maternal death concerns not only medical but political agenda as well. Such state of affairs, triggered by the demographical national anxiety, also predetermines the multiplicity of the state's efforts to 'modernize' or somehow improve the system of maternity care and to make control more rigid and detailed. In practice, all these efforts comprise another set of institutional uncertainties, which enhance the professional's vulnerability.

The path of the healthcare transformation started with the Soviet collapse in 1990s, when the key trends of the reforms were the liberalization of material provision (in particular, cuts in state's expenditure on healthcare). Transformation in this period also launched the process of patients' consumerization, in particular, resulting in transformation of providers' power, authority, and domination in their relationships with patients [39]. As a result, clinics and doctors became dependent on volatile state funding and patients' pocket money.

Another unintended consequence of this perpetual institutional change is that it increased uncertainties and led to the emergence of new institutional and organizational gaps. Each of numerous reforms taken in the sphere requires adaptation to the organizational settings of the particular medical organization. The neoliberalization of the system joined with the extremely-rigid bureaucratized way of its regulation, considerably restricting the range of such adaptive strategies. For example, state orders limit both the options in medical equipment and medicines to be obtained and the procedures of procurements of the state-funded organizations (most of the maternity units in Russia). Healthcare

practitioners are to manage compensation personally (to bridge the emerging gaps) and appear to be in routine institutional uncertainty in their practical work.

Since the Soviet collapse, social processes such as the consumerization of patients' behavior [17], the commercialization of medicine [40], and the (neo)liberalization of healthcare regulation [41] have been challenging an initially paternalistic state of affairs from different angles. Patient's demand is rising for more person-centered and less medicalized approaches; care and patient-friendliness are articulated as key components of medical services, and new institutions protecting patients' interests and wellbeing are appearing. However, paternalism in doctor–patient relations and that between the state and healthcare practitioners remain an important feature of maternity care service provision, arrangement and regulation. Russian regulatory and authority bodies at various levels target the sphere of childbirth as a priority for their policies. Consequently, the state is rather reluctant to establish more egalitarian relationships between key social actors interacting in this sphere. Paternalism can thus be considered to be a core characteristic of healthcare in post-Soviet Russia, in terms of both doctor–patient interactions and relations between the state and medical practitioners as state employees.

Managerial control in combination with state paternalism frames every medical organization as the site of endless control from the side of multiple state administrative bodies with contradictory and volatile demands, who check increasing volumes of bureaucratic documentation.

In all the domains, doctor–patient relations in Russian maternity care have been transformed throughout the last two decades. In particular, consumerization of patients' behavior transforms providers' authority and domination, and maternity care remains a field of power struggle for decision-making and ability to influence care provision and organization. But at the same time, Russian childbirth services still remain a limited means of empowerment for patients and providers [39], while the state, through the increasing control and bureaucratized machinery of regulation, remains a dominant actor.

Within the last decade, we can observe a noticeable decline in trust to doctors and a growing number of those, who "find it difficult to answer" [42], which indicates the complexity and discontinuity of patient–doctor relationships. Since paternalistic model does not include much explanation and communication, patients tend to fortify their opinions and decisions with information from Internet sites, forums, blogs and channels. On the basis of this information, they can make decisions to refuse medical manipulations, vaccination, drug intake or deny the disease [43]. Besides, some medical professionals are aware of the interconnections between patients' trust and their compliance. Therefore, they are trying to implement models and protocols of communications with proven effectiveness into their practice [44].

The crisis of trust to medical professionals encourages the growth of new market segments, specialists of which pretend to have their own expertise in the field of maternity care. These include, in particular, perinatal specialists (for breastfeeding, baby sleep, baby-bearing), doulas (assistants in childbirth), specialists for postpartum recovery ("closing of birth", bath rituals, massage). In some cases, their opinion contradicts medical recommendations, which enhances distrust because, as a result, more institutionalized medical help can be interpreted by women as unnecessary and excessively medicalizing.

3.3. Perinatal Center in Russia as a Special Case

Since 2006 the state's investments to the sphere of healthcare in the frame of the National foreground Projects increased ('Health' initiated in 2006 and 'Modernization' in 2011–2013) and women receive a choice of maternity hospital. During the 2010s, in the frame of the 'Modernization' program, many maternity facilities have been renovated across the country, and new Perinatal Centers—the largest and the most technically advanced maternity hospitals—were constructed. However, concurrently with the statist measures, several neoliberal policies have been implemented as well, resulting in many cases in personnel and services cutbacks. In spite of the general rhetoric of the financial support, most of the healthcare organizations in Russia became a subject of so-called 'optimization' and were forced

to follow the self-maintenance logic in material provision, though still considerably restricted by the bureaucratized managerial regulation [45,46]. Therefore, position of healthcare organizations and professionals became even more unstable.

Risky cases are routed to a maternity facility equipped to assist with definite pathology, illness or complication, each of which has different equipment and personnel and provides appropriate services. The Decree № 572n, issued in 2012, specified the order of pregnant women's hospitalization, depending on the risk of complications or pathologies associated with pregnancy or childbirth [47]. As a result, since 2012 maternity care has adopted the three-level system of medical facilities, which provide different services, have different equipment and receive different financing (with a fixed price for services at each level) in accordance with their assigned status. Large maternity hospitals and perinatal centers constitute the third level of maternity care and work as medical organizations that ensure life-saving interventions for mothers and newborns. Women with high-risk pregnancies are admitted to such facilities, which are equipped with advanced technologies and highly skilled personnel.

Such a position of a perinatal center within the whole system of maternity care in Russia predetermines its organizational and institutional specificity, which in turn enhances the vulnerability of professionals working in it. The setting of a perinatal center—a particular kind of maternity facility, which deals with medical complications and pathologies—is associated with the high probability of having emotionally sensitive and even traumatic experience by pregnant women, women in labor and young parents. Such type of organizations by design accumulates the most complicated childbirth cases, and the probability of the fatal outcomes here is much higher than in any other maternity facility. As a result, it increases the emotional burden of healthcare practitioners, who inevitably deal with life and death issues.

Being the most technically developed, often the largest maternity facilities in a region, and providing multiple medical services, all perinatal centers represent a very complex organizational structure, which requires complex intraorganizational coordination and coordination with different regions of the country. Depending on the medical specialization and the presence of the research or scientific activities, perinatal centers can consist of dozens of wards and departments and hundreds of medical personnel and technical staff. In practice, this considerably increases the organization and coordination of personalized work of health practitioners and managers, sometimes, taking most of their time and attention. In addition, a perinatal center symbolically and institutionally appears to be at the cutting edge of the maternity care in Russia, and hence, is a subject of even more increased state interest and control.

New perinatal centers since 2012 deal with those cases of childbirth, which are associated with the risk of complications estimated during pregnancy. This measure implements prenatal state goals and, as statistics demonstrate, has decreased the rates of maternal and infant mortality in most of the Russian regions [48]; however, it unintentionally has led [45,46] to the centralization of maternity care and deterioration of the healthcare accessibility in regional peripheries.

4. Results

Our conceptual model and empirical material prove that doctors—a powerful, resourceful, agentic group—can be vulnerable and acutely aware of their helplessness when faced with the inability to save or cure a patient (or her unborn/ baby). We refer to this vulnerability as "existential." Another kind of vulnerability arises when doctors encounter "unjust" (in their terms) interpretation and evaluation of their actions. We label this vulnerability as "moral". For instance, it inductively arises when doctors are assigned responsibility for situations they could not control, have to follow contradictory regulations or get baseless complaints from patients. Both unfair claims from patients and from regulatory authorities can have legal consequences, which create symbolic and real threats.

4.1. Existential Vulnerability of Professionals: "There Is Something That Will Never Be Forgotten"

Existential vulnerability concerns the fact that experience related to death is "universal"—as everyone sooner or later experiences helplessness in front of death or an unbearable suffering. Nevertheless, medical professionals perform a special role in these situations, and hence, they have very specific experiences, which make them vulnerable in a special way. First, their professional role appears to be limited by the opportunities of biomedicine, which objectively cannot manage every physical condition and save every patient, but professionals tend to take such "failures" personally and emotionally hard. This is exacerbated by the fact that in reproductive medicine, death or threat of death occur to "nonconventional" demographic groups (the ones who 'should not' die)—young women and babies. Second, contemporary demographic pronatalist politic of the state concerns the increasing the birth rates and attracts a lot of attention to maternity care. As a result, every case of maternal mortality (regardless of its inevitability and numerous complications) is becoming an issue for special attention from controlling and law-enforcement bodies and a potential legal threat for all professionals who were involved in the process of treatment.

Medicine in general and midwifery and obstetrics in particular are full of situations in which a patient feels pain, suffering and fear; experiences loss or encounters negative prognosis of the treatment. Situations, in which a patient feels herself most vulnerable, include complicated clinical cases, reproductive losses, abortions for medical reasons, complications of pregnancies and births, newborn malformations and birth traumas. Medical professionals aim at saving and helping in such situations, but sometimes it goes beyond their capabilities.

Our informants have reported that they make much effort to fix any health problems they face. However, doctors, midwives and nurses still encounter situations in which there are questions of existential character and in which they feel themselves hopeless while coping with patient's death:

> "Because anyways, there are many difficult ones [clinical cases]. On a certain stage, after all, I had another sphere of medicine, I didn't lose as much as here, but here, the level of difficulty is so that loses are inevitable … And kind of night calls and screams … I mean there is something that will never be forgotten. That's when we were sitting at the department, when we were running to the resuscitation [with the baby] on our arms, you realize that the baby is terminally ill … That's why these are such hard, the most difficult moments" (Interview with a pediatrician)

Doctors explain to us that they will keep on trying to save the patient even in a hopeless clinical situation or in situations with negative prognoses. In cases of lethal outcome, they feel their hopelessness and this experience leaves scars for the whole life:

> "At the intern's room we find out who passed away last week. A woman, right after the operation, a severe pathology, delivery at 34th week (pregnancy was contraindicated), the baby has probably survived, there are no complaints yet. It is said that doctors from different departments rushed there and some of them were only disrupting. Note: we had planned fieldwork on that day, but we were asked not to come" (field notes, researcher's observations)

Despite the fact that the situation was rather prospective (it became clear later, during the clinical examination of the case) and was not followed by relatives' complaints or legal trial, many professionals got engaged; the case was widely discussed as stressful for the personnel. The physical condition of a woman carried fatal risks, "It was irresistible, there were no medical mistakes", (field diary, conversation with a doctor). We (as outsiders) were asked not to come to the Center for some time, presumably not due to the fatal outcome itself but due to the emotional resonance and strains of professionals.

It is important to notice that existential vulnerability arises not only in cases of lethal outcome but also in cases of negative prognosis (both for health or for life quality) and risks of lethal outcome or grievous harm. Constant encounters with complicated clinical tasks, pathologies, deaths, severe physical conditions of babies, bad prognoses unleash the process of deep reflection:

"We don't speak in a room (so that there is no noise), girls [young doctors and interns] are knitting octopuses, we speak, caress, hug, kiss. Treat babies with love. And we are very compassionate to these mothers. Pathology of nervous system is a trouble indeed. And we understand that this premature baby—we will nurse it. But what's then?" (field notes, conversation with a neonatologist)

Different wards face hard cases, death and emotions of patients to different extent. In these terms emergency room or consultative-diagnostic department would dramatically differ from resuscitation or labor wards:

"Obstetricians always fight at the forefront for life and death" (field notes, conversation with neonatologist)

"If for other departments clinical death is a stress, for us it's a job. We are the most stressed department" (field notes, conversation with intensive care nurse)

Doctors in perinatal center specialize in working with severe clinical cases; therefore, mortality, bad outcomes and poor clinical prognosis are always an inevitable part of their work. However, professionals tell about severe cases or loss with personal emotional troubles. They are worried, frustrated and it is hard for them to tolerate every case of maternal or neonatal death.

One of the emotional situations that we observed during the fieldwork was related to the potential threat for the life of a patient who refused to admit the problem and accept treatment. Professionals tell that they spent several working days on endless talks with the patient trying to convince her and one of the doctors "was so nervous that she couldn't fall asleep and was walking the streets at night" (field diary, conversation with a doctor). Professionals feel and express the existential helplessness which is accompanied by the fact that in the context of lack of trust, patients do not believe in prognosis, and doctors cannot persuade them to act in a necessary way (from their point of view).

The situation was as follows. In the hospital there was a young woman who had just given birth in another hospital and was transferred to the perinatal center for clinical reasons. Doctors believed that there was a serious threat to her life. The patient was in the intensive care unit, subjectively felt normal and insisted on discharge from the hospital. Her husband also insisted on discharge and accused doctors of overdiagnosis and forcibly keeping the woman in the hospital:

"Husband: "She was living a normal life, you found heart [problems], that's you who cannot decide, whether it is heart or kidneys . . . You make her, you forcibly hold her in the hospital . . . you can't make her do something you want. She wants to go home, she is feeling good"

Doctor: "She has a risk of death". (field notes, researcher's observations)

Professionals think that the decision of a patient is fatal—"*They make a mistake which is the size of life*" (field notes, conversation with a doctor). In this case, the doctor supposed that the patient did not realize the threat to her life despite the fact that she was given medical explanations many times. The patient and her husband relied on their previous lay experience and the experience of their social environment, interpreted the situation as an ordinary one and demanded to be discharged from the hospital. In a conversation with us, the doctor said: "We can expect nasty things, she will write to the President", i.e., there is a potential possibility of complaints and follow-up checks, especially when there is a potential threat of maternal death, each case of which is controlled by the Ministry of health and regional authorities.

As a result, patients become even more vulnerable because numerous involved professionals use "aggressive" techniques to persuade patient in order to minimize medical risks and to subordinate patient to their decision. In the described situation the doctors and the patient do not come to an agreement, and the woman refuses to continue the treatment; however, after difficult negotiations with

patients and consultations with different medical committees, professionals find a solution and transfer her to another hospital to which she agrees to go to (it is closer to home, though not specialized).

This situation is sensitive for medical practitioners not only because they can be legally prosecuted in case of death of the patient or serious harm to her, which they could predict but could not cope with, but also because they do not have enough authority and trust in the eyes of patients to protect them from lethal or disabling outcomes of clinical situations. This additional responsibility forces doctors to behave more assertively towards patients who do not believe and refuse to follow their recommendations. As a result of the lack of mutual trust, doctors are urged to use affective and "forceful" arguments, while patients respond to them with aggression and even greater distrust:

> "[Doctors] are speaking quite rough . . . It was emotionally hard for me, maybe because of the hopelessness of the situation and inability to negotiate . . . Verbally doctors are threatening and bullying her to make her stay. Although—no doubt—they make it for her benefit and may be even saving her life. [One of the doctors] doesn't sleep at night, [the other] is outlining his brutality". (field notes, researcher's observations)

At the same time, neither doctors nor nurses have professional tools and special skills for communicating sensitive topics, which at the same time is a routine for them. Neither is there a practice of calling a mediator. This often affects patients, whose emotions remain unrecognized or ignored (perceived as grotesque, or demonstrative behavior). Topics related to ethics and communication with the patient are underrepresented in the curriculums of medical schools and colleges. Psychologists, who could provide both doctors and patients with professional help, can hardly get a position in hospital because they lack legal regulations of their work and trust within medical organizations. As a result, medical personnel can usually only count on their own experiences and collective practices while discussing difficult topics with patients. Moreover, they have to direct their efforts not to emotional assistance to patients and their relatives, to colleagues or themselves, but to protecting themselves and their professional collective from subsequent sanctions connected to maternity or infant death, and then, patients suffer more as they fell themselves helpless and cheated in such kind of communication.

4.2. Moral Vulnerability of Professionals

Moral vulnerability emerges when professionals face unjust evaluations and critical interpretation of their actions made either by regulatory and controlling bodies (with their constantly threatening sanctions) or by patients.

4.2.1. "Big Brother Is Watching You"

Doctors constantly feel themselves objects of all-round control. They tell about their precarity and insecurity under controlling gaze, which is perceived as a threat to their professional status and personhood in general. Threat is a kind of "outer force" ("God forbid something happens"), which lies beyond the professional's control and creates the feeling of hopelessness:

> "I say personal insecurity when you realize that in case, God forbid, something happens, nobody will be on our side, nobody will help" (Interview with a doctor)

> "Nobody will protect doctors" (field notes), "nobody advocates for physicians in front of the public" (Interview with a pediatrician)

Doctors are meant to strictly follow the laws, recommendations, procedures and rules. As we described earlier, they have constantly been controlled by various authorities (such as SanPiN, Rospotrebnadzor, Ministry of health), which produce the rules that rapidly change and sometimes contradict each other. This is one of the consequences of ongoing reforms and hybridization of governmental paternalism and new managerialism. The legal insecurity and vulnerability are generated by multiple institutional circumstances, uncertainties and organizational gaps, which in turns are

produced by conflicting legislative requirements, organizational rigidity and material constraints that professionals are talking about (see Section 3). Professionals constantly feel their precarity in such conditions. In addition, the control over doctors is strengthened by the promotion of state demographic priorities of increasing fertility and growing attention to maternity care. Professionals say: "Big brother is watching you" (field notes). During the fieldwork, we could regularly see health practitioners discussing future inspections and dangers they can possibly bring:

> "Fines are inevitable. [The nurse] believes that they just have to reconcile with it. The only question is about the size and the legal subject—a (physical) person or a corporate body (organization). Sometimes it is easier just to put the responsibility on oneself than to arrange an administrative commission". (field notes)

> "I ask her [the nurse] why is this so bad (about administrative commission). Is it because there are so many violations or because they cannot be fixed? She says yes, there are too many inconsistencies, which she (and nobody) doesn't know how to fix for the period of inspection. "My fantasy is not enough to pull the wool over inspectors' eyes! (she means—how to represent themselves in the best way for the inspection"". (field notes)

Our data supports the claim that formal requirements are often contradictory and cannot be met in full due to circumstances which are beyond professionals' control. In emic terms, the phrase of the doctor would be "*the chaos is everywhere within the medicine*" (field notes). Professionals act in patients' interests and cope with gaps in their professional daily routine by frequently breaking certain formal rules and recommendations. Consequently, they can potentially be accused or sanctioned. Professionals clearly understand it and say with irony that: "my task is to prepare everything for the prosecutor so that he can't get to me" (field notes).

Take the example of solving a problem of insufficiency of medications and equipment, which is derived from the organizational inability to buy them quickly. The doctors can face the two options: not to follow clinical recommendations and cure the patient with available treatment or search for the prescribed recommended medication by using informal instruments. For instance, professionals sometimes make purchases themselves, which is considered illegal:

> "Nurses buy containers and special tools with their money. This weekend they plan to go shopping together" (field notes)

> "They [parents] bring [money] to the discharge—doctors leave it in the department for medications. [My relative] brings suitcases of a foreign medicament. Resuscitation [department] also brings it from vacation. Sometimes we buy it ourselves" (field notes, conversation with a doctor)

> "They borrow [medication from other departments], but this is a serious violation of rules" (field notes)

Professionals are vulnerable also due to the risk of detention for informal payments, which are explained by low wages and a necessity to survive: "There is informal money, and that's life. And so how could one live on these wages, when you need to feed the family" (field notes, conversation with a doctor). This is a hidden topic which is ambivalently evaluated in medical community (about informal payments see [39]).

Moral panics in media incite mistrust and aggression towards medical professionals. Cases of infant and maternity death, birth traumas and various iatrogenic conditions regularly become a topic for massive public debates. All together, the increased attention of the Investigating Committee, media coverage and institutional controversies comprise the particular settings, which stimulate patients' complaints and invent new forms of control but leave little opportunity for medical professionals to deal with it. The control becomes more pervasive due to new instruments, such as audio- and

video-recordings of sessions with patients, online sites for commenting on and evaluating doctors and medical organizations, professional associations aimed at representing the interests of patients (League of Protectors of Patients, Investigation Committee). At the same time, medical professionals lack resources and social and professional support, to protect themselves in situations of legal prosecution or media scandals, which makes them feel constantly vulnerable. On the one hand, patients try to get a voice and empowerment, which were unachievable within the paternalistic model. On the other hand, mistrust makes them more demanding and blocks the possibilities for dialog, cooperation and compliance. Some patients are conscious that doctors and medical organizations are very sensitive to complaints and therefore try to get profit during the process of cure (extra services or financial compensations). This practice was reflected in terms used in medical environment—"the patients' terror" and "an extremist patient".

4.2.2. "An Extremist Patient"

Another type of injustice and vulnerability is related to the rise of complains and grievances of patients, many of which are deemed as unfair by physicians. Professionals take complaints very hard as they can lead to administrative and material sanctions. Patients are becoming more demanding in their ethics and style of communication and self-sufficient explanations. The principle "Doctor knows best" does not work universally any more. Patients are trying to get more control over the situation, evaluate doctors and hospitals, describe their experience, write down comments on the Internet. Patients are becoming more exacting as consumers [39].

For medical professionals in Russia this is a relatively new situation, and they often feel themselves helpless victims of unrealizable demands and injustice and unready to solve the problem. They distinguish a certain type of patient, which represents a threat—these are "aggressors" or "extremists". They write complaints to different controlling bodies and online sites. According to professionals, they act aggressively, behave unethically, make unrealizable demands and "biased" complaints:

"Oh, mother, within three days she managed to write eight complaints to all instances of the world! Listen, we … we are absolutely unprotected from this. A person can write anything: a positive feedback, a negative feedback. I like—I didn't. Absolutely biasedly" (Interview with an administrator)

"The doctor says: a mom was brawling (today) because she didn't get the medication. It costs 16,000 rubles; we ordered it; it will be delivered (in a few days). But she wants to get discharged on Saturday, because of the birthday. She says: "Take it wherever you want, at least buy it and pay it yourself"". (field notes)

Complaints lead to reputational loses and emotional costs. We were told about a complaint, which was considered unsubstantiated. The doctor, who was mentioned in the complaint, was taking the situation very hard and was even about to quit the job:

"There were two proceedings. The doctor had been going crazy all five days before that. She was sending messages to me: "Maybe I should quit my job?" … Reputationally this is very painful … not to crush this person". (Interview with an administrator)

Complaints can also be made on the basis of communicational and service problems. The doctor tells about a complainant who considers,

"The childbirth went well, thanks to your specialists". And then, somebody didn't open the door in a right way, somebody offered something wrong, something that made them indignant and provoked to [write down] two pages. They didn't like the magnet key (for exit) for some reason; I mean, and so on … You were not served? What you were not served? In what way you were not served? … Do you understand that all this, in truth, deeply hurts medical practitioners". (Interview with an administrator)

Hospital meal, late discharge, intrusive photographers in a check-out room and other reasons which lie beyond the responsibilities of a health practitioner, can become a basis for a complaint. The aim of "patients-aggressors", who are selfish as considered by professionals, is to get financial profit or moral satisfaction.

Doctors are in a situation where they are becoming more controlled by the patients; they can be complained about every single moment. Every patient can record a conversation and post it on the Internet: "Patients are taking pictures of us with their mobile phones, and we feel and consider this" (field notes, conversation with a nurse).

According to our data, lack of trust and absence of compliance become a background for blaming physicians for negligence, disregard or dishonesty. During a fieldwork, we repeatedly observed how hard it can be for doctors to conduct a dialog with patients, especially those in a critical or threatening situation. Doctors who are striving to solve difficult clinical tasks describe their job as physically hard and emotionally charged, frequently telling about emotional burnout. Patients often do not appreciate their efforts—they do not see and cannot evaluate the complexity of this work under the conditions of institutional contradictions and multiple all-round control. Patients, who are physically and emotionally vulnerable themselves, are suffering of neglect, discomfort, and misunderstanding.

As a result, a lot of (potential and real) situations of discontent and complaints are based on a conviction that the doctor is dishonest and acts in his or her own interests. Patients tend to see deception when the actions and interpretations of doctors remain unclear, confusing and contradictory to their own life experience.

Therefore, doctors, whose social position is provided with power, resources and competence, in some cases appear to be vulnerable both in terms of existential events, which are out of their control, and in terms of unjust evaluations of their actions and sanctions against them; their power and resources appear to be insufficient. Vulnerability of professionals remains invisible as it does not correspond with their social position. However, it negatively affects the patients. For a doctor who is herself hardly struggling with existential situations and threatening sanctions, it is difficult to provide sufficient support to suffering patients or their relatives. A doctor who does not have the opportunity to act in the best interests of a patient or has to break the law in order to do so can only aggravate the vulnerable position of a patient. Therefore, as a result of doctors' vulnerability which is related to institutional and organizational contexts, patients become even more vulnerable.

5. Discussion and Conclusions

This article contributes into the contemporary discussion on vulnerability of medical professionals. We are reacting on two trends in literature on vulnerability. The first one focuses on deprivation, marginalization, disadvantage, poverty and social problems [49]. Doctors cannot be attributed to this group. Another trend considers stress and burnout of professionals, but ignores structural and contextual basis for their vulnerability. Our research aims at filling in this gap.

We set the task to examine an invisible vulnerability of a group, which is considered as powerful and resourceful, doctors in Post-Soviet context, in a special site, perinatal center. As a rule, vulnerability is attributed to patients (especially such as terminally and mentally ill) as passive and not enough knowledgeable help recipients. In spite of the politics of neoliberal choice and empowerment of patients', their agency and resources are restricted; they experience bodily and emotional suffering. Within binary approaches to the understanding of power relations, doctors are opposed to patients—they have power, agency, they are not supposed to suffer and are not considered vulnerable. We critically refer to this point.

Our first conclusion refers to the subject of vulnerability. It is methodologically important not to define certain groups as (not) vulnerable by default. Such artificial narrowing of the field of analysis might derive into disregard for "unexpected" forms of vulnerability. We have to be sensitive to practices, interactions and emotional displays of all the participants, not only the ones who are determined as a priori less powerful. During an ethnographic fieldwork we discovered multiple vulnerabilities whose

boundaries are transparent. Doctors are conventionally perceived as powerful and affectively neutral, but in a number of situations, they lose power, cannot manifest their agency and face lack of resources. Their sufferings (existential and moral), as a rule, are invisible, denied and ignored.

Our second conclusion relates to the meaning of context in exploring vulnerability and vulnerable groups. In a context of hybridization of paternalism, managerialism and marketization of Russian healthcare, doctors feel the injustice of increasing and constantly changing requirements from different instances, which cannot be simultaneously met as they contradict each other. Doctors' autonomy is restricted, their actions are regulated by multiple and frequently contradicting rules; one can hardly influence one's own working conditions or choose optimal treatment strategies for patients. As a result, doctors turn out to be not only existentially vulnerable but they feel themselves legally insecure and experience injustice—that is moral vulnerability.

Our third conclusion is that patients who a priori can be vulnerable, in certain conditions might suffer even more because of (subjective) insufficiency of care and lack of attention from vulnerable doctors. Due to the low level of mutual trust, some patients ("extremists" in emic terms) accuse doctors of deception or neglecting their interests. Doctors consider such complaints unjust. They make more efforts to protect themselves from sanctions than to support their patients.

Our last conclusion concerns the position and actions of the researcher in the empirical field when dealing with multiple vulnerabilities. We recognize this position as complex and ambivalent. On the one hand, the vulnerability of informants is associated with sensitivity, which they do not want to show, and it can be emotionally difficult or dangerous to openly discuss it. Or just the opposite, the stories and the situation become emotionally oversaturated. Moreover, the researcher experiences emotional difficulties during such conversations or observations, which are not always easy to cope with. Cases of existential vulnerability also create additional challenges and limitations for accessing the field and collecting empirical data—in an emotionally overcharged situation, a sociologist in the field as an outsider creates extra burden for participants, so she probably will be excluded from the most problematic situations.

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Invisible Vulnerabilities: Ethical, Practical and Methodological Dilemmas in Conducting Qualitative Research on the Interaction with IVF Embryos

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Abstract: The burden of deciding the fate of the supernumerary human embryo created in vitro in the context of Assisted Reproductive Technologies rests on the beneficiary couples or individuals who conceived the parental project. The beneficiaries must also take on the responsibility of choosing whether to donate surplus embryos either to others or to scientific research, or to request their destruction. Vulnerable beings, weakened from the point of view of their identity (facing the social stigma still associated with some circumstances such as being infertile, lesbian or a single mother), are required to have skills such as reflexivity and autonomy in dramatic situations that concern their relationship with their own reproductive body. Given the urgency of this issue at the socio-anthropological level, we are conducting ethnographic research aimed at analysing how specialists and lay people objectivate, evaluate and circulate different conceptions of the human embryo in vitro. Based on our research experience within this ongoing project, we intend to discuss some ethical, practical and methodological concerns for the researcher in accessing the field and conducting fieldwork. We take into account the fact that this research is focused on sensitive topics and on individuals who can be considered people in vulnerable situations.

Keywords: human embryo in vitro; infertility; vulnerability

1. Introduction

There is a long tradition within the social sciences of reflecting on and discussing the potential impact of different research methods on research participants. The level of interference of social research may vary according to the methods used, the population studied, and the researcher's level of engagement. As such, this methodological reflexivity seems particularly relevant when using qualitative methods that require the researcher's direct engagement with the field and with research participants. Additional caution is required if the research is focused on a population that may be considered vulnerable or that may be harmed by the research process, although this vulnerability is not always easy to establish.

Unobtrusive methods may be an alternative, due to their advantages in reducing the unintentional effects of the researcher's presence and interaction with research subjects [1]. These methods include the analysis of public statistics, written narratives of personal experiences, media, and several online research fields where there is no interaction with subjects. Yet, unobtrusive methods may be limited and inadequate when examining a scientific object that is not visible or accessible without interaction.

Researching health services and healthcare experiences poses additional challenges. Healthcare settings allow for a wide array of possible methodological approaches, yet, given the complex nature

of the social dimensions of health, unobtrusive methods are often a second choice resorted to when other methods are deemed to be too difficult to implement (e.g., as reported by Pruvost on her indirect research on women's birth experiences [2]). On the other hand, interviews and ethnography (where the researcher interacts with research participants) may provide a more comprehensive set of data, but may simultaneously have a direct impact on the subjective experience of health, illness and care that is meant to be captured by research. Among qualitative methods, interviewing usually interferes less than ethnography. However, some authors report limitations of the use of interviews in healthcare settings, due in particular to the reluctance and general defensiveness of health professionals when asked to report aspects of their practice [3]. Acknowledging these limitations, researchers often select interviews in healthcare settings as an initial way into the field when aiming to perform participant observation, but the direct access to the field proves to be challenging. Highly engaged research techniques, such as participant observation, often seem not only the most adequate for fulfilling the research objectives, but also the only ones capable of producing good quality, meaningful data.

Some authors report strategies to reduce the impact of their presence, such as avoiding taking notes when others are watching [3]. Still, there is general consensus that, instead of aiming to make his or her presence unnoticed and insignificant, the researcher should try to identify and weigh up the impact of a given research technique, keeping this in mind throughout the reflexive and analytical process [4,5].

On the basis of an ongoing project, in this paper we intend to discuss some ethical, practical and methodological concerns that emerge when conducting fieldwork in a particular healthcare setting, namely, in the contexts of assisted reproductive technologies (ART) and laboratory-based embryo research, to find out how people interact with in vitro human embryos. These concerns are heightened due to the sensitive nature of the research and the presumed vulnerable status of the ART beneficiaries. Beyond questioning the level of the researcher's interference and pointing to its potential problems, we discuss how this interference may in fact be productive, rending visible the otherwise invisible social existence of human embryos.

2. Invisible Vulnerabilities

We first need to discuss and critically review the use of the concept of vulnerability in a research project in the social sciences, particularly when qualitative methodology is used. How can we classify certain human subjects or populations as vulnerable? What are the key features of a vulnerable situation? Is it defined by a condition? Is it characterised by set of social indicators? Or must it be regarded as a dialectic relationship within a certain context?

According to the Council for International Organisations of Medical Sciences, vulnerable persons are those who "are relatively (or absolutely) incapable of protecting their own interests"; and, more specifically, these people may have "relative or absolute impairments in decisional capacity, education, resources, strength, or other attributes needed to protect their own interests" [6] (p. 57). Additionally, a person can also be considered vulnerable when a particular feature of their living conditions (whether temporary or permanent) makes it less likely that others will be vigilant or sensitive to their interests, thereby increasing the likelihood of putting them at risk, whether intentionally or not. For example, this may happen when people are stigmatised, marginalised by virtue of their social status or behaviour, or face social exclusion or prejudice.

There are many ways of defining those who are vulnerable in a research context. This notion may include the following groups: sick people (dependent on clinicians for care), namely individuals with a life-threatening illness or condition; children; ethnic or racial minorities; individuals who are not fluent in the language the study is being conducted in; the educationally or economically disadvantaged; individuals with a debilitating mental health condition or cognitive impairment; institutionalised persons (such as residents of nursing homes, mental institutions, and prisons); and pregnant women (and also human foetuses and neonates of uncertain viability in the case of biomedical research). The notion encompasses individuals with physical, psychological, and social vulnerabilities, such as

emotional stressors, as well as cognitive, language or cultural barriers that limit their ability to give informed consent [7–16].

According to Von Benzon and Van Blerk [16] (p. 897), "vulnerability is socially-constructed and dependent on the way in which power relations are created". These authors stress the need to discuss the relational nature of vulnerability, as doing so demonstrates that vulnerability is context-dependent, with groups being more or less vulnerable to exploitation (in the widest sense of the word) according to the particular circumstances of an encounter. Horowitz and colleagues [17] have even argued that participants in any research are vulnerable to some degree. All of this attains particular relevance in sensitive research, since asking people about their experiences connected with sensitive topics is considered to render the participants vulnerable [18].

Sensitive research focuses on topics that might be considered personally intrusive or have the potential to cause participants (and/or researchers) any kind of distress and discomfort. Interviewing participants about potentially sensitive topics requires special skills and innovative techniques, identifying ways to avoid potentially embarrassing situations. This is imperative to ensure the value and integrity of the research.

Research may be classed as sensitive when it deals with emotionally charged events, the vested interest of powerful people, and areas of human life considered private, intimate or sacred, among many other issues [19]. All of these topics are of direct concern to research on ART beneficiaries and decision-making about their cryopreserved embryos.

ART beneficiaries can be considered vulnerable subjects for a complex web of interrelated reasons of different kinds. These exist due to the social construction of parenthood and the consequent social pressure these beneficiaries (mainly the women among them) feel to become parents; to the social construction of infertility, and a still-perceived stigma resulting from this biological but also social condition; and to the particular Portuguese scenario of these technologies being offered by the public health sector (Serviço Nacional de Saúde, or SNS) with long waiting lists, on a geographically unequal basis and with a maximum of three treatment cycles permitted. In the private sector, the picture is completely different, but the costs are prohibitive for most beneficiaries [20,21]. Despite the possibility of using ART for its treatment, infertility still represents a potential cause of psychological imbalance and may negatively impact quality of life and emotional well-being (e.g., depression, anxiety, frustration, relational problems, sexual distress or stress within the couple, etc. For this last topic see Vitale et al. [22]).

Along the same lines, other studies have also highlighted the problems that infertile couples face in using ART with a third-party donor, in both Portugal and France. These include: delayed diagnoses (e.g., difficulties in obtaining a prompt and precise diagnosis of endometriosis); poor information on infertility-related diseases and treatments; long waiting lists for oocyte donation along with discontinued treatments in the public health sector; lack of state-run information campaigns and donor recruitment; standardised clinical protocols; difficulties communicating with the medical team; a dearth of psychological support; and an absence of insurance coverage [23,24].

As a result of changes in the legal framework, there have also recently (since mid-2016) emerged new kinds of ART beneficiaries: single women and lesbian couples, who have other kinds of frailty that add to those previously mentioned. All of this makes these subjects particularly vulnerable, as most of them become ART beneficiaries after a long and painful quest for a child.

But there are other less visible reasons why ART beneficiaries can be considered vulnerable subjects, especially when it comes to decision-making regarding their cryopreserved embryos. As the result of a powerful conjugation between medical science and technology, the field of ART is highly medicalised and scarcely accessible to lay people. The esoteric nature of biomedical knowledge and a codified language, combined with medical specialists' symbolic power, all put ART beneficiaries in a certain relation of dependence with respect to the medical domain [20].

Nevertheless, ART beneficiaries also appropriate and retranslate the medical discourse. Research on infertile couples who resort to third-party reproduction shows how beneficiaries convey an

anonymised and biologising conception of gamete donation and reduce life to its functional aspects [25]. An abstract evaluation of third parties by heterosexual ART beneficiaries may be seen in their perception of donors as gamete providers (instrumentalisation); gametes are reduced to cells that, in the specific case of French couples, can even be compared to other body parts such as blood or bone marrow. These beneficiaries may thus adopt the official discourse on donation, which is especially evident in laws on bioethics [26,27].

Returning to Von Benzon and Van Blerk's [16] discussion about the relational nature of vulnerability and its dependence on the way power relations are constructed, and to their view that vulnerability is context-dependent and connected to the particular circumstances of an encounter, allows us to define ART beneficiaries as vulnerable subjects, given the nature of their ART-centred relationships (which have a clear power imbalance) and the context in which their ART-focussed encounters occur (a medical one).

However, vulnerability is not a stable, permanent state. ART beneficiaries—specifically infertile people—are, at different points in their lives, both vulnerable and empowered human beings, who are asked to assume a "grammar of responsibility" [28] in order to make a decision about the fate of cryopreserved embryos. This ambivalence and transience from one state to another—from the empowered to the vulnerable and vice versa—brings us to the exchanges of solidarity between donors and recipients of the good, to a capability conceived as an enabling capacity [29]. But it also highlights the multidimensional and contextual nature of vulnerability.

Beauchamp and Childress [30] outline some guiding ethical principles that researchers should adhere to when studying vulnerable groups, providing a framework that can protect participants' rights and ensure their wellbeing at both a physical and a psychological level:

1. Respect for autonomy (a respect for the rights of individuals and their right to determine their lives). This means that participants involved in the study should be informed about the broad aims of the research and that their participation must be voluntary and can be withdrawn at any stage of the proceedings.
2. Beneficence (doing or promoting good). This relates to outcomes in the form of the scholarly body of knowledge that respondents believe will result from their participation in the research. It is important to disseminate those findings that could offer new perspectives on a certain topic and, for example, improve healthcare.
3. Non-maleficence (avoiding or preventing harm). This refers to researchers' efforts to minimise participation risks, namely by avoiding methodologies, research settings and data analysis that could result in negative psychological and emotional consequences for respondents such as distress, anxiety or frustration.
4. Justice (respect for individual and group rights). This concerns the investigator's responsibility to protect the confidentiality, privacy, and integrity of the research process. They should not identify any names either of individuals or institutions, and should anonymise any dialogue extracts used to illustrate the research findings.

Current ethical guidelines must address the potential for the data collection process to harm participants at any point, for instance by producing frustration and anxiety. Seeking informed consent in a qualitative inquiry must therefore be viewed as an ongoing process [31] that protects participants' autonomy and integrity [32], providing them with the opportunity through constant and open dialogue to withdraw from the study at any point in the research proceedings. Participants should be encouraged to express any personal concerns they may have throughout the data collection process, in particular those about the potential risks and benefits of being enrolled in the study.

When it comes to interpretation and analysis of the collected data, the involvement of third-party researchers in the study can raise ethical issues [33]. For example, although it could be beneficial to hire professional third parties to assist in transcription or data analysis (since the process of transcribing interviews can be time consuming), this could threaten participants' autonomy and anonymity as well

as the confidentiality of information, if not discussed previously. Participants should be informed about third-party involvement in the transcription phase of data analysis to ensure the validity and reliability both of the findings and of the project itself.

Several sociocultural barriers have been cited as affecting the recruitment and retention of vulnerable populations in social science research on sensitive topics. These include distrust, suspicion, fears or concerns about the research goals, and lack of knowledge or awareness about the study's requirements, timeframe or propensity to interfere with work, family, or personal responsibilities. Some of these difficulties in participant recruitment and retention are well-documented in the existing literature [34–37]. The use of standard recruitment methodology may, then, not always be effective. Additionally, it is necessary to take into account that not all the beneficiaries undertaking ART treatments will have the same educational level, nor will they be living in similar social and geographical spaces.

The ethical acceptability of a study is assessed by research ethics boards from an institutional standpoint: current protocols and board guidelines for health and social care research are concerned with sample sizes, funding resources, recruitment strategies and confidentiality of the collected data [38]. However, conducting community-based qualitative research entails different strategies. When working with patient organisations (in our case, the Portuguese Fertility Association) or LGBT associations (such as Rainbow Families), permission from these community agencies is essential in order to get access to target populations, even if the study has been approved by research ethics boards. A community member may serve as a peer-to-peer recruiter and also as a potential informant, sometimes with dual and conflicting roles.

Another important dimension is the researcher's own feelings of vulnerability and personal distress when conducting studies focused on sensitive topics among vulnerable groups. Hamilton et al. [39] argue that the protection of vulnerable research subjects has attracted much debate across all disciplines, but that little attention is given to the impact of such research on the researchers. Although researchers occupy an inherently dominant position when conducting research (despite all efforts to minimise it), they are also open to vulnerability. Sensitive research can impact on both participants and researchers, especially in qualitative studies given the level of contact between the two that they require.

Researchers may experience emotional, psychological and social injury throughout the data collection and data analysis processes [40]. Conducting interviews and doing ethnographic observation in a clinical setting may harm researchers' emotional wellbeing, especially if they are listening to intimate and saddening stories or becoming involved with informants. For example, tearful interviews can lead to researchers having to face their own emotions, such as anger or powerlessness, and those emotional responses can be reactivated several times in the course of reviewing and transcribing audio recordings and analysing field notes and subjects' narratives [41] (p. 390). When dealing with difficult and traumatic experiences during research with people perceived as vulnerable, the classical methodological principle of the researcher's axiological neutrality and detachment from the object of study is thus put to the test. To assume the role of the researcher will not prevent us from feeling vulnerable and distressed; the opposite is more likely to happen in qualitative research, which is a reason why we anticipate a good amount of what some authors have termed emotion work, and others emotional labour, in research [42–44].

Actually, the terms "emotion work" and "emotional labour" were initially developed by Hochschild [45] (p. 7) to describe different realities. For her, emotional labour means "the management of feelings to create a publicly observable facial and bodily display; emotional labour is sold for wage and therefore has exchange value". The term "emotion work" refers to the same acts done in a private sphere, for instance with family or friends. Exley and Letherby [46] (p. 115) use the term emotion work to "describe the skills and efforts required to deal with one's own feelings, and those of others within the private sphere", and analyse the emotion work in which terminally ill patients and infertile and/or involuntarily childless individuals engage in the management of the disruption to both their daily life and life course. But they also mention the emotion work they were engaged in conducting research with these individuals due to the sensitive nature of the topic.

Considering the original definition of Hochschild's concepts, it seems more adequate to refer to researchers' emotion work than to emotional labour. However, Blix and Wettergren [47] argue that emotion work can be seen as a type of emotional labour of the researcher because emotion work is a necessary skill to build a successful rapport with the research subjects in qualitative research. Also, Nutov and Hazzan [48] state that research work is not only an intellectual labour, but also an emotional one. Part of the labour of qualitative researchers is emotional labour, which for them "refers to the effort a person invests in expressing or coping with his or her emotions so as to achieve objectives pertaining to his or her work" [48] (p. 20). Dickson-Swift et al. [42] stress that the two concepts are often used interchangeably in the literature and, in fact, they make no distinction between the two terms in their paper concerning the emotional and physiological phenomena experienced by researchers dealing with sensitive health-related topics.

3. Making IVF Embryos Visible

The ETHICHO project aims to conduct an in-depth and far-reaching sociological study on conceptions and understandings of the human embryo in vitro. Its goal is to establish the basis for empirical knowledge that will: improve existing forms of care in ART, specifically communication between health professionals and beneficiaries, as well as information provision about decision-making with respect to cryopreserved human embryos; and have positive impacts on the scientific community (increased sociological knowledge) and civil society (citizen accountability and inclusive health governance).

Over a conventional IVF (in vitro fertilisation) or ICSI (intracytoplasmic sperm microinjection) cycle, there is a chance of obtaining more embryos than those required to be transferred to a woman's uterus. In Portugal, a maximum of three may be transferred, and surplus embryos can thus be cryopreserved (kept in the cold) to be used by the individual or couple as part of a new embryo transfer process within three years, which may be extended to six years in duly substantiated cases. After this period, these embryos may be donated to other ART users and/or used in scientific research and/or thawed (which entails their destruction). This decision will be taken by the beneficiaries (by signing an ART-informed consent form).

Recent legislation (Law no. 32/2006 of July 26, later amended by Law no. 17/2016 of June 20) has opened up ART to all women, regardless of their marital status or sexual orientation, and thus to both single women and lesbian couples. Although the deliberate creation of embryos for use in scientific research is prohibited by this legislation, it is nevertheless lawful to conduct research on surplus embryos with serious genetic anomalies or whose condition does not permit their transfer or cryopreservation. The objectives of this type of research may include the prevention, diagnosis or treatment of genetic conditions in embryos, the improvement of ART techniques, or the establishment of stem cell banks for transplantation programs or for any other therapeutic purposes.

The burden of deciding the fate of the supernumerary human embryo created in vitro using ART rests on the beneficiaries who have conceived the parental project. In addition to having to deal with infertility diagnoses or other difficulties in conceiving (be they medical or social), the woman or couple must also take on the responsibility of deciding the fate of the surplus embryos. Potentially vulnerable beings, weakened from the point of view of their identity (because they face cultural taboos and social stigmas still associated with being infertile, lesbian or single mothers), are required to have certain capacities and skills such as reflexivity, self-determination, individual autonomy and the ability to engage in cost-benefit analysis based on information in dramatic situations in which their relationship with their own reproductive body is concerned. But to what extent is these subjects' ability to act and make decisions compromised?

The main objective of our research project is to analyse the similarities and divergences between experts' and laypeople's objectivation and evaluation of the human embryo, both in medically assisted procreation and in scientific research, examining how embryos are socially constructed, between being a "potential person" within a parental project and a biological material for scientific and medical

advances towards the promotion of public health. Objectivation is understood here in hermeneutical terms, as the establishment of objective concepts within the sphere of understanding via the process of interpretation. Nevertheless, in the case of surplus embryos, this objectivation may also refer to a process of bio-objectification by the life sciences, where cryopreserved embryos understood as life-forms or living entities are transformed into objects through scientific labour and its associated technologies, subsequently being assigned specific identities [49]. Furthermore, we aim: to identify the medical vocabulary used by clinicians to inform beneficiaries about the possible fates of surplus embryos, and by embryologists to inform beneficiaries about in vitro embryos' quality and implantation potential; to determine how experts construct a communication process to enlighten ART users about embryos, as well as how biomedical discourse is perceived and interpreted in a lay manner by beneficiaries; to understand how both expert and lay actors cope with complex situations within the decision-making process itself—specifically those that involve doubts, dissonances and disagreements about the embryo's status, role and fate; and, finally, to use the data generated during this study to transfer knowledge to society, helping not only to increase professional and political awareness of current challenges but also to enrich legal, medical and bioethical debates on this subject.

Given the present context, the main concerns and challenges facing the researcher relate to how to access this vulnerable population, and in particular how to operationalise the project, gain effective access to the field, collect empirical data through fieldwork, and further process the information collected, always protecting subjects' rights and bearing in mind their likely vulnerability.

Both quantitative and qualitative research methods will be used to collect data, specifically:

- A non-representative survey questionnaire distributed to ART beneficiaries, which is now being disseminated through a fertility association, LGBT associations, and social networks.
- Ethnographic observation of interactions within infertility consultations, multidisciplinary team meetings and laboratory settings, for 18 months, in four geographically and socially contrasting ART centres (e.g., public versus private sectors, north and south of the country) and in one laboratory conducting research on embryos and embryonic stem cells (the only one with an ongoing research project in Portugal, approved in 2016, to study the process of embryo implantation).
- Approximately 80 semi-structured interviews with beneficiaries and professionals. In total, we plan to interview 50 ART users (26 of which were already conducted), 15 ART doctors, and 15 embryologists.

The option for a mixed methods approach was based on the specific aims of this study, recognising the complexity and multidimensionality of the research topic [50]. This multimethodology for data collection, as a whole, is expected to contribute to better understand, from different angles, the different meanings of the human IVF embryo according to both ART users and ART professionals, and also how these concepts circulate between them. Different methods conducted in tandem are more likely to lead to unanticipated outcomes and data redundancy [50]. As such, at first, interviews to ART beneficiaries were conducted aiming at capturing narrative accounts about IVF treatments and IVF embryos within each personal trajectory and intimate experience. At a later stage, interviews will also be conducted to ART professionals (medical doctors, embryologists, and others) to capture their narratives on the professional practices and their dialogue with institutional norms.

The survey questionnaire was designed after the first interviews were conducted, targeted at the wider population of IVF users. It aims to combine social and demographic variables with some of the main topics emerging from these first interviews: the conceptions of parenthood within ART treatments (including dimensions such as the parental project, the use of ART techniques, the experience of treatments, and the relation with the medical team), and the decisions regarding IVF embryos.

Participant observation, in a later stage, is expected to allow for a comprehensive analysis of everyday practices and social interactions in ART centres, between users and professionals but also among the latter. More than validating data drawn from interviews, we expect to develop an in-depth

understanding of the social dynamics surrounding decision-making and communication processes that may not be visible in users' or professionals' narratives.

So far, in order to recruit participants, we are identifying and selecting experts working in public and private ART centres and in a research laboratory, as well as ART beneficiaries who have resorted to in vitro fertilisation, and inviting them to join the proposed study. Interviewing ART beneficiaries demanded, from the start, a high degree of engagement from the researcher in order to promote the establishment of trust-based relationships. Without an institution or organisation that could mediate the recruitment process, a public call for participants was disseminated in online social networking websites through the personal profile of the researcher. It could be argued that recruiting participants for a research project on such a sensitive topic would require a formal, institutional presentation of aims and methods. Yet, keeping an informal tone in all communications and adopting a personal rather than an institutional identity seemed to foster closer relationships between interviewer and potential interviewees. In fact, establishing such close and informal relationships prior to the moment of the face-to-face interview allowed for a detailed, comprehensive informed consent—an ongoing process [31] that went far beyond the formal, circumscribed, and rather limited moment of informed consent at the beginning of the interview. In most cases, when the interview took place, the interviewer was no longer a stranger and already knew part of the story the interviewee had to tell.

These interviews with ART users are being conducted either individually or in couples, since we aim to include all the beneficiaries of these techniques in Portugal, comprising single women, lesbian couples and heterosexual couples. Regarding couples, most interviews were conducted with a woman; in only very few cases, both partners were present. A portion of the interviewees have been recruited through online forums about ART, where women prevail [51,52]. Moreover, in most cases, practical issues (e.g., conflicting schedules) prevented interviews from taking place with both members of the couple. The current literature has been discussing the methodological aspects (at the ethical, practical and analytical level) of interviewing couples, namely whether to conduct joint or separate interviews with both partners, although not being conclusive about their advantages or challenges. Recent studies [53] have argued the benefits of conducting dyadic analysis in relational research about health and illness, i.e., interviewing partners separately but taking the couple as the basic unit of study, for allowing the comparison of perspectives (capturing both shared and individual interpretations, experiences, understandings and meanings).

Nevertheless, interviews are being conducted by a researcher with previous experience of dyadic or group interviews, who has reflected earlier on how to tackle specific challenges that may arise. The researcher has thus used some strategies in order to circumvent the potential bias in the data collection process, which cannot be neglected. When conducting individual interviews due to the absence of the other partner, whenever the interviewee reported to the couple ("we … "), this apparent homogeny was deconstructed, asking for a validation of whether there was an acknowledged agreement between both on the subject, or if it was the personal perspective of the one being interviewed. More specifically, in such cases interviewers may ask if, in their perspective, the interviewee believes the partner thinks and feels the same way. When interviewing the couple, it was also essential to make that same validation, summoning the experience of both partners in the interview and being sensitive to nonverbal communication, in order to understand if the experience being reported by one of the partners was the same for both. Even when there was someone who dominated the interview, speaking more, the interviewer created opportunities for both partners to speak, so that the personal, subjective experience of the one who speaks the least or who feels that their experience is less interesting for the study is not underreported. In fact, there is clear potential in having both partners in co-presence and capturing this interaction. In addition to the dialogue with the interviewer, both partners also talked with each other. Couples often engaged in a conversation that had never happened before, coming to different conclusions from what they had assumed for themselves, or even discussing some sensitive topics, thus providing a richer relational account of the couple's experience and of gendered subjectivities.

Qualitative research can be highly relational. And, indeed, in this ongoing project, it seems to be through these relationships that participants find a safe and meaningful way to contribute with their narratives and personal experiences. This can partially explain why, a few days after the first call for participants, nearly 50 ART users promptly accepted being interviewed face-to-face, while our online, anonymised survey, which could be seen as a safer way to participate, given the absence of a face-to-face interaction for data collection, up until now gathered far less than what would be expected from an online survey: a few more than 50 responses in the first 2 weeks and, one month later, it seems to be struggling to reach 100 responses.

Focusing on the relational dimensions of data production in this project seems to be the key to addressing such sensitive topics, to accessing the field, and to creating the adequate conditions for the participation of vulnerable subjects, transcending the idea of a directiveness continuum in interviews and moving beyond the principle of axiological neutrality. Interviewing was not restricted to listening and guiding the interviewer's discourse. It involved the sincere expression of emotions and feelings from both interviewee and interviewer, it encompassed constant attentiveness and, often, it included tears and hugging. Empathy, trust, openness, and the ability of the researchers themselves to recognise and embrace their own vulnerability became cornerstones for involving vulnerable subjects in this research.

4. On the Productive Potential of Researching Vulnerable Subjects

It is unavoidable to recognise the potential distress and suffering of the subjects participating in sensitive research. Yet, it is also crucial to discuss, on the one hand, the productive potential of such participation and, on the other hand, the emotions of the researchers themselves.

Several authors stress the need to address the negative consequences of the emotion work and of emotional labour in which mainly qualitative researchers frequently engage during fieldwork and beyond. Watts [54] says that researchers working alone may experience overwhelming emotions, which is the reason why he advocates for the existence of a support network that can help researchers to deal with the emotional strain when researching sensitive topics. Also, Dickson-Swift et al. [42] consider that it is important to create a space for researchers to explore the emotional nature of their work and to ensure an appropriate support at both individual and institutional levels. They claim that assisting researchers in dealing with emotional challenges of sensitive research is very important, especially if we take into account that the concept of emotion work is undervalued in universities.

Some studies mention strategies used by researchers to deal with their emotions throughout the research. Watts [54] emphasises the relevance of negotiating the boundaries between researcher and participants in pursuing a balance between the need of proximity and maintaining some distance. In the same line of thought, Blix and Wettergen [47] (p. 692) stress the need for a distinction between "a private self" and a "professional researcher" to deal with possible negative self-feelings. In Dickson-Swift's et al. [42] study, researchers reported using a number of strategies to distance themselves from the data, including reminding themselves that the research was not about them. Some, in the absence of another kind of institutional or professional support, turned to friends, family and colleagues for support and relief.

In addition to the provision of professional emotional support, Nutov and Hazzan [48] recommend that, in some areas, researchers should be trained to cope with emotional aspects of their work. The truth is that qualitative researchers are often expected to manage emotions throughout the research, our own and other's. However, as Blix and Wettergren [47] state, entering the field, and gaining and maintaining access, demands using a set of emotional skills that are rarely analysed or trained.

Conversely, it is worth critically discussing the harm-focused literature concerning the participation of vulnerable subjects in research, particularly when addressing qualitative research within the social sciences. We acknowledge that, in addition to well-known constraints on access and on conducting fieldwork in research related to health projects, other ethical, practical and methodological questions are placed on the researcher in a study that focuses, as ours does, on informants that can be viewed as

subjects in situations of vulnerability. Besides the need for a strong justification for such research, the ethical and procedural standards governing its execution are much higher. It is crucial to ensure that core ethical principles are upheld and critically applied throughout the study; researchers must obtain informed consent, maintain the anonymity, confidentiality and privacy of collected data, and limit unnecessary risks.

This study surely requires the researcher to have ethically sound procedures in place to protect the needs, rights and interests of the potentially vulnerable participants, ensuring that the risks of their involvement are as minimal as possible, and that the scientific contributions and potential benefits of the study are significant enough to justify exposing vulnerable individuals to the burden of research participation. More specifically, researchers must formally demonstrate that the overall potential or actual benefits of conducting this qualitative research outweigh any possible harm to participants, thus showing how the study will make an original and significant contribution to advancing general knowledge. One of the aims of this research is to develop a manual of best practice for health professionals, as well as a policy brief to help build more inclusive and citizenship-promoting public policies on health and science. Yet, subjects will also be informed that the results of the study will not contribute to any change in policies or practices that would benefit themselves in their current use of ART, but to other users who resort to ART in Portugal in the future. Moreover, participating in research may potentiate the negative experience of undergoing ART treatments, for example the impossibility of anticipating results, the succession of failures to achieve the desired pregnancy, and the intrusion into the intimate life of the individual or the couple [23,26].

A significant part of the data for this project is expected to be produced through institutional ethnography, in ART centres. In these settings, negotiating the presence of an unknown investigator takes on even greater importance in sensitive situations such as an ART consultation, the moment of signing the ART-informed consent form, or even the discussion of embryos' quality and future viability. It is thus necessary to work at the level of the very particular, that of intimacy, in order to analyse how much broader political and scientific interpretations are constructed, as well as how we move from very private experiences to public constructions. The research team will take special care to ensure the comfort and protect the well-being of the human subjects participating in the study. We will respect the need for a phenomenological approach, one that requires greater subtlety and empathy on the part of researchers: the ability to understand what is expressed by the actors involved (emotions, distress, and non-verbal communication), and the capacity to describe the occurrences in situ (collecting field notes, informal conversations). We will implement an ethnographic approach that adapts to suit each member of the target population, one sensitive to the fact that different periods may be more or less difficult for potential participants, and that they may have intimate reservations, and which adheres to clinical centres' confidentiality and privacy principles. Within healthcare settings, there is also a possibility that participants may be uncertain about the role of the researcher as a social scientist, in contrast to a doctor, a nurse or an embryologist. It is thus important to discuss the practical and methodological barriers encountered during fieldwork in regular meetings with other research team members.

In order to prevent being subject to discrimination or stigmatisation, members of vulnerable groups may avoid identity disclosure to non-members before establishing a researcher–participant relationship. An infertility diagnosis and the need to use ART to have a child can be self-damaging to the person or couple, thus requiring researchers to recognise and respectfully negotiate the limits of their relationship with those they are studying. Researchers should then develop specific and effective adaptation strategies by considering vulnerability on a case-by-case basis. Nevertheless, a previous study has shown that infertility organisations' members and representatives may voluntarily disclose their identity, even when the researcher makes every effort to keep it confidential. These forms of identity disclosure include the participation of these members and representatives in information sessions, awareness campaigns, television programs, newspaper interviews and academic studies [24]. They do this by pushing for greater political awareness of ART-related problems, especially through the media and in the academic world. Therefore, tensions and paradoxes arise from the conflict between

the patient's right to privacy and the requirement of public visibility through patient associations, due to a double moral injunction (ibidem).

In point of this fact, despite the risks and necessary measures mentioned above, vulnerable participants may benefit from a study without necessarily realising it. Besides being treated as key informants and being given the opportunity to express their opinions, individuals and couples who take part in this research will be helping to improve the treatment and well-being of countless other beneficiaries who are also already using ART, as well as others who may use it at some time in the future. To be involved in research can often be a positive experience, although people may have different reasons for wanting to be enrolled in a study and/or different expectations about their participation. In past research projects, interviewees claimed to be better able to organise their understandings of, feelings about and personal experiences related to the topics discussed with the researcher following their participation, even thanking researchers for the opportunity to reflect upon and talk about issues not normally subject to self-analysis. Other studies have also shown that vulnerable subjects are willing to discuss sensitive topics, often welcoming the opportunity to talk about their experience. Participants in those studies stated that they experienced some positive outcomes of their participation, including a therapeutic benefit, catharsis, new knowledge, altruism, empowerment and a new perspective on or understanding of the event or experience about which they were being interviewed [18,19].

Participants may derive additional benefits from our study as its results will be disseminated (published, presented, or otherwise shared) externally. In each ART centre where the study takes place, we plan to hold a public presentation of results, open to health professionals, management structures and users. These one-day sessions will allow the research team to return, in non-technical language, the scientific knowledge produced on the topic to the actors involved in this study and to reflect together upon the research findings. ART beneficiaries will thus have the opportunity to learn the provisional conclusions of the study in detail, and also to discuss them with the research team during these same sessions. In previous projects, community partners have emphasised the need for research studies not to be framed strictly for academic purposes but rather to be accessible to the general public in order to improve healthcare, service delivery and public policy.

This study is likely to enhance a sense of empowerment in participants (the feeling of taking an active role in one's own healthcare), as well as to yield generalisable knowledge of vital importance resulting from the subjects' enrolment in research (i.e., the study may provide valuable information for understanding how both scientists and lay actors manage these complex situations of ambiguity and discord that bear on the embryo's role and fate). The overriding rationale for this study is that the knowledge gained will improve institutional caregivers' competencies and professional expertise about the existing forms of healthcare and information provision, as well as citizen accountability in decision-making.

Alongside addressing the ethical, methodological and practical challenges of studying vulnerable populations, researchers may also play other roles and assume responsibilities related to vulnerable research subjects. A research study, particularly a qualitative one, may be a way to give voice to the narratives of those who are most fragile and/or deemed least powerful in society. By taking an interest in the experiences of those populations who have suffered social discrimination or whose voices are less well represented in public discourse, researchers help to include or involve those who have traditionally been marginalised or absent from socio-economic and political agendas (such as infertile patients, single mothers, or gay people).

As we have already discussed, the field of ART is a very medicalised one, framed by scientific and technological knowledge; it is still a domain of expertise that beneficiaries access mainly from a powerless and vulnerable position. Debate around ART and decision-making concerning the fate of surplus human embryos is still dominated by expert actors, both medical and non-medical (e.g., from the legal and bioethics fields). Besides all the expected contributions already mentioned, this study also has the potential to further the involvement of citizens in a more public debate, enabling them to become aware of matters that concern us all, preventing this and other related issues from remaining

enclosed in expertise monopolies. To be able to participate, to be involved and to be informed is a matter of exercising citizenship.

5. Conclusions

The question of what we should consider to be vulnerability in social science research, of how we should define the concept and identify the possible subjects, situations and contexts it describes, does not yield a straightforward answer, given the concept's complexity and its relational and context-dependent nature. We sought to illustrate this complex and compound nature by discussing ART beneficiaries as potentially vulnerable subjects, basing our insights on an ongoing project studying interactions with and decision-making about human embryos. Although we maintain that these subjects qualify (for all of the reasons pointed out) as vulnerable, we must also stress the fluid, potentially changing and ambivalent nature of this state, as they can also be considered empowered human beings, who are asked to assume a "grammar of responsibility" [28], in order to make a decision about the fate of cryopreserved embryos. It is also important to critically think about the reification of these subjects' vulnerable status given their active participation and engagement in patient organisations (e.g., The Portuguese Fertility Association) or LGBT associations that defend their interests (such as changes in the legal framework or in healthcare practices) or even their increased access to health information through a varied range of sources, and specifically the internet.

Throughout this paper we have discussed the ethical, practical and methodological dilemmas involved in conducting qualitative research on sensitive topics with vulnerable subjects. We have done so using the framework of a particular project and the lived experience of designing and carrying out research in an exciting, demanding and emotionally charged empirical field. To this end, we described the reasons for choosing the research topic as well as the project's implementation and management, namely how we are actually making this research happen and how we intend to make embryos visible.

However, besides identifying the problems raised in an ethical, practical and methodological level, and presenting some solutions to overcome them, it is crucial to highlight the benefits of conducting sensitive research, and of conducting this specific study in particular. We based our discussion of these benefits on our experience in this and in other previous projects. In fact, even potentially vulnerable participants may experience accountability and a sense of empowerment through the feelings of being listened to, of becoming an important part of the scientific process, of providing a relevant contribution to knowledge and thus making a difference. An important part of any sociological undertaking, but mainly of qualitative research, can be giving voice to the voiceless, rendering visible the invisible and making the apparently incomprehensible understandable. Enabling people to understand and participate in matters that concern them is a way of countervailing their potential vulnerability and possibly of helping to reduce their emotional distress and suffering.

Just as we make a point of emphasising the benefits of conducting sensitive research (and of conducting it in our research topic, in particular) despite all the challenges and risks it entails, there are also those who underline the positive outcomes of engaging in conscious emotional labour either for the researcher or the research. Blix and Wettergen [47] argue that both the quality of the research and the well-being of the researcher benefit from the awareness of researcher´s emotional labour. They say emotions are both sources of information and tools of interaction and stress the importance of researchers analysing their own emotions in relation to the field, which, in their opinion, calls for a more active than reactive approach to emotions in the fieldwork.

We dare to say that researching sensitive topics requires a sensitive researcher, one in touch with his/her emotions and able to engage in emotional reflexivity, a researcher able to build the necessary rapport with participants in the study, of showing empathy and the adequate emotions during fieldwork and of using information resulting from emotions' analysis (of both parts) in the process of data analysis.

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The Emotional Risks of Turning Stories into Data: An Exploration of the Experiences of Qualitative Researchers Working on Sensitive Topics

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Abstract: A great deal of research has been undertaken into areas involving sensitive topics. In spite of longstanding acceptance that such research can be emotionally risky for participants, interest in the impact of this work on the researcher has only relatively recently become a topic of concern. This paper reports on a roundtable convened with qualitative researchers working in sensitive research areas. The article explores their views in relation to the emotional risks they encountered in relation to their work. A grounded theory, thematic analysis was used to analyse the data and comparisons are made between researcher experiences and those highlighted by earlier studies. We illuminate how researchers described personal concerns about the emotional risks, before focusing on how the researcher's sense of professionalism contributed to, or protected against, these emotional risks and emotions. This paper also discusses the faltering nature of the support provided to these researchers and the challenges created by the need they felt to create impactful research. The authors conclude by arguing that current support and guidance provided to researchers working in sensitive areas fails to address the complexity of the emotional reaction of the researcher. We call for the development of specialised training and improved use of theoretical concepts such as emotion work, to guide those undertaking this challenging work.

Keywords: ethics; sensitive research; reflexivity; qualitative methods; emotional risk

1. Introduction

Over the past 50 years, qualitative methods have become established as producers of valid forms of evidence, with studies now being published in a wide number of journals [1]. At the same time, a great deal of research has been undertaken into areas involving sensitive topics. The exact definition of sensitive research varies between texts. Authors such as Lee [2] have focused on it being a broad type of research that is accompanied by an intrusive threat because the research asks participants to reveal information about a deeply personal experience within their private sphere. Lee went on to examine three different types of threat; the first refers to an 'inclusive threat' as being those in which the topic of study is private, stressful or sacred (p. 4). While a second threat posited is that of 'sanction' which includes data which exposes forms of deviance or stigma. A final type can be identified as a 'political threat' which emerges when researchers are investigating a form of social conflict. Other authors have focused on the sensitivity of a topic as being related to the likely impact of the research. For example, Dickson-Swift et al. [3] suggest that sensitive subjects are likely to evoke distressing emotions for the participant. While Sieber and Stanley [4] suggest that 'socially sensitive' research is that in which "there are potential consequences or implications, either directly for the participants in the research or the class of individuals represented by the research" (p. 49).

It has been claimed that sensitive research methodology developed in response to research on taboo topics [5]. This area of research has been particularly dominated by qualitative approaches and feminist researchers have been forthright in suggesting that sensitive subjects particularly lend themselves to investigation via qualitative methodology because they have the ability to empower the researched [6]. However, the impact that ceding power to participants has on the researcher has only recently been highlighted as being potentially problematic [7]. Others, including Fahie [8], have highlighted the broader emotional impact involved in sensitive research, with Lee and Lee [9] stating that these demands are now "difficult to ignore" (p. 47). In this paper, by exploring the patterns within the literature that have been produced to date, we will argue that despite growing interest in the impact of research on the researcher, there have been few studies that have examined the issue across discipline boundaries and qualitative methodologies. The paper commences with a broad discussion of the theoretical backdrop of both vulnerabilities and emotions in sensitive topics, before moving to discuss the findings of a roundtable event held on the issue of emotional risk with a wide range of qualitative researchers, working in this area of research.

2. Vulnerability and Emotions in Sensitive Research

In order to fully grasp the emotional risks to which researchers are exposed, it is helpful to first consider the theoretical background of vulnerability in the qualitative research process. Evidence of the influence of this issue on sensitive research is apparent through the special consideration that is given to the vulnerability of the participants; for some time, ethics committees concerned about the impact of this type of research on participants, have required researchers to carefully consider the consequences of this type of research on those being studied [10]. Feminists and other critical researchers have been particularly concerned about the vulnerability of research participants. Writing in the 1990s, Behar [11] went so far as to argue that in asking for revelations from others while revealing little of ourselves, "we make others vulnerable but we ourselves remain invulnerable" (p. 273). This type of assertion is typical of an influential and longstanding reluctance within social science to acknowledge the potentially vulnerable position of researchers, with Davenport and Hall [12] even suggesting that admitting to vulnerability can lead to shame and disgrace.

At the turn of the millennium, deLaine [13] commented that sensitive research came with "unknown ramifications for self, research and career" (p. 85). However, within the context of sensitive research, the idea of researchers as potentially being vulnerable participants in the research process is a relatively new concept that has received intermittent attention. This is despite assertions that qualitative research is a social encounter in which "emotional processes are crucial components" that may leave participants feeling exposed or vulnerable [14]. Furthermore, the direct participation and emotional engagement of researchers as 'participants' in the field has, for some time, been actively encouraged by various methodological frameworks [15], with some authors suggesting that the broad turn towards reflexivity may have opened up further vulnerabilities [16]. This gap in our understanding about the vulnerability of researchers may be significant; Bloor et al. [17] have pointed out how we may not be aware at the outset of the research of the vulnerabilities within ourselves that may be touched by our engagement in work. By contrast, vulnerability among therapists is well theorized and discussed. Although they differ from researchers by having an explicit therapeutic intention, there are constants between the two roles, in that actors in both enter similarly emotional arenas with individuals in which they must be open and receptive to distressing details of their lives [18]. Rather hopefully, the recent literature demonstrates a shift that sees increasing numbers of researchers giving up their 'cloak of invulnerability' to make available their experiences both as confessional accounts and as tools of research onto themselves [19]. In a particularly revealing account on the topic of vulnerability, Emerald and Carpenter [20] write of being "awed" by the resilience of the women they interviewed, while simultaneously beginning to "wonder about our own resilience" (p. 741).

There has been considerable hesitancy in the literature to overtly acknowledge vulnerability of researchers within the research process, there has been some substantive interest in the emotional

impact of this work on the researcher. An early example came from Moran-Ellis [21] who used the term 'pain by proxy' to describe the emotional upset that can occur when researchers listen to the painful events experienced by their participants. In contrast, Harris and Huntington's [22] seminal edited collection helped to gain wider acceptance of emotionality as a central tenet of the qualitative research process. However, Campbell [23], Johnson and Clarke [24], and Dickson-Swift et al. [25] were among the first to undertake qualitative work into the emotions of researchers as a topic in its own right. Their studies suggested the emotional demands placed upon researchers who undertake research in these areas may be considerable. Recent and growing interest has led to a number of studies that have usefully highlighted the importance of protecting the researcher against harm [8,19] as well as demonstrating the embodied impact of the work [19]. These papers have continued to enlighten our understanding of emotional vulnerability and have helpfully made some recommendations in regard to working towards establishing the emotional stability and safety of qualitative researchers. Nevertheless, their findings are limited because in spite of Dickson-Swift et al.'s [25] call for empirical qualitative studies on researchers from a range of backgrounds and from other global contexts, many of the studies have been undertaken in a particular context [26]. Others continue to be dominated by single or dual authored accounts [27,28] or those based on teams of researchers working on the same project Bowtell et al. [29]. The recent literature also shows a turn towards those that take an auto-ethnographic approach [19] or autobiographic accounts [8], with few researchers writing frankly about their experiences in accounts that are directly integrated within their methodology [30]. It has also been suggested that such conversations still tend to happen in "the hidden spaces and fringes of knowledge production" [31].

Some of the recent studies have sought to use the 'emotion work' theory to contextualise researchers' responses to their fieldwork [32,33]. These studies include a discussion of 'emotional labour' as dealing with the emotions of another individual and in doing so also working to regulate your own feelings [34]. In an early example, Campbell [23] argued that in undertaking interviews with victims of rape, her research team were undertaking emotional labour. However, other researchers have been slow to apply this theory to sensitive research [3]. In addition, despite concerns about the emotional labour and potential risks to researchers involved in this type of work, professional research bodies have been slow to respond to the issue [17]. Similarly, within a policy context the issue has received little attention. In the UK, the recently published Framework for Mental Health Research, offers a collective view of how mental health research should move forward over the next decade [35]. However, it makes no mention of the need for research that evaluates the impact of this type of work on the mental health of those conducting the research. This is surprising given our increased awareness of the importance of good mental health at work, which includes 'good work' dimensions of control, meaning, agency [36].

As a result, the area of emotional responses and risk among sensitive topic researchers remains relatively poorly understood. Given the types of social problems and issues that now require research, and the broad increase in qualitative studies, the number of researchers working on qualitative studies into sensitive areas is only likely to increase [13]. This would suggest that there is a worrying gap in our understanding of the potential emotional pitfalls within sensitive research and a need to develop a set of action points that can guide researchers and their supervisors when undertaking research on sensitive topics. It is this gap that this paper intends to address.

3. Aims

We set out to explore the emotional impact of work on sensitive topics among researchers working across a range of qualitative research studies. We were particularly interested in building on previous research by Dickson-Swift et al. [25] in exploring the issue of emotional risk among this group. Our overarching aim was to broadly examine emotional responses, with a focus on emotional risk, and how researchers have responded to it. Our purpose was to explore how this might have evolved over the last decade and to develop recommendations which could inform researchers and their supervisors on

the emotional risks associated with undertaking this type of research and guide them on what can be done to manage these risks.

4. Subject and Methods

The concept of holding a roundtable was established following a discussion between the authors about their personal experiences of undertaking qualitative fieldwork on sensitive topics and of having responsibility for supervising other researchers working in these areas. The authors both have a long history of researching sensitive subjects working within the academic, public service and the charitable sectors. Our objective in holding a roundtable event was to facilitate a broad intellectual debate among qualitative researchers that would enable the production of a framework for taking this agenda forward.

The roundtable took place in May 2015. The authors identified a range of key informants from across the UK, all of whom under Lee's [2] definition of sensitive research had undertaken qualitative research into an area that could be considered to be sensitive. To enable our findings to be as inclusive as possible, we set out to speak to a wide range of individuals across a range of disciplines, including psychology, sociology, social work and nursing, who were at various stages of their career. As a result, researchers invited included those from a range of sensitive topic areas. They were invited to participate in the roundtable by email, with those who were unable to attend being asked to nominate a suitable replacement. The membership of the group was intended to draw upon a wide range of experiences, including those of researchers who had only been working in the area for a short amount of time and those who had considerable experience across a number of studies. In total, eleven researchers attended on the day of the event; those who eventually participated in the study included those who had undertaken research into areas as diverse as death and dying, stillbirth, homelessness, abortion, suicide, drug addiction, lived experience of mental health issues and those who had worked with peer researchers. They ranged from those who had a few years' experience researching to those who had been involved in multiple studies and were currently operating as lead investigators. All the disciplines set out above were also represented.

We captured informants' critical reflections on professional practice by starting with a main roundtable discussion with all participants. Contributors were invited to share their thoughts and experiences of working as qualitative researchers across their areas of research. A list of topics developed from the literature that related broadly to the issue of emotional risk were put to the panel (See Appendix A). These were designed to act as conversational trigger points, and they ranged from operational and practical issues, to those related to the institutional role in managing risk. These topics were considered to be anchor points only and researchers were encouraged to discuss any insights they had from their personal experiences of acting as researchers in this area. We also wanted to gain an awareness of how emotional risk varied across the various stages of execution involved in a research study. Therefore, we included questions about the perceived demands of different parts of the research process, including the use of different forms of qualitative research and those that used mixed methods, though the focus of the discussion tended to be on interviewing and the emotions attached to this encounter. To reflect the potentially sensitive nature of the topics under discussion, approximately half way through the main roundtable we also formed two break out groups. This gave researchers an opportunity to discuss issues within a more intimate setting.

During all the roundtable discussions, we used digital recorders to capture the researcher's conversation; participants were asked to consent to the use of these recordings in the production of research publications. These recordings were subsequently transcribed and analysed by both authors. The analysis began with a first round of open coding of the interview transcripts. This was completed line by line by both authors. During this phase, our main concern was 'what are the main issues being faced by participants?' The next step followed the process of conceptualization as set out by Glaser [37] in which codes with similar content were clustered together to create broader level concepts. Constant comparison of the concepts that emerged through this analysis ensured that eventually the emergent

social pattern was revealed. What follows in this paper is a thematic presentation of the emergent topics from our analysis of the issues discussed during the roundtable. The findings are organised around a series of themes and subthemes that we have embedded within the discussion. We have included direct quotes from these discussions in this paper; identifiable features have been removed to protect the confidentiality of those individuals who took part.

5. Results

Descriptive detail of the four dominant themes that repeatedly arose in the discussion are presented in this section. These are: Personalisation; Professionalism; Sources of support; Endings. A discussion of the subthemes identified is also provided.

5.1. Personalisation: Guilt, Shame and Risk

The majority of researchers perceived the qualitative research they had undertaken into sensitive topics to be inherently emotionally risky. Researchers' strength of feeling about this risk was such that they considered it to be a distinguishing feature of this type of research. Although some of this risk was attributed to the personal nature of the topics under discussion and the intimate depth of the conversation, a significant degree of risk came from unanticipated disclosures during the interview:

> ... *qualitative research is something that really lays itself open to disclosure of very unexpected things, you know. (Participant A)*

These disclosures contributed to a lack of control over the interview encounter. Researchers described having far reaching conversations with participants about unforeseen issues that were not related to the topic they had been employed to research:

> ... *too often ... in qualitative interviews ... you ask a question and then you know they start answering and they want to talk about something else ... and trying ... some ways to kind of move back onto the interview schedule. (Participant B)*

The challenges associated with making sure recruitment targets and overall expectations of principal investigators were fulfilled received universal comment. As the following quote suggests, in many cases these expectations appeared to work against the narrative that research participants were attempting to convey. The tension this created was a consistent concern for the researchers, many of whom reported long-term feelings of guilt at the process of turning stories into data:

> ... *you are supposed to turn these experiences and stories into data but they are not, they are still stories and experiences with you (...) they just sit with us for years and then we mine them every now and again and then feel guilty about it. (Participant C)*

As this quote indicates, in some cases it was the passivity associated with the research role and lack of direct therapeutic intervention possible as a researcher that became a source of tension. For those researchers who felt they had gained professionally from the interview, there were additional emotional burdens:

> ... *I felt like I was using people's tragedies for my own gain almost, because you know, it was about finding out about what had happened to them and ... hopefully changing practice through dissemination but there is always that worry that actually it was almost a bit selfish to go in there and sort of use a story which would get me a PhD and then would later get me a job. (Participant A)*

For some of the researchers, discomfort around the balance of risks and benefits to the participants underpinned these emotions:

> ... *I feel like I am kind of going in and hearing a lot from them [...] they take part in research, they are giving something of themselves and hopefully they do get something out of that as well but I think, there is a risk for them as well as a benefit. (Participant D)*

One researcher was candid in speaking about her frustration at feeling unable to publish 'honest' accounts of her experiences of working with people, who upon reflection may have been too vulnerable to take part in the research:

> *(a fellow researcher), has written (in an article) that we are beneficial to participants. I want to write up the ones where I don't think I was beneficial, where actually I felt they should have been left alone and I should not have gone out . . . (Participant E)*

Although all of the researchers spoke about having careful procedures in place to protect the participants of their research, there remained a sense of shame about the disparity of giving and receiving that occurred during the research interview:

> *. . . (there) was a feeling of slight shame actually, . . . something about it which is to do with the ethics of . . . going into someone's home . . . interviewing them about very intimate issues (. . .) but then withdrawing going back out into the world, going back to the office or wherever and then maybe actually having no further contact with them for months, if at all . . . (Participant E)*

5.2. Professionalism: Permission, Identity and Personal Intrusions

This theme was concerned with the broad issue of professionalism. It contained three sub-themes that characterised the reactions that were placed under this heading. The subthemes were permission, identity and intrusions.

The issue of permission arose when researchers spoke about having experienced an emotional reaction to the data. There was often a sense of tension associated with this admission. For some, this tension revolved around allowing themselves permission to experience these reactions:

> *. . . I had this kind of perception that you know, I should be able to handle it, I should be able to manage it . . . because I didn't recognise my own needs in that situation . . . and I didn't have that kind of acceptance around, because I just thought it was part of the job description of what we are supposed to do. (Participant B)*

This act of permission was significant as the difficulty of engaging with participants within their own homes, on topics that are emotionally challenging often without feeling able to show one's emotions, required there to be a safe space for researchers outside this environment in which they could explore their own reactions. Furthermore, it was clear that while 'permission' was an issue of concern for most researchers, it was complicated by the sense that the particular emotional reaction varied from one team member to another. For example, one researcher indicated that this sense of 'professional permission' seemed to be easier for male members of the team:

> *it's amazing to see how I think anxious (she) was that she wasn't perceived as being an over emotional hysterical woman. Where (he) and I were able to just throw these things out unproblematically and know that people would understand how traumatic this had been . . . (Participant C)*

Researchers also spoke about the challenges and risks associated with speaking out about their emotional response to the research because of the sense of hierarchy within the research team:

> *. . . you feel emotionally attached to these people so when your supervisors start to critique what they have told you, that is a problem, you know . . . But you are not in a position where you can say actually hold on a minute you know . . . (Participant A)*

Their personal sense of vulnerability in this regard was obvious:

> *. . . some of the interviews we were doing, I found them very emotionally affecting and then I had all the dilemmas about (it) but I want to be seen as a professional researcher, I don't want to risk being signed off sick, I don't want to risk losing my job, all those things, but sometimes I just couldn't help it . . . (Participant E)*

Fears of being seen as unable to handle the work or being seen as unprofessional resonated in many of the accounts. Professional identity was particularly fragile for those on short-term research contracts and PhD students at the beginning of their career. The same researcher spoke clearly about this sense of personal risk and how it had changed now she had a permanent contract:

. . . now that I am not a contract researcher any more I feel much more comfortable . . . How do you as a contract researcher admit that you are struggling because it is your job, you can't, you need to not be signed off, you need to not damage your career, your reputation, so that nobody will employ you to do that job again . . . (Participant E)

For some researchers, this sense of vulnerability was a double-edged sword, as their concern for themselves combined with worry that their emotional state would also impact on those they were interviewing:

. . . it is not only (for) ourselves but it is also (for) participants in the research as well, like an emotional risk for them if we are not really grounded . . . (Participant F)

One of the researchers suggested that rather than having to gain permission for her emotional reaction, it should have been accepted as a natural part of the process:

We are humans, we get affected and impacted by other humans so, acceptance around that . . . being in a supportive framework that allows, like that's natural that is going to happen . . . (Participant B)

Researchers particularly struggled to maintain a neutral emotional stance when conducting interviews on topics with which they personally identified. Significantly, this struggle continued even after the interview was over, as one researcher described how outside of the interview setting, her outlook remained altered:

. . . you are listening to stuff that was so close to your heart that it was just really distressing to sort of see people that you identify with . . . it kind of heightened my emotional sensitivity. Then when I was out in the world it made me much more emotional when those issues just came up. (Participant F)

The longer-terms effects of undertaking sensitive research were a common feature among our group. Researchers described how intense memories stayed with them long after the fieldwork had been completed. Note the embodied, physical nature of the memory recounted in the following passage:

. . . a few years later, I can imagine myself right back in that room and I can see the person, I can hear them, you know. So we are talking about going in once but actually we revisit these stories many times don't we . . . (Participant A)

The stories sometimes intruded into their memories at times completely unrelated to the research process. This situation is best described by the following quote, which recounts vivid details from a research interview:

. . . one of the (interviewees) . . . talked about going down and standing by the river and hearing the waters rushing and then hearing this voice saying to him no it is not your time . . . but just every now and then that quote comes back to me if I am out for a walk or something, I see a river and think oh my goodness that was probably 15 years ago that we did that work, it is still there somewhere. (Participant D)

5.3. Support Needs: Family Intrusions, Peer Support and Self-Care

In this section, we explore the theme of support needs. We examine how these needs presented themselves and how researchers spoke about the challenges they faced in this regard. We also reflect on the researchers' agency and strategies for self-care and management. We begin by considering the issue of intrusion as this illuminated how, in the immediate aftermath of the interview, researchers became aware of its emotional impact on them. As the following quote illustrates:

. . . I was coming home and telling my 16-year-old son, and thinking afterwards that I was traumatising him, you know just having to talk about it to somebody. (Participant G)

The intrusion of the research into family lives was widespread; this type of informal debriefing was common among researchers. However, there was almost unanimous concern about the involvement of family members in this way. It was only when some researchers found alternative sources of support that they realised they had been acting in a way they subsequently found unacceptable:

peer (support) thing . . . happened by accident and that was when we realised that we were going home and being and saying things to our families that we didn't want to. (Participant C)

Surprisingly, there was a degree of consensus around the limited role that the principal investigator could be expected to take in relation to providing support for the day-to-day emotional challenges faced by researchers. A number of reasons for this emerged from the data but it appeared that a sense of competing demands was a common issue:

your principal investigator is too close to the material and has this other hat on, wanting you to finish your research (Participant B)

For others, issues around power and hierarchies appeared to be the driving force. Again, in these cases, a valued peer emerged as a vital support:

Both myself and my colleague . . . anticipated that it wouldn't be ok to ring . . . the principal investigator . . . we didn't have access to anybody outside so we used to ring each other . . . (Participant D)

The ability to select the person with whom you formed a supportive relationship seemed crucial to creating a supportive peer to peer relationship:

. . . (the) peer supervision that we set up within the research team it became a lot easier because of being able to be kind of raw, honest outside of the hierarchy . . . that was incredibly useful that you were able to choose the peer . . . (Participant C)

There were, however, some mixed views about the value of some forms of peer support. One researcher pointed out that teams are often made up of contract researchers who may ultimately compete with each other for positions within the department. For these reasons, it was reported that support needs were best met if they were culturally embedded at the departmental level.

. . . there needs to be somebody who is . . . familiar with research but not involved in that project to be giving some sort of emotional therapeutic supervision . . . where supervisors are like you will be giving therapeutic supervision to my PhD students and I will be doing it for maybe your PhD students . . . (Participant B)

Letting researchers know what to expect was seen to be a crucial part of the process and it was suggested that it should be part of the researcher's induction programme:

. . . if you are working on a research project, these are the sorts of things that if you are working in this department. This will be provided for researchers. There will be a forum for discussion . . . (Participant C)

Institutional responsibility in relation to the support needs of researchers was generally perceived to be lacking. It was clear that while institutions acknowledged the physical risks associated with research, consideration of the emotional risks was worryingly absent. This researcher described how:

. . . the university . . . was very good at you know, lone worker policy, so if I went into a house on my own I would have to ring (a nominated person) . . . but (they) didn't acknowledge that emotional risk is a thing . . . (Participant E)

This reflected a troubling tendency among institutions to think purely about the risks of research more broadly, without asking questions about the particular complexities of undertaking research into sensitive subjects.

Researchers described feeling dazed and numb after doing the interviews. Notably, they struggled to identify when they should press the principal investigator for greater guidance, especially when faced with unfamiliar situations. In most cases, over time they came to develop their own self-care techniques:

Sometimes I find it quite hard because I don't always have support (. . .) sometimes . . . I come out from doing an interview, I think, oh there's stuff in there . . . I can leave the office, I go for a walk . . . that is one of my strategies, coping strategies . . . (Participant D)

In most cases, the principal investigator had not budgeted for external support for the researcher. This led to a situation where even if such support was needed, it was not available. In a couple of cases, this resulted in private therapy being utilised for work-related issues:

I have been to see a therapist in fact and I had gone to see them about some stuff that was nothing to do with work and actually then when I started doing research that was having an emotional impact on me I used our sessions, to talk about that . . . (Participant G)

There was strong agreement from all researchers that it would be helpful to have regular access to a counsellor who understood research. For many, this was a considered a necessary "resource":

I do think that counsellors should be available for researchers, not compulsory obviously, if and when the individual researcher feels that they need that . . . (Participant H)

Opportunities to talk about their emotions appeared to be limited for most and a number highlighted that the roundtable had been the first time they had been able to discuss freely these issues:

I think what I am struck by is that we have talked a lot about peer support and this (the roundtable) very much feels like it's peer support but . . . there doesn't seem to be that outside of this . . . (Participant I)

The lack of an established professional space to share concerns was a particular challenge. It was suggested that a sense of professional identity and reflective practices forged through training, would be helpful in protecting researchers:

. . . if you are a clinician there is a kind of expectation of reflection as part of your practice . . . you're professionally trained that that is part of what you do . . . but I don't really get a sense, (that) this is a valuable professional practice for researchers (Participant F)

5.4. Endings: Ownership and Outcomes

The final theme identified in the data was concerned with researchers' reactions to the outcomes of the research. Our analysis showed that as a result the final outcomes of the research took on a particular significance. Some researchers felt particularly discouraged when undertaking research on sensitive topics by their inability to influence the impact of the research, beyond the production of the standard end of study "report":

you feel like you want to give something back in a way . . . you type your findings up and at the end you can send someone a report and that's where I always felt a bit, you sometimes feel a bit empty that you can't do more with your research . . . (Participant J)

Most of the researchers who took part in the roundtable were professional researchers and not clinical practitioners. Their accounts showed the negative emotions they experienced when they felt they were not delivering research that could contribute effectively to real change:

. . . if you are working with these things day to day, then you could have a very direct relationship to the processing of those experiences into strategies of care, care plans, whatever else, but we don't, do we?. (Participant C)

It was notable that those who had been able to ensure that outcomes were meaningfully designed from the outset found this to be emotionally protective:

> *we were clear that there was something going to happen with that; that was written into the project from the outset. Actually for us at least that was quite a heavy protective factor because . . . you are clear about that with the participant . . . you go in and say "this is what this (research) is for" and "are you ok with that?" and actually that clarity of objective I have found really useful . . . (Participant C)*

However, this was not a universal feeling. Many researchers felt that insufficient steps were being taken to cultivate an integrative culture within sensitive qualitative research; these steps should include mechanisms to allow researchers to take a greater role in decisions relating to the research. The challenges of including researchers in the design phase in a world of short-term contract research was acknowledged. Nevertheless, a number of researchers felt they could have been assisted in overcoming some of emotional challenges they encountered by being encouraged by the principal investigator to develop an objective that would allow them to reframe their role to the research:

> *. . . you have got the kind of formal objectives of the research project but also it is fine to have your own personal objectives which may well be related . . . (Participant G)*

This sense of ownership and goal setting were echoed by another participant who recalled how direct campaigning eased the emotional reaction she experienced after speaking to participants:

> *I am much more involved outside in campaigning . . . and I think rather than make that more emotionally challenging for me I think it makes it somehow easier because you feel as though you are doing something as well . . . (Participant F)*

6. Discussion

This roundtable event explored the emotional experiences of qualitative researchers working in sensitive areas. Our findings echo earlier works that have raised awareness of the emotional risks faced by this group [23,25], and supports more recent studies that have called for renewed and substantive attention to protect the emotional safety of qualitative researchers [9,38]. Collectively, these, and other such studies, have revealed some of the unique challenges that face researchers who work in these socially, politically, and sometimes ideologically sensitive areas. However, in contrast to many of the existing studies, our data capture the collective experiences of researchers speaking in a group setting, from a wide range of sensitive research areas, working across a range of disciplines, with a varied career trajectory. Our analysis thus adds updated and broadened insight into this under-researched area. We begin our discussion by examining both the resilience and vulnerabilities of researchers in this field, before examining some of the overarching themes in the data through the lens of the emotional labour theory. We conclude with a series of actions points we believe are supported by our findings.

6.1. Resilience and Vulnerabilities

The individuals who took part in the roundtable were reflective and insightful research professionals, each of whom reported experiencing complex personal and professional emotions in direct response to their work. On a positive note, they demonstrated considerable resilience, and openly discussed the range of techniques they had developed to manage the challenges associated with qualitative interviews on sensitive topics. These reflect the strategies set out in a recent publication about self-care in ethnographic research [39], thus reinforcing the importance of self-responsibility as a key strategy used by researchers to manage their vulnerability and emotions in this field of work. Our researchers had motivations similar to Vincett [39] in being keen to publicise practical strategies for managing emotionality in research. They echoed the concerns of Lee and Lee [9] and Clark and Sousa [38] in also stating that further encouragement was needed to allow other researchers to both acknowledge their emotional reaction to their research, and to assist them in their efforts to develop the capacity for self-responsibility in managing them.

However, their accounts also clearly demonstrated the exceptional emotional burden that continues to be placed on those working in these areas of research; without exception, these researchers thought the work they had been involved in had long lasting and sometimes negative consequences on their mental health. At times, some of the researchers continued to struggle in making sense of their reactions to the research and to those they interviewed, continuing to question their professional abilities for some time after the work had concluded. In addition, some had experienced intrusive and embodied memories long after they had completed their fieldwork. These intrusions are not surprising; Ahmed's [40] work, among others, tells us that fieldwork involves emotional encounters that may become bodily memories. However, the discomfort these unexpected intrusions continued to cause demonstrates how poorly de-briefed researchers were, both on the impact this type of research might have on them or how they might manage this. Furthermore, these revelations are in contrast to the positive 'personal growth' narratives that are so often evident in similar autoethnographic and biographical accounts of emotion in research [20,29]. Our sense, as conveners of the roundtable, was that their revelation within this peer setting reflected both the benefit of group discussion in opening up these issues, as well as the value of the anonymity afforded by the knowledge that the eventual reporting of this data would be undertaken by two authors unconnected to the researchers' original roles and supervisors. This allowed researchers to more comfortably shed their 'cloak of invulnerability' without having to attach it to some greater 'confessional', epistemological purpose and in the safety of knowing there can be no potential comeback from supervisors. This has important implications for those who want to explore the impact of this type of research in the future.

6.2. The Theoretical Position of the Emotional Labourer

As set out at the beginning of this paper, we believe theory has an important and under-exploited role to play in offering researchers a way to both relay and manage their emotional responses to their research. Although researchers continue to be slow to apply the theory of emotional labour to sensitive research [3], there is growing interest in this area (See [7,41,42]) and recent examples have helpfully used it to add to our understanding of the emotions experienced during both fieldwork and analysis [33,41]. We believe the value of this theory in sensitive qualitative interviewing is further supported by our findings around both the emotions that researchers experience when undertaking sensitive research and the responses of their supervision to efforts to communicate these emotions. For example, we argue that the emotion work undertaken by researchers is clearly demonstrated in Theme 1: 'Personalisation' in which researchers attempted to describe the emotions they experienced. Theme 2: 'Professionalism' illustrates the complexity of the emotional labour involved in this work, as these researchers' attempts to regulate and rationalize their emotions clashed with their sense and expectations of their professional identity. The latter theme also sets out how, despite previous acknowledgement of emotional labour in similar situations and within the literature, the researchers undertaking this work had little or no theoretical understanding of its role in explaining and validating their responses to these sensitive encounters. Perhaps more crucially, we believe that the evidence provided in the final two themes suggests that this emotional work continues to be unacknowledged by either their supervisors (Theme 3) or their funders (Theme 4).

Furthermore, our findings in both Themes 2 and 3 suggest that the emotional labour required by researchers is exacerbated by the suppression they must undertake to avoid revealing their 'inappropriate' emotions to their superiors [43]. This is disappointing because shifts in the ideology and attitude of the broader qualitative research community have included repeated and renewed calls for our emotions to be used as an "epistemological tool" [7], (p. 83). However, our evidence shows that there remains a dominant culture of hierarchy within the supervisory relationship, be it between a PhD supervisor and student, or principal investigator and the research assistant, that continues to see emotions in the research process as "suspect" [6], (p. 2). Instead of being seen as an authentic aspect of the research process, and one which can be mobilised through theoretical reasoning, it becomes an

additional burden, one which is borne not only by the researcher but potentially by the researched who may be affected by researchers who themselves have become 'sensitive' to the research.

6.3. The Realities and Professional Position of the Emotional Labourer

The lack of engagement by all parties in the emotional labour involved in this work is further demonstrated by the evidence that these researchers continue to be failed by a lack of supportive leadership. Our data clearly highlights the ambiguous role that was played by the employers of these researchers in providing practical support. Participants at the roundtable spoke forcefully about the need to encourage a new approach to sensitive research that provides external supports for those impacted by their work on these interviews. This aspect of our data is particularly disappointing as these emotional responses and the need for support to manage them, were remarkably similar to those described in other studies of sensitive researchers [25]. In addition, we heard how in the absence of institutional support researchers relied upon family members to provide important debriefing opportunities; many felt they had little or no guidance on providing self-care or obtaining peer support. Worryingly, the lack of meaningful support, or a safe space in which to reflectively analyse their emotions, also meant that researchers became worried their struggles would affect their ability to undertake fieldwork and to protect their participants. Again, this is concerning because as ethics boards have been keen to stress, the participants of sensitive research are potentially vulnerable to further distress from their participation in the research.

The experiences reported here thus clearly indicated that previous recommendations in regard to providing support for researchers have yet to be substantially taken up by principal investigators, or their institutions in the UK [17,25]. Given the increasing evidence of support needs among these researchers, it is perhaps worth reflecting upon why it is that qualitative researchers working in these areas continue to have limited training and support. The emotional responses of these researchers have much in common with those who work therapeutically in counselling settings with clients presenting with sensitive or traumatic issues. Yet within these settings, it is widely acknowledged that such work carries with it an emotional risk that needs to be professionally managed. In addition, research in other areas associated with work-placed trauma has shown that with proper support and professional training, a great deal of this emotional risk can be minimised or avoided [44].

6.4. Responsibility for Supporting the Emotional Labourer

From our findings, it thus appears that complex questions remain about whose responsibility it is to provide support and what that support should look like. We shall discuss each of these areas next. Firstly, in terms of whose responsibility it is to provide support, our researchers' testimonies in relation to the current lack of funds for external supervision, minimal emotional support offered by principal investigators, as well as the lack of institutional level protocols, show that this is not currently considered to be part of the formal conditions of employment. In addition, from a policy level there has not yet been a systematic role for relevant professional research bodies and government agencies in accepting or planning for the potential and unique emotional risks to researchers involved in this type of work [17,35]. As already suggested, this contrasts with clinical fields where supervision is systematically provided to protect the emotional health of professionals and their clients, and in which this need has been set out in relevant policies by associated professional bodies [45]. Our evidence suggests that taking up some of the responsibility for protecting the emotional health of researchers would therefore require a crucial shift in the mindset of leaders involved in designing, funding and ethically reviewing qualitative research in sensitive research areas. Furthermore, for any sea change to be successful, it would need to be clearly embedded within the governance structure and financial decision-making process proposed at the outset of the research design process.

Secondly, in terms of what form the support should take, we have developed some action points in relation to the support needs that emerged from our analysis of the roundtable discussion (Appendix B). We particularly want to stress our recommendations in relation to two areas that were particularly

prominent in the analysis. The first relates to researchers' comments about the absence of a formal community of sensitive topic researchers with whom they could share their concerns and dilemmas. This is something that can be quickly addressed by qualitative research leaders. At the time of writing, we note that some moves to respond to this are already evident within the UK, with the establishment of a number of events relevant to emotions in sensitive research. Our study shows that there are many commonalities among researchers working in sensitive topics, therefore we sincerely hope these events become a routine part of the culture of qualitative research and a formal part of relevant national and international conferences, instead of being hidden within informal spaces [31].

Our second point relates to the power wielded by principal investigators within qualitative research. As our final set of findings revealed, there is a fundamental tension within the supervisory/managerial relationships of researchers in which researchers must juggle their commitment to the research subjects and those of the funders. Mc Queeney and Lavelle [7,46] raised similar issues in relation to critical ethnography and our research shows that researchers from across a range of subjects and disciplines involved in broader qualitative methodologies experienced similar tensions. It has been suggested that attending to our emotional reactions can allow us to gain insight into our position as researchers operating within larger power structures [31]. The emotional reactions described here show that the positionality of the researcher within the research power structure was a source of emotional distress in itself. The emotional impact of this type of research was thus determined not only by interactions in the field, but also by the material they produced from it. They reported strong emotional reactions in relation to having to balance representing the lived experience of participants, with the imperatives of what they perceived to be outcome-driven research. There was some evidence that focusing relentlessly on funder-driven aims made researchers particularly vulnerable to longer-term negative emotions. There were particularly high levels of concern among the researchers about how to manage their personal sense of responsibility towards their interviewees with their status as short-term contract researchers who had little or no long-term job security. To some extent, managing the strategic funding requirements of funders is layered among all qualitative research, not just those on sensitive topics. However, it has been suggested that sensitive topic researchers feel a greater burden in this regard [24]. This aspect is especially concerning in the post austerity research climate within which many researchers now operate [47].

It has been clear for some time that researchers play an important role in the delivery of this type of qualitative research and that their participation has emotional consequences. It is therefore important they feel a sense of confidence in their own mental health, and their ability to maintain this, especially when faced with challenging situations and listening to material they may find traumatic. It thus appears that acknowledgement is needed of the 'coal face' role of the researcher in this process and formal recognition should be given to the emotional toll this may have on them. Their connection with participants is vital in allowing us to link the everyday experiences of those they interviewed on sensitive topics, with the sometimes remote world of report writing and journal article production. Here, and elsewhere, it has been shown that a shared sense of purpose and control over the research process can develop a culture of empowerment for the researcher and this appears critical in ensuring that researchers maintain a good sense of mental wellbeing [48].

7. Conclusions

Over the past fifty years, qualitative studies into sensitive topics have fundamentally changed our understanding of emotional issues that were once considered too challenging and intimate to research. However, these important research studies are only able to deliver valuable knowledge because of the skills and commitment of the researchers who collect and analyse these data. Our study adds broad insight and new cultural context to the area of emotions in sensitive research, and collates the experiences of researchers working across a range of topics.

As qualitative research becomes more popular, and we become more aware of the potential emotional impact of this type of research on the researcher, it is important that we move forward with

our exploration of the issue of emotional risk towards the researcher, in meaningful, practical and non-alarmist ways. Maintaining the mental wellbeing of those involved should be a prime objective for all those involved in safeguarding the research process.

Our conclusions and action points have been developed as a renewed prompt, with the intention of impressing again to leaders in qualitative research, host institutions and professional bodies, that the approach to undertaking research into sensitive topics must acknowledge and manage the potential impact of this work on the researchers. We look forward to, and envision a dynamic process, whereby the inclusion of these supportive elements is an integrative part of the research design process.

Appendix A Topic Guide

- What were the emotional reactions and risks and reactions experienced by researchers and how have these been managed in research projects?
- What aspects of research practice are particularly emotionally risky?
- Was their role in the study impacted by their emotional experiences and reactions and how did they manage this?
- What training did receive in relation to the emotional impact of this work? What training would have been useful?
- What factors impact upon the degree and effect of emotional risk?
- Are certain methodologies more emotional/emotionally risky than others?
- Which theories are relevant to understanding research and emotional risk (self care and management, creating boundaries)?
- How do emotional experiences link with the stage of research?
- How were researchers affected after completion of the project?
- What kinds of supports have they been offered or made use of?
- How useful has this support been—and what factors determine this?
- How do you feel you/others process these emotions?
- What do you do to look after yourself (before/during/after event, ongoing, over time)?

Appendix B Action Points for Qualitative Research into 'Sensitive' Topics

Appendix B.1 Action Points for Supervisors and Principal Investigators

- When developing budgets for funding applications, include costs for external support for researchers.
- Let researchers know what they can expect from the interview/fieldwork stage of the work and brief them on how the issue of vulnerability may affect researchers as well as research participants.
- If appropriate, sensitively explore the researcher's motivation for working in a particular area of sensitive research.
- Work towards creating an environment and supervisory relationship in which researchers can openly discuss the emotional impact of this research both on their personal and professional identity.

- Work with researchers to ensure that outcomes are meaningfully designed, and develop opportunities that allow them to influence the impact of the research.
- Assist researchers in the management of emotions that emerge during the work by using examples from the literature and in particular by engaging them in the concepts of emotional labour.

Appendix B.2 Action Points for Institutions and Funders

- Invest in counselling supervisors who can be available to researchers undertaking interviews with participants about sensitive topics.
- Set up peer support networks within institutions to address issues of isolation among researchers.
- Ensure training and induction packages for research roles involving sensitive research topics, include training on issues relating of self-care and support services available to employees and students.

Appendix B.3 Action Points for Ethics Committees

- Check that applicants have acknowledged and considered both the emotional and physical risks associated with any proposed research into sensitive topics.
- As part of the review process, be mindful of and ask questions about, the particular vulnerabilities and impact on researchers of proposed research into sensitive subjects.
- Ensure research proposals provide researchers with both formal and informal opportunities to debrief, where they are able to freely discuss emotional reactions without fear of professional consequences.

Appendix B.4 Action Points for Researchers

- Acknowledge that research may have an emotional impact in ways that are not anticipated or easily rationalized.
- Keep a research diary to track ongoing areas of concern, identify particular areas of vulnerability and monitor the emotional impact of the research and responses to individual interviewees.
- Seek out both formal and informal opportunities to debrief, where it is possible to freely discuss emotional reactions without fear of professional consequences.
- Ask for supervisory guidance in identifying external, professional peer networks with other researchers undertaking similar research.

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Who else Needs Protection? Reflecting on Researcher Vulnerability in Sensitive Research

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Abstract: Ethnographic research characterised by immersion, reflexivity, and rapport can be unpredictable and uncontrollable, producing a wide range of emotional responses. Much of the literature on sensitive research focuses on ethical requirements and strategies for protecting participants while less attention has been given to the need for researcher protection. In this paper, we share some of the concealed and/or overlooked aspects of researcher vulnerability that are commonly disregarded or under-explored. Based on our fieldwork experiences with a vulnerable population, it considers some of the different ways doing sensitive research with people experiencing homelessness has had an impact on our research team and wider. Specifically, we analyze the emotional impact of distressing and painful research experiences on those directly and not directly involved with the collection of research data (i.e., transcribers and coders). The themes that are discussed include: i) blurring of roles in the field; ii) dealing with heart-rending life stories; and iii) handling emotionally charged experiences. By reflecting on our fieldwork experiences and emotions, we also explore the ways in which emotional impacts can be managed in practice. Strategies for emotion management that have helped us deal with the unique challenges of this research are outlined.

Keywords: researcher vulnerability; sensitive research; emotional labor; homeless people

1. Introduction

The impetus for this article came from first-hand fieldwork experiences revealing vulnerabilities and the need for researcher protection during our research with homeless people.[1] This recognition of researcher vulnerability raised a number of methodological and ethical issues that were not initially foreseen in the approved and funded research proposal.[2] Given the open-ended and long-term nature of fieldwork with a vulnerable group such as homeless people, the research proposal for this study primarily focussed on the protection of research participants. In other words, from the design and planning of all research phases to dissemination, this exploratory study was primarily concerned about the effects of our involvement with and consequences of our work with research participants. However, it became quite apparent in the early stages of this study that it should also responsibly consider consequences for researchers. In sum, although there was a predominant focus in the research design upon managing and protecting the well-being and emotions of research participants, researcher risks were neglected at the outset. This is not uncommon as Kumar and Cavallaro [1] contend that much of the literature on sensitive research focuses on ethical requirements and strategies for protecting

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1   Although the first author is the Principal Investigator of the Croatian team, she is actively involved in ethnographic fieldwork
     for this project.
2   This is an ongoing joint research project entitled: *Exploring Homelessness and Pathways to Social Inclusion: A Comparative Study
     of Contexts and Challenges in Swiss and Croatian Cities* that is a part of the Croatian–Swiss Research Program.

participants while less attention has been given to the need for researcher protection [2–5]. Nonetheless, although our research proposal had sufficiently met the requirements of international and institutional review boards as well as funding bodies, we further felt the need to responsibly address researcher vulnerability in our research.

The reasons for addressing researcher vulnerability are twofold: to protect the research team, especially younger and less experienced members, and to foreground the importance of considering researcher vulnerability issues throughout the research process, particularly in sensitive research. As a feature of the research process, threats and risks to the researcher that make them vulnerable need not be negative but can be methodologically and theoretically productive [6]. Appropriately, these authors argue that researcher and participant dangers are often interconnected and difficult to disentangle. It has also been acknowledged that some dangers are more visible and acceptable than others; serious physical risk has often been the only form acknowledged in accounts of qualitative research [6] compared to researchers' mental, emotional, and psychological safety [7]. Namely, the practical concerns and constraints of field researchers doing sensitive research with vulnerable populations as well as the emotional impact on the research team remains largely invisible in research publications. Rowling [8] notes that nothing had prepared her for the emotionality of the research process e.g., the impact of listening to people talk about their grief, their fears and anxieties, sometimes being expressed for the first time and in times of crisis. Chronic interpersonal stressors such as these can lead to burnout[3] that has been recognised in various people-oriented professions, such as human services, education, and health care [9]. Although acknowledged as an occupational hazard in therapeutic or service professions, this risk also needs to be understood and recognized in research professions. In particular, qualitative researchers engaged in intense contact with people in emotional distress may also be susceptible to burnout. Based on our fieldwork experiences, we would like to share some of the concealed and/or overlooked aspects of researcher vulnerability that are commonly disregarded or under-explored in the literature. Hence, we will draw attention to the ways in which we become emotionally threatened and vulnerable in our research with homeless people. Importantly, we do not negate participant risk in this study[4] but argue that researcher vulnerability and protection should not be ignored.

2. Researcher Vulnerability and Sensitive Research

A number of studies and reports have examined the dangers (i.e., physical and emotional risks) researchers can encounter in the field [5,6,14–17]. Lee-Treweek and Linkogle [6] discuss four main types of danger (physical, emotional, ethical, and professional) that relate to 'the experience of threat or risk with serious negative consequences' faced by researchers engaged in qualitative research. Dickson-Swift et al. [15] found that researchers do confront a number of physical and emotional risks and that training, preparation, and supervision must be taken into account so that risk to researchers can be minimised. An earlier study by Lee explains that a researcher may suffer from isolation, anxiety, stress and depression [16], even in relatively straightforward fieldwork. Beyond doubt, doing research

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[3]   This is defined as a psychological syndrome emerging as a prolonged response to chronic interpersonal stressors on the job. The three key dimensions include overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and lack of accomplishment [9]. A recent systematic review that investigated burnout and its possible consequences in working populations provides relevant evidence of the physical (e.g., cardiovascular diseases and pain), psychological (depressive symptoms) and occupational consequences (job satisfaction and absenteeism) of this syndrome [10].

[4]   In line with more critical engagement in the research process and ethics, one of the aims of this study is to conduct dignified research with homeless people that is non-exploitative and considers ethical complexities and dilemmas at all stages of the research process [11,12]. As homeless people are generally positioned as vulnerable, we acknowledged a need to transform research from a 'top-down' researcher-led encounter to a 'bottom-up' participant-led encounter [13]. In this study, particular attention and effort are given to issues of informed consent, gaining access and trust, reciprocity, anonymity and confidentiality, as well as engaging some research participants as co-researchers in an attempt to create less hierarchical relationships between researchers and research participants.

on a sensitive topic such as homelessness and social exclusion with a population undergoing stress and fatigue is not straightforward. For instance, Lee-Treweek and Linkogle [6] warn that serious threats to a researcher's emotional stability and sense of self are often involved when undertaking qualitative research with participants undergoing stressful life events. Likewise, it has been suggested that researchers may be viewed as particularly vulnerable when working with marginalised people because they will be exposed to emotional encounters that are upsetting and difficult to deal with [18]. Predictably, risks and vulnerabilities for researchers are amplified in sensitive research which is defined by Lee [19] as 'research which potentially poses a substantial threat to those who are or have been involved in it'. Research with homeless people in this study could also be defined as "emotionally demanding research," which is research that demands a tremendous amount of mental, emotional, or physical energy, and potentially affects or depletes the researcher's health or well-being [1].

3. Emotional Vulnerability among Researchers and Other Team Members

In their edited collection, Danger in the field: Risk and ethics in social research, Lee-Treweek and Linkogle [6] define emotional danger as the experience of severe threat due to negative 'feeling states' induced by the research process. They elaborate that this does not just mean feeling uncomfortable, but real distress, which can spill over into other areas of the researcher's life, such as their family and personal relationships or connections with colleagues at work. Researchers have shown that there is potential for distress and trauma among researchers when investigating topics which are, in themselves, inherently sensitive and emotional [4,20–24]. According to Morse and Field [25] the stories that the qualitative researcher obtains in interviews will be stories of intense suffering, social injustices, or other things that will shock the researcher. Shaw [26] notes that when participants retell their story the researcher invariably becomes an actor in the tale and is at risk of emotional distress. Etherington [27] recalls that as a researcher she felt powerless and like a passive bystander after hearing graphic descriptions of violence, neglect, and physical, sexual, and emotional abuse day after day. She explains that as a counsellor she would have been able to use her skills and understanding to respond actively. The emotional drain from listening to research participants' stories and distress for a long period was so great that Brannen believed that 'no psychiatrist or psychotherapist would work (or be allowed to work) under these conditions' [17].

The face-to-face proximity of researchers to people whose stories are heavy with sorrow, loss, disappointment, or grief make it easy to understand that there will be an emotional cost to undertaking these kinds of studies [20]. Campbell [28] reminds us that although researchers are not service professionals they do deal with people on a face-to-face basis and their involvement with research participants involves a considerable amount of personal interaction. Significantly, doing ethnographic fieldwork is an intense embodied experience [29] and it is realistic to expect that researchers may be emotionally affected by the work that they do. From listening to painful narratives or seeing destitution and poverty close-up, these first-hand experiences resonate more powerful and intense meanings.

The emotional impact of distressing and painful research materials on those not directly involved with the collection of research data (i.e., transcribers and coders who may be students) has also been reported. Studies have shown that transcription [30–33], coding [34], and data analysis [32] can also be emotionally taxing. For instance, Kiyimba and O'Reilly [31] explain that transcribing is not merely a neutral and mechanical process, but is active and requires careful engagement with the qualitative data. They conclude that repetition has a cumulative effect on the transcriber and hearing narratives of a sensitive or distressing nature can have an emotional impact. In the words of Warr [33], transcribers are 'absorbing the voices and stories of research,' which may have an emotional impact on them. In a similar vein, Liamputtong [17] concludes it is probable that some transcribers will become emotionally distressed if they have to listen to and type powerful and often distressing stories of the researched participants.

4. Ethnographic Fieldwork and Researcher Vulnerability

One of the difficulties faced by social researchers is that the consequences of lengthy, intense and dynamic fieldwork can be difficult to predict or control. Okely [35] claims that there are no blueprints in fieldwork; it depends on individual inclinations and potential. Fieldwork may range from endless waiting and everyday occurrences to moments and periods of great stress and fatigue. Immersion of this kind may yield the possibility of danger and risk for researchers because they often cannot anticipate anything in advance and may not be able to control what evolves. Linkogle [36] reminds us that 'the researcher must not become so immersed in the machinations of research and the social identity of their profession that they lose sight of their own physical and emotional vulnerabilities.' In a clarifying way, Nilan [5] shows how she struggled to reconcile the combination of two different approaches (i.e., 'formal' methods such as interviews, surveys, and focus groups compared to ethnographic methods) in qualitative social science research. She recognised that the major problem was effectively moving between the two subject positions of researcher in contrasting research paradigms; the first is constituted within a discourse of control, objectivity, even emotional detachment while the second is constituted within a discourse of immersion, reflexivity, and rapport. Nilan [5] concludes that the possibility of danger and risk most commonly arises in the second position of least control and enhanced emotional vulnerability. Referring to ethnographic fieldwork, Okely [35] aptly instructs us that the voices and material lead the researcher in uncontrollable directions; this is *not* a controlled experiment. Importantly, there is a need to reflect on the bearing of the researcher's identity on both the fieldwork and the data since the 'self' of the ethnographer has an effect on every aspect of the research process, especially the gendered aspect of the self [37]. Bloor et al. [20] maintain that women researchers are seen as more vulnerable to sexual harassment, for example, and to the emotional demands of fieldwork. They propose that women are often required to do considerable emotional labor and emotion management in the context of qualitative research and think that this is partly due to the gendered expectations of research participants, expecting female researchers to be sympathetic, interested, and concerned confidantes. Moreover, Bahn and Weatherill [14] suggest that researchers have different perceptions of risk in that differences between risk rankings can vary considerably from one person to another and may be the result of previous past experience or 'close calls'. Thus, the definition of what is distressing differs from person to person and may also change over time and life course events [6]. Although researchers do not experience sensitive research in the same way, the fact that immersion in this type of research can have a number of physical as well as mental, emotional, and psychological effects on researchers needs to be acknowledged.

5. Method

This article draws on detailed field notes from reflexive research diaries kept by the authors of this article. These reflexive diaries were a good way of recapturing fieldwork (i.e., descriptions of people, places, situations, conversations, and events) as well as our reflection on and interpretations of these observations and experiences. In addition, we also recorded how we felt about what was going on during the research process; to capture the emotional impact of the fieldwork experience or interview that otherwise would not be evident in descriptive field notes or a transcript. Special attention was paid to these personal feelings and emotions to identify particular areas of vulnerability and anxiety. Mazzetti [38] reminds us that it is important that there is a safe outlet for these emotions and we found that a reflexive diary is an ideal space for unloading and reflection. Field notes are also helpful because they give us an opportunity to scrutinise our own prejudices and biases as well as positionalities during all stages of fieldwork. In sum, we attempted to include observational, theoretical, methodological, and personal notes in our reflexive research diaries to enhance the quality of our research and analysis. We also had regular de-briefing sessions and meetings as a team and in collaboration with the Swiss research team, which provided us with an opportunity to discuss fieldwork experiences and challenges. All materials were coded thematically, and the selection of quotes presented in this article were chosen to illustrate key themes and turning points during research.

They mainly include: practical and emotional difficulties; fieldwork issues and challenges; research concerns and coping strategies; research relationships and changes; personal feelings, thoughts and emotions; as well as motives, ambiguities, and inconsistencies.

6. Findings

The following section considers some of the different ways doing sensitive research with homeless people has had an impact on our research team and wider. The themes that we would like to discuss include: i) blurring of roles in the field; ii) dealing with heart-rending life stories; and iii) handling emotionally charged experiences. By reflecting on our fieldwork experiences and emotions, we also explore the ways in which emotional impacts can be managed in practice. Hubbard et al. [3] reminds us that the research process is not an emotion-free experience: fieldwork can lead to a sense of euphoria where we feel jubilant and satisfied but it can also evoke feelings of guilt and anger, leaving us upset and miserable. To reiterate, research team members also react differently depending on their positionalities, understandings, empathies, and past experiences. The same research settings may produce diverse and dissimilar emotions in researchers, which are almost always contingent on interactions with research participants. Importantly, the authors of this paper have educational backgrounds in anthropology and sociology but not in social work. For instance, we have not been taught how to establish borders or how to protect our privacy as researchers or how to react if a person breaks down while describing a difficult life situation or how to resolve conflict situations. The following examples elucidate our learning experiences whilst in the field and the diverse ways we can safeguard our different selves.

7. Blurring of Roles in the Field

The younger authors of this paper participated as volunteers in an outreach group that prepares and distributes food to people living in poverty, including homeless persons twice a week in the centre of Zagreb. Although their roles as researchers in an ethnographic project involving homeless people was clearly presented to the organizers and others from the start, blurring of roles did occur. Namely, even though this voluntary role gave them ample opportunity to learn as participant-observers close-up on a regular basis and the chance to establish trusting relationships, there were some challenges. For example, some research participants had 'their own agenda' and only saw these researchers as a way of accessing resources that they needed. Apart from depleting their reserve supplies, financial resources and time, both Stephanie and Suzana began to feel concerned as this was drawing them away from their researcher role. Endless requests for different items of clothing as well as running errands and writing letters of complaint became overwhelming. Suzana's field diary note reveals her frustration and disappointment:

> Although I try to help - Ivan asked me to search some ads for a room with a bathroom for Petar and I will have a look, he also asked me if I could buy some credit for Petar's cell phone and that he'll return this money in a few days ... I didn't question, for a second, whether I should be doing this, but I feel like helping the two of them has become more mechanical and that a true sense of humanity that I feel when communicating with other rough sleepers has been lost. (15th October 2019).

Naturally, we can expect that a researcher may get caught up in their feelings during fieldwork or may feel constrained in their role as researchers because they want to help. Although these young, new researchers are more than willing to help, this did cause frustration and confusion on many occasions for both of them. In a project of this kind, it is only inevitable that we will meet people with different kinds of needs. This may range from simple things such as food, clothes, searching for jobs or a bed in a shelter to more complex, long-term kinds of help e.g., to exit homelessness. Obviously, we all have different boundaries and levels of comfort as well as resources and knowledge.

Regardless of how much support we are willing to offer, we learned[5] that it is important to balance our personal contributions and give 'small' things to avoid dependency, especially since these research relationships are relatively short-lived. It became quite clear that we should always foreground our roles as researchers and never promise anything that we could not fulfil. In the researcher role, we can provide different types of information but should not assume responsibility for these tasks e.g., we can inform homeless people about the locations of different soup kitchens rather than obtaining food for them. On a continual basis, meeting their everyday needs would just lead to learned helplessness. Crucially, we learned that we should not make these 'our responsibilities' because this effectively negates a vulnerable person's agency. Based on this experience, we also learned it is better to suggest the available options but not to propose which one would be the best option. It is not our responsibility to make any final decision for them. We have also learned not to become frustrated if they choose an option that we would not recommend. Moreover, we were mindful that we can provide support (that suits our capacities and possibilities) and motivation for change but that we do not need to feel disappointed if we do not help our research participants or are unable to help.

The second example is also related to blurring of roles and the threat of physical as well as emotional danger. As the need for a business cell number was not foreseen in the research proposal, the younger researchers initially provided their personal cell phone numbers to some rough sleepers. However, as young women they felt quite vulnerable when a couple of men repetitively called them at all hours, day and night. In all probability, these callers were lonely but the timing of these calls also shows that they did not respect their privacy and need for leisure as many of these calls were made outside working hours. Although this problem was promptly rectified before it developed into serious harassment, it did cause some discomfort and stress. Through these experiences, we learned that it is important to establish boundaries to mitigate frustration and ensure safety as well as privacy to researchers. This is essential because a lack of and/or undefined boundaries would have had a profound effect on our future involvement in this research project in the long run. We also learned that it is important to keep channels of communication between research team members open while in the field (e.g., cell phone call-in before and after interviews or walk-alongs) to ensure our safety.[6]

8. Dealing with Heart-Rending Life Stories

Being a detached observer is often not realistically possible when working with vulnerable people experiencing stressful life events such as homelessness. On the contrary, doing fieldwork and interviews with homeless people requires more personal interaction and emotion work to establish rapport, trust, and a close relationship.[7] It has been noted that this emotional labor is widely recognized as an important part of the qualitative interviewer's role and effectively encourages research participants to 'open up' and talk about their experiences [3]. Emotional labor has also been defined as "the labor involved in dealing with other people's feelings" [40]. Incontestably, qualitative research yields rich and complex data but absorbing and processing these research materials can be emotionally draining for any engaged researcher. For instance, fieldwork in this project has been dynamic and intense involving countless embodied experiences. Accordingly, many different types of emotions have been recorded by the researchers directly involved (as well as others indirectly involved). Those that can have an emotional toll on the researcher include: sympathy, distress, sadness, anger, shock, horror, worry,

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[5] Owing to the unpredictable nature of fieldwork and not always feeling prepared in fieldwork situations with persons experiencing homelessness, we recognized the need for professional guidance in the early stages of this project. A social worker, Adrijana Hadžić who works closely with vulnerable groups conducted a workshop for all the members of the Croatian research team. Some of the themes that were covered included: expectations, roles and boundaries; recognizing and overcoming stressful situations; as well as developing and strengthening resistance to stress.

[6] Although we give our research participants the freedom to choose interview locations (that are not hostile or under surveillance) and interview times we as a team also evaluate the dangers of some locations and times.

[7] Studies have shown that homeless people withdraw into themselves and withhold personal information if they lack a space of their own [39] or if they feel they have nothing to gain [12].

pain, and disappointment. An open-ended interview format has definitely given us an opportunity to listen to people tell their life stories but many of these journeys have been heart-rending. Listening to descriptions of homelessness pathways and trajectories with disclosures of painful experiences as witnesses or victims of sexual and/or physical abuse is emotionally demanding. For logical reasons, we have also learned to regulate our emotional responses and to suppress others such as shock, despair, and anger; otherwise this would have had significant effects on our research if not properly acknowledged and managed. Dickson-Swift et al. [41] explain that this active management of feelings is central to research on sensitive topics as researchers often change the way they would normally act while engaged in research. They elaborate that many researchers in their study placed an importance on being professional which may include having to mask a felt emotion in order to manage how they display their emotion to the participant. Typically, these accounts describe a series of traumatic events that evoke distressing images that do not disappear when the interview is over. One concern is that the more vulnerable the research subject, the more likely it is that both subjects and researchers slip into quasi-therapeutic relationships [20]. Although these heart-rending experiences made us highly aware that homeless people generally lack support we also realised that any serious and meaningful commitment would more than likely draw us away from our research work. The other is that we are not trained in counselling or managing other people's distress and not acknowledging these challenges could also affect the quality of our research work.

As a self-care measure, we have been reflectively keeping tabs on and recording our emotional states in a diary. We also openly admit to other team members when we feel emotionally exhausted, without fear that this will be regarded as researcher incompetence. In the literature, this emotional exhaustion is known as compassion fatigue or the 'costs of caring'[8]. In more practical terms, Dickson-Swift et al. [43] also note that emotional labor can lead to physical and mental symptoms such as insomnia, nightmares, exhaustion, depression, headaches, and gastrointestinal problems. Although she initially negates the hardships of working with homeless people, Stephanie records the emotional toll of this work in her field diary:

> When I explain to people what I do, people often say that this is a very difficult theme and they ask me how I manage. I have to admit that I was even amazed at how well I was coping – I'm not insensitive, quite the opposite, I feel empathy and I feel sorry for these people, but it also doesn't "throw me off balance" and doesn't overburden me. I would respond to them in this way. And then, even though I don't think I think about them that much during my free time, I started to dream about homeless people, the situations they are in and the ways I could help them. I dream about them all night – these are chaotic dreams through which one can sleep but cannot rest. (23rd July 2019).

As another precaution, we have also limited interviews to a maximum of two a week for each researcher followed by debriefing sessions with all team members. Apart from discussing the research materials from an analytical perspective at these meetings, this time and space allows us to exchange and compare feelings about our fieldwork experiences in a supportive way. This is an important exercise because we have also become acutely aware of spill over into other areas of our lives, such as family and personal relationships, which do not need to be unnecessarily traumatised and burdened.

Undisputedly, the intense nature and immediacy of fieldwork can be emotionally draining and requires a constant management of self during the research process, especially in situations where there is a high level of expressed emotion. However, this is also applicable beyond fieldwork. For example, transcribing a research interview on a sensitive topic can be an emotional experience for the transcriber who often listens to powerful stories in research on sensitive topics with vulnerable persons. Liamputtong [17] in her book *Researching the Vulnerable* refers to studies where transcribers

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8   Compassion fatigue refers to the emotional and physical exhaustion that can affect helping professionals and caregivers over time [42].

experienced powerful emotions and high stress; they grieved and became angry as the lives of the participants unfolded. For these reasons, we also work closely with other members of the research team such as transcribers and coders by informing them about the interview beforehand if it contains sensitive materials as well as providing them with our ongoing support.

9. Handling Emotionally Charged Experiences

Researchers exploring sensitive topics with vulnerable persons are acutely aware that the interview has great potential to be an emotional experience depending on the research relationship, duration, and contexts. More generally, all fieldwork encounters between research participants and researchers can also be emotionally charged experiences involving traumatic events or moments. A death or a serious injury or illness can have a very strong emotional impact on the researcher and coping with such unpredictable events is often not part of the job description. Handling emotionally charged experiences may require considerable emotional labor, especially if the researcher feels that they lack control. It has been noted that researchers may be viewed as particularly vulnerable when working with marginalised people due to a perceived increased risk of erratic or irrational behaviour on the part of the participant [18]. In research on homelessness, especially involving rough sleepers, researchers need to be prepared for all sorts of unpredictable stressful situations. For example, suicide ideation and responding to this reality that someone might die during fieldwork was a very emotionally disturbing situation for one of the authors who experienced this for the first time. An appropriate response not only demanded her emotional labor but also involved physical or task-oriented labor. She was required to call the emergency health services as a response to this crisis situation even though she was not present 'doing research' at the time. Namely, she received a call from one of her informants who was experiencing high levels of psychological distress; he had already communicated to her that he wanted to commit suicide. As a legal requirement, she also had to inform the police and help determine his exact location. In cooperation with the police and medical staff, she agreed to accompany him to the hospital so that his physical injuries could be treated first. She stayed with him at the hospital all day and acted as a mediator in communications with the police and medical staff who behaved in a professionally correct way towards him in her presence. In the end, despite medical recommendations and all her efforts and support, he refused to be transferred to another hospital to see a psychiatrist. All in all, this was a very stressful experience for all team members, especially for the author directly involved who felt helpless and vulnerable during this ordeal. It was only after these events had passed that she was able to write about them: "*I tried earlier to write notes about this incident, but I had writer's block and I simply couldn't*" (25th August 2019). Through this experience, we learned that we cannot be disappointed if our efforts or suggestions are not accepted by our research participants. In other words, we cannot force or expect them to make decisions that we would make but need to understand the power dynamics at work and that they often cannot control the forces that restrict their opportunities.

10. Strategies for Emotion Management

It has been noted that being new to the field is personally and professionally challenging [44] and that novice researchers are particularly vulnerable to the emotional challenges of sensitive topic research [34]. As Suzana and Stephanie are young female newcomers to this project, the first author's role as supervisor has also been challenging and a source of concern. Inevitably, there is more possibility of danger and risk in ethnographic fieldwork that involves immersion, reflexivity, and rapport.

I have been keeping tabs on them over the months, watching them carefully, checking and re-checking, asking them if everything is all right ... over the phone or at work or whenever we meet. They are usually quite forthcoming about their field encounters with people experiencing homelessness and like to discuss this with me in detail. I know that they have each other but I'm still concerned about their safety and how much they can take and whether they can handle all this intense emotional engagement ... and whether they will be able to cope until the end (of the project). I certainly didn't explain these fieldwork

dangers and complications in explicit detail at the job interview. Being able to cope in all these situations (e.g., suicide ideation, heart-breaking testimony, manipulation, deception etc.) was not part of the job description! I was primarily interested in persons that had had some experience in working with a vulnerable social group and expected them to realise that engaged anthropology on sensitive issues would entail some dangers and risks. At the beginning, I learned that S's mother was quite concerned about her well-being when she started fieldwork with rough sleepers. To preserve's her mother's mental health, S told me that she has stopped sharing 'all' the details with her . . . I feel responsible because I took this for granted and a little bit guilty because I didn't warn them or prepare them properly. It was only when they started to have problems that I knew that I needed to concentrate on these issues more carefully . . . to find further ways of dealing with these unpredictable challenges and dilemmas (September 2019).

Inevitably, encounters with vulnerable people during fieldwork as well as open-ended interviews on sensitive topics can be emotionally draining, producing a wide range of emotional responses. It has been suggested that actually knowing that emotional distress is a natural part of the research experience lessens its impact [45]. Recognising this as an intrinsic feature of sensitive research, Hubbard et al. [3] advise that grant holders/project managers should address the potential impact of emotions on all members of the research team at every stage of the project. Importantly, they point out that the purpose of emotion management is not to learn how to avoid emotional experiences but to learn how to acknowledge and utilize them effectively throughout the duration of the project [3]. Key strategies for supporting researchers, which range from debriefing, writing notes, and to nurturing oneself have been identified in a number of studies [3,32,33,46,47]. To effectively manage emotions, diary keeping or writing field notes has been identified as a good self-debriefing strategy [32,45,47]. Sherry [32] notes that journaling was a key strategy that evolved during her research experience with street soccer participants who were all experiencing disadvantage: homelessness, drug and alcohol addiction, and mental illness. She explains that it provided a timely and relatively effective process of self-debriefing during any difficult or challenging situations. Unquestionably, we can be touched and affected by the stories that we are told or by whatever our other senses collect in the field, regardless of the extent of our experience. Informal and formal debriefing needs to be planned and part of the research process; researcher-support or peer support groups to improve psychological well-being and morale is particularly important in helping researchers to work through difficult issues encountered in the field [3,45,47]. For this reason, in a supportive way we try to be available to discuss with each other any personal or emotional difficulties that evolve in this study. Working in pairs in the field was another strategy that was employed in this study to lessen the impact of such emotional labor. Outside the field, when not engaged as researchers, Kavanaugh and Campbell [46] support the use of self-care strategies that include exercise, relaxation therapies, socializing with other research team members and friends, and in general finding a balance in work and personal life. Overall, besides these stress management techniques the above-mentioned strategies have been useful for emotion management and have helped us deal with the unique challenges of this research with people experiencing homelessness.

11. Discussion

To reiterate, we have shared some of the concealed and/or overlooked aspects of researcher vulnerability in this article that are commonly disregarded or under-explored.[9] Based on our fieldwork experiences with a vulnerable population, we consider some of the different ways doing sensitive research with people experiencing homelessness has had an impact on our research team and wider.

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[9] It should be mentioned here that one possible limitation of this article is that it was written during the research process rather than following completion of the project. As this is a work in progress we have not been able to present the full array of experiences that we will encounter in the future within the framework of this project.

Given the open-ended nature of ethnographic research that is never straightforward, we have drawn attention to how experiences that are emotionally challenging in research may occur unpredictably and might not even be related to the planned or actual research theme. At the outset of this project, we were relatively unprepared for these challenges as no safety measures to protect field researchers and others such as transcribers and coders were envisaged in the design stage of this study. Likewise, institutional review boards and funding bodies that approved this study did not subsequently request strategies of emotion management or researcher risk assessment. Even though taking field notes and keeping a research diary throughout the research process was planned for all research team members involved in fieldwork, assessment and management of researcher risk were not envisaged. In other words, keeping a record of our anxieties, weaknesses, and uncertainties and how we overcame these challenges were not the original intended purposes of these self-reflexive accounts. Conversely, their main purpose was to document the ethical complexities and dilemmas involved in this sensitive research work and reveal when we need to ensure safety or protect our research participants. Despite this first and foremost sense of duty to our participants, we realized quite quickly that we also have a responsibility to ourselves.

Acknowledging and dealing with any difficult or emotionally challenging situation has become a very important aspect of this study especially in relation to the younger, less experienced team members. Lee-Treweek and Linkogle [6] remind us that negative emotions can affect the researcher's sense of self and ultimately the quality of their research. They argue that a central concern is the need to manage the emotions of research participants and not leave them with painful baggage from the research experience but this also applies to the research team. In this paper, we have outlined the various strategies of emotion management that we successfully use to mitigate researcher risks that have been largely neglected in research publications. It is hoped that these strategies will be beneficial to researchers working in similar fields and contribute to what should become standard guidelines and practices in qualitative research.

As emotional challenges are very difficult to predict or eliminate from the field and hinge on researcher's positionalities and field contexts, research crucially needs to be risk-managed from the design stage to dissemination and perhaps even beyond these stages. Significantly, Lee-Treweek and Linkogle [6] encourage us to look outwards to others around for help when it is needed and to be honest about our limits and capabilities when under stress. As Nilan [5] suggested there is more possibility of danger and risk in a discourse of immersion, reflexivity and rapport. For these reasons, we sought and will continue to seek help from professionals when needed. In the same vein, we also acknowledge that as researchers we are not qualified to provide professional services that vulnerable populations often require (i.e., we are not social workers or trained counsellors). Nevertheless, as researchers we need to embrace and acknowledge our emotions because this can lead to important new knowledge and understandings about our research topics, relationships, and processes.

By foregrounding researcher vulnerability issues in this paper we have drawn attention to the impact this can have on the quality of research and research outcomes. Aptly, Hubbard et al. [3] concluded that unless emotion in research is acknowledged, not only will researchers be left vulnerable, but also our understandings of the social world will remain impoverished. They elaborate that a researcher's own emotional response to a respondent's experiences can be used to interpret data and may indeed be a necessary part of the reflexive process. Undeniably, emotions experienced in reflexive research can be insightful and useful as they can potentially shape the analysis as well as understanding of the phenomenon that is being explored. As a final note, we also understand, as Ellis [48] explains: *that there is the vulnerability of revealing yourself, not being able to take back what you've written or having any control over how readers interpret your story*. Nevertheless, regardless of the broad insecurity that writing about researcher vulnerabilities creates, we hope that this article will inspire more discussion in this relatively new and growing field of research.

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