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Should prenatal screening be seen as ‘selective reproduction’? Four reasons to reframe the ethical debate

Short title: Prenatal Screening as ‘Selective Reproduction’?

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Abstract

There are a number of problems with the classification of prenatal screening as a form of ‘selective reproduction’ that has become an increasingly dominant classification scheme in the last decade. [1] Since the term ‘selection’ implies choosing one out of several (at least two), it misdescribes the decision to terminate a pregnancy. [2] Deciding whether to have this child is a decision taken within the relationships that constitute the pregnancy. [3] ‘Selection’ is a loaded term, connecting prenatal diagnosis to negative eugenics or to population genetics. [4] Deciding against the birth of a child who would suffer or would not be able to flourish is a decision taken within a negotiation of personal responsibilities. The characterization of prenatal screening as selective reproduction is, in a very narrow way, defensible to reconstruct why prenatal screening is permissible in a liberal state and should not be banned, but it needs to be rejected as a general frame for understanding the substance of the ethical issues around prenatal diagnosis and screening. Ethics should rather attempt to create a respectful space of mutual understandings and reflect how women and couples, who are ultimately responsible for these decisions, perceive their responsibilities in care.

Key Words

Ethics, Prenatal Screening, NIPT, Prenatal Diagnosis, Genetic Counselling

Introduction

Triggered by Stephen Wilkinson’s seminal work of 2010, the liberal bioethics literature within the past decade has adopted the label of ‘selective reproduction’ for classifying the choices occasioned by technologies such as prenatal diagnosis (PD) or prenatal screening (PS) – with or without non-invasive genetic tests (NIPT), and, hypothetically, also germline genome editing (GGE). What these choices have in common, so it is claimed, is that people attempt “to create one possible future child rather than a different possible future child” because one is “in some way, more desirable than the alternatives” [1, p. 2]. Health is seen as the most uncontested criterion of desirability. (Who would not wish their child to be healthy?) This characterizes the special type of choices that are essential for PD, PS and GGE and preimplantation genetic diagnosis (PGD), sperm or egg banks. This classificatory scheme has become what Simon Reader called the “orthodox liberal eugenic view of selective reproduction in philosophical bioethics” [2, p. 25].

For people who decide about actions the words matter, which they use to describe and understand the practice in question. In ethics, the categories we use to classify and characterize the meaning of an action or a decision make a difference. It is not technology alone that determines the purpose of its use. A ‘social practice’ is created as a shared meaningful behaviour that ‘one does’ in a society and for which one deserves justification or praise. In the sociology of practices a ‘social practice’ can, according to Schatzki, be broadly described as “a nexus of doings and sayings” [3, p. 25]. A practice is not only an established way of doing things but also an established way of understanding the meanings of what one usually does in certain situations [4]. Words define how we understand what we do; shared words are part of our communicative ascertainment. Therefore, inherent in a social practice is also a hermeneutics operating within a shared social world. The words used are part of that practice. A label such as ‘selective reproduction’ itself needs to be scrutinized from an ethical perspective; sensitive categories such as ‘selection’ come with narratives attached. Their meanings (i) frame the ethical discussion in a particular way, and also (ii) shape the moral understandings in individual decision-making.

Advocates of prenatal diagnosis since the 1970s have categorically rejected the accusation of a ‘eugenic’ drift, and have instead positioned PD and PS as grounded in women’s right to freely choose whether they wish to give birth to a disabled child [5, p. 71]. Language that connects the practice of PD/PS to the frequency of ‘defective’ genes in a population and to a practice of selection has been carefully avoided. In 2001 Sheldon and Wilkinson used the description “selective termination of disabled foetuses on the grounds of their disability” in a paper that defends the legality of free choice about all abortions, “regardless of any foetal disability” [6]. Wilkinson later generalized the idea and formally introduced “selective reproduction” as a category of practices that covers PD, PS, NIPT, GGE and more. The appeal of this term is that utterly divergent technologies and actions share one common denominator: they allow for selective choices about future children based on genetic characteristics. The broad definition allows for argumentative economy. If we answer the question ‘Is selective reproduction permissible?’ we will at least have the principle of an answer for all the particular technologies so classified.

However, this approach, I will argue, does not convincingly characterize the ethical gist of the situation and the moral point of view of a woman or a couple confronted with the decision about termination after PD/PS. Used as a general framing of the morally complex ethical issues of PD/PS, ‘selective reproduction’ is a rather troubling concept.

Acts of selection

In ordinary English, the word ‘selection’ is used to name an act or a process of selecting. ‘To select’ (lat. *seligere*) is the basic verb. It means to choose from a number or group [7, p. 2058]. A number or a group is more than one. Based on this definition, it would be simply wrong to call the decision to terminate a pregnancy on the grounds of a prenatally diagnosed disability a selection, since there is not more than one future child from which the woman or the couple could choose. At the time of decision-making after a prenatal diagnosis, there is only this one future child to decide about. The woman in this situation has two *options* to choose from – to terminate the pregnancy or to continue it and to give birth – but she does not have two children to choose from.

She might indeed wish to get pregnant with another child afterwards and the couple might hope that the new pregnancy will lead to a child without the disability. But she cannot decide at that moment about this, since it is a matter of wishing and planning. In the temporal mode of *futurum passatum*, anticipating a future in which she could look back from a point in time after the birth of another healthy child, she could describe her conduct in the long run as selection: as a result of a sequence of actions going through two (or more) pregnancies, she has had an able-bodied child rather than one with a disability, and in this sense she has selected. But it is inaccurate to describe the decision she makes at this point in time as a selective practice.

This analysis of the concept of selection is notably not based in a criticism of PD/PS as ‘eugenic’. It only focuses on the options available in a situation. Using the description ‘selective reproduction’ despite its inaccuracy falsely attributes an overarching selective plan to a woman/couple who may make a decision while feeling deeply troubled and conflicted.

This can be illustrated by one woman from a comparative interview study we conducted in Germany and Israel with women and their partners who had either used or refused to use NIPT [8, 9]. Ute, a German woman who had used NIPT, explained it by referring to her husband’s sister who was 38 and had a severe form of Down syndrome:

“... I have known her for 5 years already, and (.) well, this has ... a big influence on me, so that I just see a life I wouldn’t want for me, wouldn’t want for my child.” (#40 Germany, lines 215-218)

The narrative that she gave about her decision was not built around any selective purpose whatsoever, and she did not express any rejection of her sister-in-law.

“Well, I believe my sister-in-law is quite happy in her world, but her world is not connected to our world.” (line 216 f.)

She and her partner had instead thought about what they were capable of and they felt, as she said, that she just could not wish *this* life on herself and her child.

In the process of PGD, however, there is indeed a choice to be taken from a number of embryos created previously *in vitro*. The term ‘selection’ could be used correctly to characterize the decision that must inevitably be taken during PGD: after each embryo in the laboratory is tested, one or more are selected to be implanted. But the term ‘selection’ may still be alien to the motives and intentions of the couple who, like Ute with PD, use IVF plus PGD because they have reasons to fear having a child with a severe genetic disorder and do not want *their* child to be affected by it. If this is so, they are not practising ‘selection’ either, even though they are not deciding to use PGD during an existing pregnancy, as is the case in PD/PS, but before establishing a new pregnancy, often after the experience of one or more miscarriages.

A reconstruction of Wilkinson’s argument

In the bioethical literature on reproductive genetics, ‘selection’ has appeared mostly with a negative overtone – as a name for a problematic development. Asch and Barlevy, for instance, begin their encyclopaedic formulation of the ‘disability critique’ of prenatal testing with this statement: “Selecting against embryos or foetuses on the basis of predicted disability reinforces the belief that disability is inimical to a worthwhile life.” [10, p. 1] They use ‘selection’ as a key descriptor, emphasizing its ambivalence: one future child is selected to be born, while another is selected out. This, according to their main argument, reinforces the belief that a life with disability is not a worthwhile life. The essence of the disability critique is not that PD/PS itself is discriminatory, nor, as has frequently been claimed, it consists in the ‘expressivist argument’: sending a negative message to those living with disability. Rather, it is “the mistaken belief that disability itself, not the social discrimination against people with disabilities, is the problem to be solved.” (p. 2). Ilana Löwy, writing from the perspective of a historian, also sees selection as problematic, as she considers public debates on PD to be “frequently centred on the risks of a gradual and imperceptible sliding into increasingly selective reproduction.” [5, p. 186] Selective reproduction, in her take, characterizes an undesirable state of societies where the “backdoor to eugenics” is opened by the individualized “parental dream of a perfect child” (*ibid.*). This problematic state could emerge unintentionally: societies could gradually and imperceptibly “slide” into it.

It is therefore surprising that Wilkinson starts his discussion with a formal definition of selective reproduction, using the term without reservation:

“By ‘selective reproduction’ I mean the attempt to create one possible future child rather than a different possible future child. The reason for wanting to practise selective reproduction is normally that one possible future child is, in some way, more desirable than the alternatives.” [1, p. 2]

Instead of dismissing Wilkinson’s argument on the grounds that it misrepresents PD/PS from the perspective of the woman or the couple, I acknowledge that it argues on a different level. He does not focus on individual decision-making at all but on the laws that regulate them. Unlike Glover for instance, who has treated the question of whether using “genetic and reproductive techniques to have a healthy child rather than one with a disability” is “justifiable” [11, p. 5], Wilkinson asks whether laws should allow or ban this practice, regardless of the motives individuals may have for using PD techniques, and without judging whether it is justifiable for them. “Permissibility” is therefore the term of choice. While *justification* works on the level of the actors involved, *permissibility* works on the level of regulation, which needs to tackle this question: are there sufficient reasons to forbid the action regardless of the actor’s motives?

Within a Millian liberal approach to legal philosophy, an action is “permissible (neither wrong, nor obligatory, nor supererogatory) until an argument can be found that shows it to be otherwise.” [1, p. 13] This is what Wilkinson calls the ‘presumption of permissibility’. The task of an ethical analysis on this basis is then rather negative: to search for arguments that might overturn this presumption. As long as none can be found, the action should be permitted. If this method is to produce a reliable result, it of course needs to examine counterarguments (i) comprehensively and (ii) each in their strongest possible form. To do so, Wilkinson could argue (iii) it *should* not assume that the actors all have ethically justifiable motives. They just may do what they prefer to do for whatever reason. Applied to reproductive genetics, we may assume that with the routine use of NIPT, social expectations are changing and societies may indeed “slide into” selective reproduction on the basis of predictions of disease and disability; parents indeed intend to ‘replace’ a terminated pregnancy with a new one and perform sequential selection (the term ‘replace’ has been suggested by Tarkian [12] to interpret Wilkinson’s definition). Therefore, we may concede that the use of the term selection, *even though* inappropriate for many parents who have no selective intentions whatsoever, may therefore be warranted as a realistic description of the practice.

I would therefore reconstruct Wilkinson’s argument about PD/PS in the following way:

- Premise A: PD/PS is a form of selective reproduction.
- Premise B. Selection to avoid disease or disability is mostly uncontentious.

- Result of a comprehensive vetting of objections: There are no concerns strong enough to oppose permissibility of selective reproduction.
- Conclusion: PD/PS to avoid disease and disability should be allowed.

The most difficult and ambitious step is the third. Wilkinson tackles a number of objections that have been raised in the debate: eugenics, the equal value principle, harmful consequences for those living with disabilities, the expressivist concern and more (space does not allow me to go into the details of his discussion). None of these arguments proves strong enough to justify forbidding selective reproduction. Going further than Mill, who allows only harm to others as the single criterion for the validity of an objection, Wilkinson allows two more criteria: exploitation or instrumentalization. Most forms of selective reproduction do not harm others, and do not exploit or instrumentalize anybody. Hence, since according to Premise A, PD/PS is one form of selective reproduction, PD/PS should basically be seen as permissible.

Beyond liberalist individualism: responsibility and inclusion

The same argument could be made about PD/PS directly, without using Premise A. Permissibility of PD/PS then does not depend on its classification as selective reproduction. Wilkinson obviously wanted to achieve more than justify the legality of PD/PS alone - to argue for the legality of any form of liberal eugenics, in the widest possible meaning of the term, as long as it does not harm children or other people, or exploit or instrumentalize them. The argumentative thinness of his liberalist approach however reduces the scope of ethics. It reduces the sensitivity to the changes in intergenerational relationships both in families and in societies. Not all that is ethically relevant, that affects justice and a good life, can be captured by harm, instrumentalization or exploitation. As I have argued elsewhere [13], GGE needs to be analysed in the light of the shifts in the moral constitution of intergenerational relationships that it would effectuate, if widely used. Previous generations would assume responsibility for the genetic constitution of their offspring, and also for those parts of the genome that are not altered, for all the good and bad that is in a genome. This could possibly create new forms of injustice and intergenerational guilt.

There is also much more to say about autonomy than the liberal individualist approach allows for. Autonomy in the context of abortion is essentially an embodied and relational concept [14]. As Mianna Meskus has demonstrated in a qualitative study [15], the expectation that they will make autonomous decisions about pregnancies and be responsible for a 'personalized ethics' can be perceived as a heavy burden by women who have to make

these decisions. They are vulnerable in many ways: to social pressures, demands from their families, or expectations of their healthcare providers. If they have a test mainly for reasons of conformity, perhaps without thinking twice, and subsequently find themselves inadvertently in a difficult situation where they have to decide about termination, they are arguably harmed. If society started to treat women as producers of only healthy progeny to fulfil a social demand, counting on their ‘autonomy’, it would come close to instrumentalization. On the other hand, PD/PS would also harm people with disabilities if societies used it as an excuse for making less effort towards support and inclusion. If the routinized use of PS (triggered by the perceived easiness of NIPT) leads to an even more black-and-white social idea of disability, without seeing the good of variant forms of embodiment [16], one can argue that a social practice of PD/PS is at least strongly ambivalent. This in turn would reduce the well-being of children with disabilities and put more pressure on women to avoid giving birth to a child with a disability. The two factors are therefore related: (1) freedom of decision-making (which presumes adequate information, communication and support, and (2) social inclusion of those who live with the conditions PD is testing for [17, 18, 19]. If both criteria are satisfied, it would be difficult to argue for banning or restricting access to PD. The other side of the coin is however that, if PD is practiced and improved, societies create two mutually related social obligations: (1) to respect and support women’s free decision-making, while improving the conditions of decision-making wherever needed, and (2) to improve inclusion of and support for people with disabilities, in order not to create moral pressure to spare a child with a disability suffering because of insufficient support and inclusion. Without satisfying these social obligations, reproductive autonomy slides into a cold ideology of individualism: instead of caring for each other, societies would place this unpleasant responsibility onto pregnant women who then have to carry the burden of taking what Rothman has aptly called “impossible decisions” [20].

Problems with the ‘selective reproduction’ frame

In order to discuss permissibility in a liberal framework, it might be necessary to a certain extent to disregard the motives people might have and to focus exclusively on the evaluation of possible reasons to restrict individual choices. This way of clarifying permissibility however *cannot* help to understand the moral questions and conflicts in the actors’ perspectives, which constitute the situation of women who undergo PS/PD and their partners. They will ask themselves how to justify their decisions. To discuss this requires considering not just the legal and moral rules, but also the meanings that are connected to the

practice on which they are reflecting. It is here that I see the main problem with the framing of this practice as ‘selective reproduction’.

First, the decision about a pregnancy is inaccurately described by the term ‘selection’. It is not a situation where a choice is made between multiple pregnancies or several possible children, but primarily about one ongoing pregnancy, on the basis of available information about the future living conditions of the child. Termination of a pregnancy is not ‘replacing’ one possible child by another but terminating one foetal life. One can hope to have a next pregnancy, but this will be *another* pregnancy. Therefore, ‘replacement’ and *a fortiori* ‘selection’ are terms that do not work from the actors’ perspectives.

Second, this is not only a terminological issue; the description is also an obstacle for the woman or the couple that distracts them from seeing what is at stake in their situation. The assumptions underlying ‘selective reproduction’ are ethically problematic, since they shift the attention away from the special character of the very relationship that makes up a pregnancy. Pregnancy is not an abstract relation to plural future children, among which one could choose, but a genuinely particular and irreplaceable relationship (for a similar argument contra Tarkian, see Mitscherlich-Schönherr [21]; on relationality of pregnancy and birth, see Schües [22]). For the woman and the couple, an answer that can convince them morally must include this existential situation of pregnancy. If a woman imaginatively positions herself as performing ‘selection’ in her dealing with her pregnancy, she is adopting a point of view outside of her pregnancy, looking back at herself from an abstract population point of view. If she, or the couple, bases their thinking on this constructed ‘gaze’, they risk making a decision that disregards their existential involvement and would not be convincing in retrospect.

Third, ‘selection’ is a loaded word. It explicitly connects decision-making about PS/PD either to (negative) eugenics, which is exactly what the professional ethics of human genetics constantly argues against ever since the introduction of amniocentesis (for the specific cultural context of German bioethical discourses, see [23]). It would support reductionist thinking of disability as a person’s main feature. Or it would connect the situation of decision-making in a pregnancy to problematic social Darwinist theories.

Finally, the ethical difficulties in the decision against the birth of a child who would suffer and not flourish are rooted in the conflict between responsibilities to the child to be born, and responsibilities to oneself and one’s family. To understand and resolve this difficult conflict as carefully as possible, the selective reproduction frame is not helpful. It is rather an obstacle to addressing this conflict of responsibility adequately - both individually and philosophically.

Conclusion: reasons to reframe the debate

In the emerging social practices of PD/PS, both doings and sayings matter. ‘Selective reproduction’ is a problematic conceptual offer to people who decide about or practice PS/PD. While ‘selective reproduction’ can well be used as the name for a field of comparative anthropology investigating the emerging social practices of reproductive genetics [24], there are more ethically relevant questions than the one about the permissibility of a practice. Bioethics needs to deal with all levels of social practices of technology use: the regulatory and the individual, the social and the intergenerational, its place in national history and the comparison with other traditions. It needs to address and acknowledge all perspectives involved: the professionalism of physicians and experts involved in reproductive genetics, the concerns of women and their partners, the perspectives of families and their generations, and of course the regulators’ arguments that raise controversy in different cultural contexts. Such an ethics creates a respectful space of mutual understandings and public deliberation that helps to make ‘personalized ethics’ [15] a less solitary enterprise.

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