

Article

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, rendering 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 homogeneity 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 Wettergen [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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