

Opinion Paper

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Non-invasive prenatal testing (NIPT): does the practice discriminate against persons with disabilities?

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Abstract: The most well-known goal of non-invasive prenatal testing (NIPT) is still to determine whether or not a fetus has trisomy 21. Since women often terminate the pregnancy upon a positive result, there is concern that the use of NIPT contributes to discrimination against persons with disabilities. If this concern is justified, it could have an impact on the wider social acceptability of existing testing practices and their potential further expansion. This paper demonstrates four different versions of the discrimination worry, indicates how international policy papers have reacted to them, and identifies the ethically most relevant feature of the concern.

Keywords: Down syndrome; non-invasive prenatal testing (NIPT) discrimination; trisomy 21.

Introduction

The results of non-invasive prenatal testing (NIPT) can create difficult decision situations for prospective parents. The most well-known scenario of this kind is still the case of a test result indicating that the fetus has trisomy 21. While some prospective parents ultimately use such a result to prepare themselves for the arrival of a child with special needs, others decide to terminate the pregnancy. Since the non-invasive character of the newer test methods reduces the risk of health impacts for mother and child, there is a perception that the use of such tests will continue to increase and bring along with it a corresponding increase of pregnancy terminations. As a result, there have

been a number of ethical concerns raised against the use of NIPT. One concern – which shall be the focus of this paper – says that terminations due to prenatal test results will contribute to the stigmatization of and discrimination against persons with trisomy 21 and other disabilities. In addition to individual medical ethicists, this worry has been addressed by a number of national ethics councils [1–5], as well as a report for the World Health Organization [6], a report by the UNESCO International Bioethics Committee [7], and a joint position document by the European and the American Societies for Human Genetics [8]. This paper distinguishes between a number of different versions of the discrimination charge, introduces possible responses, and identifies the ethically most relevant feature of the concern.

The various facets of the discrimination charge

The discrimination charge can take on a number of different forms. These forms should be clearly differentiated, since ethical analysis and preventive measures might have to take on different forms depending on the exact aim of the criticism. There is a claim (i) that such decisions will lead to discrimination against persons with disabilities, and (ii) that the *parents* of children with disabilities will face increased stigmatization and discrimination (the common use of the term ‘disability’ is not intended to suggest that the controversy on whether there is a coherent individual or social account on what constitutes a disability has been resolved [9], or even just that there is a consensus on the assumption that a disability is a negative or undesirable trait [10, 11]).

There are also concerns about (iii) the *decision to end/prevent* the existence of a fetus with a disability, and (iv) the *psychological effects* of such decisions on individual members of society with a disability. In the following, I will provide a description and subsequent discussion of these four claims.

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- (i) The first version of the argument says that persons with disabilities might face increased discrimination as a result of NIPT. While such discrimination could in principle take the form of intentionally hostile behavior, there seems to be a stronger concern about indirect discrimination in the literature. In particular, there is a worry that it might become harder for persons with disabilities to find specialized health care experts [4]. If fewer patients with particular needs exist in the future, this might lead to fewer medical experts in the field and subsequently to lower-quality healthcare. This would be a form of indirect discrimination: no one would willingly try to worsen the quality of healthcare for persons with trisomy 21, but it would be an indirect effect of the lower demand. Arguably, similar negative effects could also occur in other social domains that have an impact on the lives of persons with disabilities, for example in the realm of education.

The most common reaction to this worry consists of arguing that the quality of healthcare for patients with disabilities has actually improved. Their life expectancy has increased and there has been progress in the treatment of some related health problems [12]. In addition, their social rights have been continually expanded [1]. Nonetheless, policy papers tend to emphasize that such developments should remain under surveillance [2–4], and some of them see the need to stress that society has a general responsibility to ameliorate the living conditions of persons with disabilities [3–5, 13].

- (ii) The most commonly voiced concern regarding the *parents* of children with disabilities is that they might be blamed for having a child with a disability [4], that they might be faced with attitudes that the social responsibility for their children should primarily lie with them, or that their children should live more or less separately from the rest of society [1]. There is a consensus in the medical ethics literature that such reactions and attitudes are entirely inappropriate. Even though this may still occur occasionally, it is often argued that there is no empirical evidence that there is now more discrimination of this kind than before the introduction of NIPT. Quite to the contrary, there is reason to believe that the social acceptance of children with disabilities has actually increased [1].
- (iii) Another version of the discrimination charge says that a termination of a wanted pregnancy on the mere ground that the fetus has a particular genetic trait implies illegitimate discrimination [14]. Obviously, there are comparatively few things that prospective parents can already know about their child. If they base a termination decision on the information that

there is a disability, this seems to be a paradigm case of negative treatment due to disability.

The most common objection to this worry says that such a termination is *not* discriminatory if it occurs on the ground that the parents want to make use of their reproductive choices or because the mother believes that she would not be able to take care of the special needs of a child with a disability. In other words, the reason or the intention behind the action can be a self-regarding one. Such a reason is different from a negative assessment of persons with disabilities in and of themselves, and it is often emphasized that it should not be taken to imply such an assessment [2, 3, 5, 8]. This view is a central point in statements supporting the use of NIPT.

- (iv) A further version of the discrimination charge concerns the fact that terminations of pregnancies after NIPD will have a negative effect on the mindset of children and adults with such disabilities. This concern has been to some extent confirmed by empirical findings. According to a small study by the Nuffield Council, for example, persons with trisomy 21 often feel sad about the fact that some people do not want to have a baby if it has Down syndrome, even though many of them also believe that a woman should have a choice about this. More generally, they report experiences with negative discourses about disability as well as a lack of knowledge about and fear of Down syndrome [15].

The concern about mindsets comes in at least two different versions. One of them is the so-called expressivist argument according to which – irrespective of the actual intentions of the prospective parents – these decisions send the message that lives with disabilities are not worth living [11]. The meaning of such terminations can be taken to include the conviction that it would be better if these disabilities – and the persons who have them – would not exist. A common reaction to this version of the argument consists of referring, once more, to the different possible motivations, intentions or reasons for termination. Arguably, the reason for termination can be the mother's anticipated lack of her own abilities and not a concern she might have about persons with the particular disability [11].

The mindset of children and adults with disabilities might also be affected in a further way, however. The mere thought that some women decide that a child with a disability like their own would be such a burden on them that they prefer for the child not to exist could be hurtful to persons with disabilities. This version of the charge does not imply that types of actions can carry meanings, and it is independent of whether or not the hurtful feeling is viewed

as justified or not. Reactions to this concern tend to vary. While even some liberal authors concede that this is the most serious problem that NIPT can give rise to [14], others have argued that wanting a world without disabilities does not imply the hurtful claim that certain people should not exist, but that it would be better if they did not have a disability [16]. Policy papers tend to react similarly to these worries than to version (iii) of the argument. They tend to suggest that efforts should be made to emphasize that the permissibility of NIPT and subsequent pregnancy terminations is not geared at producing a lack of appreciation for the existence of persons with disabilities [2, 3, 8].

Discussion

With regard to versions (i) and (ii) of the discrimination charge, there does in fact seem to be an ethical consensus that such forms of discrimination are illegitimate, that the situation should be monitored, and that measures should be taken in the case the situation turns out to be problematic. It should be added that there sometimes seems to be a tendency not to distinguish between discrimination as directed against persons with disabilities and discrimination against their parents. Targeted measurements against particular forms of discrimination always depend on a careful and differentiated analysis of their exact character. While parents of course tend to share the interests of their children, they are bound to be more involved in organizing a social support system, while the children might be more directly affected by the behavior of their individual teachers, neighbors or physicians.

Nonetheless, if the empirical findings are correct, the situation has improved rather than worsened during the more widespread use of NIPT. A plausible reason for this could be that it has become known that the birth of children with trisomy 21 is now more likely to be the result of a fully informed welcoming attitude by their parents. At the same time, they are more likely to be born to well-prepared parents who have had a chance to look for additional support before their birth. If the empirical findings are correct, then further versions of the discrimination argument currently have to be viewed as more important regarding the ethics of NIPT.

Version (iii) of the argument is ethically more controversial. As mentioned before, the most common reaction to the worry that the termination of a pregnancy due to a disability of the child might be discriminatory is the

distinction between a self-regarding judgment of the mother and a judgment about the disability of the unborn child. Critics of NIPT might be weary of this distinction. Human motivations, intentions and reasons can be diffuse, and it might be difficult for prospective parents to determine whether the intention behind a termination might be a thought such as “it will be too difficult for me to take care of a child with this trait” rather than “these traits of the child are a problem”. At the same time, though, it is by no means easier to guess at the exact character of an intention from the outside, and putting couples under general suspicion appears problematic as well. Arguing that the parents are unaware of their real intentions is a possible line to take, but since most parents are thoughtful individuals, and the ambiguity of intentions is a general problem including contexts outside of pregnancy, this line of argument can appear morally arrogant.

Perhaps one could still ask how the situation should be assessed if a woman claimed explicitly that she wants to terminate her pregnancy because she believes, “the disability of the child is a problem in and of itself”. This would appear to be a paradigmatic case of discrimination. The discrimination feature would indeed seem to make such a decision worse than a termination on other grounds. Moreover, in contrast to terminations on other grounds, here a couple *wants to have* a child. The decision does not occur on the ground that no child at all is wanted, but on the ground that a child *with this trait* is unwanted.

However, it should be kept in mind that the permissibility of pregnancy terminations implies that the fetus has a lower moral status than a child or adult. This lower status implies that the fetus does not yet have an equally strong right to life. This lower status, if one accepts it, also implies that fetuses do not yet have an equally strong right to non-discrimination as children or adults. In other words, there is a dependency relationship between one’s view about the permissibility of abortions in general and the permissibility of prenatal discrimination. If one takes the former to be permissible, it would not be convincing to treat the latter as a decisive argument against abortion. The thought that the potentially discriminatory character of the decision to terminate a pregnancy makes the decision worse seems to be contingent on the premise that fetuses have a rather high moral status. Under this condition, it can be argued that the decision is morally objectionable in two ways rather than just one. This dialectic demonstrates that some of the objections that are voiced against NIPT actually turn on a view about the moral status of the fetus and the

permissibility of abortions in general rather than of NIPT in particular [16].

Lastly, version (iv) of the argument concerns the effects on the mindset of those living with disabilities. The claim that pregnancy terminations after NIPT can be hurtful to persons with disabilities seems to be related to a reaction that any person can experience when finding out that their parents were considering an abortion. It is likely that parents generally hesitate to tell their (adult or minor) children about any such past deliberations. The hesitation seems to be due to the hurtful feelings potentially created when thinking that one's very existence was once called into question. The realization that, at the time, one was in many essential ways "not there yet" might simply not be compelling to one's offspring at all times. A life-shaping genetic disability as the only known feature of a fetus might increase the temptation to identify that fetus in some fundamental way with a potentially existing later adult with that disability, and might thereby make the case even less compelling. Even though the question of identity cannot and should not be reduced to any disability, the strange appeal of this conflation might make the concern about a hurtful message towards persons with a disability particularly difficult to engage with.

To summarize, there are a number of different versions of the charge that NIPT could have discriminatory effects. The worry that it might make the lives of those living with disabilities or their parents more difficult seems empirically false. Their living conditions seem to have generally improved rather than worsened during the time period during which NIPT has become available. The further concern that the termination of a pregnancy upon NIPT is a paradigmatic case of discriminatory decision seems to depend on the moral status of the fetus. This leaves potentially hurtful effects on those living with disabilities as the most difficult to assess. The plausibility of this version of the charge depends on the plausibility of distinguishing between various possible reasons or intentions of those making use of NIPT, on intricate philosophical views about the relationship between existing (or non-existing) living humans and fetuses, and on psychological coping mechanisms among the members of a vulnerable group.

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