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**Innovative approaches to ethical and methodological challenges in health research**

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Qualitative health research about sensitive topics and/or involving people in a position of vulnerability is prone to raise ethical and methodological challenges: power unbalances may unintentionally expose participants to ethical risks by leading them to perceive an obligation to answer research questions that cause discomfort, or to remain engaged in a study from which they would prefer to opt out; legal constraints to revealing one's identity may raise questions to the use of research methods that foster participant interaction (e.g. group interviewing); and the sharing of intimate information hinting at compromised well-being on the part of participants complicate boundary setting and pose questions as to when a breach in confidentiality may be considered. These challenges may cause researchers to feel uncertain and concerned about the right way to act, particularly when they arise unexpectedly. Moreover, they may lead participants to feeling compelled to participate in studies that increase their sense of disadvantage and disempowerment. Conversely, they may limit potential participants' willingness to engage in and keep on participating in scientific studies, causing the circumstances and problems that contribute to their vulnerability to remain unresearched, unknown and unsolved.

Ideally, ethical and methodological challenges would be pre-empted. This purpose may be achieved through a combination of ethical imagination and empirically-based research aimed at anticipating and defining strategies to prevent unnecessary challenges to unfold and clearly outlined pathways to deal with those that cannot be averted. However, professional guidance for ethical practice and population-specific guidelines for health research are not always unequivocal and many grey areas subsist as a result. This symposium aims to facilitate discussion about innovative approaches and study designs developed to investigate complex phenomena in the field of health. It will do so by promoting a transdisciplinary dialogue amongst researchers whose empirical studies seek to unpack the ethical dilemmas and methodological challenges associated with conducting health research about sensitive issues and/or with people experiencing vulnerability.

The four studies selected encompass a myriad of interrelated research topics including fertility, gamete donation and parenthood. Empirical research on these topics lays the groundwork for discussing: 1) ethical challenges associated with interviewing participants in spaces "loaded" with mixed emotions for both participants and researchers; and, categorising participants who do not necessarily identify with categories defined a priori by researchers; and 2) methodological challenges associated with using elicitation techniques to collect data on moral reasoning; selecting a sampling strategy, techniques for data collection and a topic guide to obtain information about the content adequacy of fertility clinics' websites; and, controlling for father's occupation when analysing couple interviews about parenting preterm infants.

**Ethical and methodological dilemmas in mixed-methods research: an empirically-based perspective about gamete donation**

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Research in the field of gamete donation has focused mostly on the dichotomy between the resource-poor countries/conditions of the donors and the richer Western countries' recipients/hosting research projects. Furthermore, most independent studies focus only on the group of donors, with a shortage of original empirical research using mixed-methods. Based on a mixed-methods study that aims to understand how social, cultural and economic characteristics intertwine with the health experiences, knowledge and identities of those involved in gamete donation (i.e. donors, recipients and health professionals), we will explore the ethical and methodological challenges that emerged in connection to fieldwork experiences associated with anonymity, confidentiality, informed consent, researchers' gender and researchers' potential impact on the participant and vice versa.

Empirical evidence derives from i) ethnographic observation in the waiting room of a Portuguese public fertility clinic ; ii) 30 semi-structured interviews with gamete donors ; and iii) structured questionnaires with 23 donors and 25 recipients. The major challenges identified are related with interviewing participants in spaces "loaded" with mixed emotions for both participants and researchers and categorising participants who do not necessarily identify with a priori defined categories. Firstly, due to space constraints in a context where interactions with

gamete donors must occur in the hospital, some interviews and questionnaires were applied in a hospital room also used for sperm collection. The room was usually very cold, the walls are white with only one spermatozoon drawn on it and one red single couch at the corner of the room. Female researchers felt disconcerted with having to apply the questionnaires or interviews in that room right after the male participants had collected the sperm in the same space. Female researchers had to deal with their own discomfort, as well as with the participants' discomfort. To avoid these situations, the room was only used as a last resource. Secondly, when applying structured questionnaires (equal for donors and recipients), researchers were unexpectedly confronted with a man, member of a heterosexual couple diagnosed with female infertility, who did not perceive himself as a recipient, but as a sperm donor for his wife, when answering to the question "What's your currently relation to gamete donation? a) I am a donor b) I am a recipient". Afterwards, we restructured the options for this specific question by "a) I am a donor, b) I am a member of a recipient couple; c) I am a recipient, but I don't belong to any couple".

Unexpected challenges resulting from our fieldwork uncovered issues of gender and ethics in mixed-methods research in a health setting such as a public bank of gametes. These should be acknowledged and discussed by the scientific community. Reflexivity around these ethically important moments and methodological challenges and how they can be overcome should be promoted to enrich the development of innovative study designs and protocols, anticipating future challenges that may arise in research about sensitive and complex phenomena in the field of health.

### **What constitutes parenthood according to (aspiring) parents of children born after gamete donation? The use of elicitation techniques to collect data on moral reasoning.**

Provoost, Veerle (Bioethics Institute Ghent, Ghent University, Belgium);

Medical developments in the reproductive field have enabled a disconnection between genetic, gestational and social ties. In the literature, many divergent moral grounds for parenthood have been suggested, for instance causal, intentional or genetic grounds. The aim of the study was to find out what stakeholders consider to be relevant concepts and criteria that can be used to determine parenthood.

We used semi-structured qualitative interviews with 75 individuals, mostly lesbian or heterosexual couples, 7-10 years after successful insemination using (known-)anonymous donor gametes or around the start of their treatment. Participants' views and moral reasoning regarding the grounds for parenthood was explored among other things by using a thought-provoking hypothetical scenario presenting three protagonists that apply for the parenthood status based on different links to the same child.

Overall, the participants demonstrated a reflective attitude, questioning their own and each other (in couple interviews) views in a respectful way. Many criteria for parenthood were used in ways that appeared entwined. Despite the fact that all couples had one partner who did not share a genetic link with their (future) child, this link was considered an important element: something which a genetic parent had as a plus and a non-genetic parent 'lost'. However, the weight attached to this the genetic link varied and the impact to the status of parent remained difficult to determine. Interestingly, some participants dismissed the social parent pictured in the scenario as a real parent based on this person's lack of a genetic link, despite being in the same situation in relation to their own child.

Overall, the participants' views on the grounds for parenthood appeared to be fragmented, meaning that, in this study, the three protagonists in the scenario could receive the status of parent based on a variety of grounds and relationships to the child. Mostly a complex pluralistic account was used, one that contained many criteria.

Criteria were considered as necessary and/or sufficient, or were used either alone or in combination with other criteria with specific combinations leading to specific outcomes. Criteria could be grounds both for parenthood and no parenthood. The pluralistic account presented by the participants differed from the ones presented in literature: in our study, the participants' accounts involved more complex combinations of criteria and included considerably more criteria than mentioned in the literature.

The findings of the project were interesting both for use in practice (for fertility counselling) as well as for theory (the theoretical debate about the significance of the genetic link between parents and children). Furthermore, the study offers insight into how data can be collected on moral experiences, moral reasoning and decision-making. In this presentation, we will also go into the features of this particular way of collecting interview data and the methodological questions relating to the use of interviewing techniques such as elicitation of moral reasoning. Finding suitable methods to collect data on moral reasoning is one of the main challenges related to qualitative research in moral science.

### **Contents about gamete donation on IVF clinics websites: how to assure that the information provided meets people's needs?**

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