Opinion Paper

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Moral ambivalence. A comment on non-invasive prenatal testing from an ethical perspective

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Abstract

Background: Non-invasive prenatal testing (NIPT) has been available for almost 10 years. In many countries the test attracted considerable criticism from the start. While most critical comments in this context deal with the (alleged) problem of eugenic selection, I will concentrate on a somewhat broader issue.
Content: I will argue that NIPT clearly has the potential to increase reproductive autonomy and benefit expectant parents. However, NIPT can also put people in a situation that is morally overwhelming for them and from which there is no easy way out. In this sense, such tests can have a dilemma-generating effect.
Summary and Outlook: I will conclude that this can be adequately described by the term "moral ambivalence".

Keywords: genetic counceling; moral ambivalence; moral dilemma; non-invasive prenatal genetic testing.

Background

Introduction

Since the mid-19th and consistently throughout the 20th century, we have been witnessing an incredible progress in medicine (for a quick and nice-to-read overview see [1]). While life expectancy has increased significantly in most countries (from an average of 47.0 years in 1950 to 73.2 years in 2020, see [2]), the quality of life has also been improved for many people, not least for the severely and chronically ill (for the changes of the Human Development Index over the past 30 years see [3]). Among other things, this is the result of medical research and technological development. Although there is still a deplorable global discrepancy in living conditions, the result of this development benefits many people worldwide today. At the same time, medical progress has made it possible for many people to live a more self-determined life than ever before, again especially chronically ill and disabled persons. In short, medical research and technological development is a success story. But there is hardly a success story without a catch. This holds true also for the field of medicine.

In this paper, I want to examine the moral ambivalence that goes along with some medical technologies. In particular, I will focus on non-invasive prenatal testing (NIPT) as a rather recent development in the field of prenatal testing and diagnosis (PD). While most critical comments in this context deal with the (alleged) problem of eugenic selection, I will concentrate on a somewhat broader issue. I will argue that NIPT clearly has the potential to increase reproductive autonomy and benefit expectant parents. However, NIPT – and PD in general – can also put people in a situation that is morally overwhelming for them and from which there is no easy way out. In fact, the mere availability of PD means that people have to take a stance on it – even if they do not feel prepared for such a decision. Because of its low risk profile NIPT can aggravate this problem. I will conclude that this can be adequately described by the term "moral ambivalence". Moral ambivalence is associated with some modern technologies and is, apparently, the price we have to pay for the great benefits they bring.

The introduction of non-invasive prenatal testing

The identification of cell-free fetal DNA in maternal plasma by Lo et al. in 1997 paved the way for the development of NIPT [4]. In 2011, the US-American company Sequenom introduced the first non-invasive prenatal test ("MaterniT21") for trisomy 21 to the market [5]. Only one year

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later, the German company Lifecodexx brought the test ("Praenatest") to some European countries, including Germany. The test attracted considerable criticism from the start. In a way, this criticism was surprising because amniocentesis was already widely available as a prenatal testing method for trisomy 21. The new non-invasive test was initially less accurate, but also less risky than amniocentesis in terms of miscarriage. The harsh criticism therefore appeared to be unfounded. However, a number of authors claimed that the lower risk would make eugenic selection a common practice and, at the same time, decrease societal acceptance of people with Down's syndrome [6]. This type of criticism proved to be quite persistent and was brought forward again in Germany when a decision was pending about whether the test should be included in the catalog of services of the statutory health insurance [7]. I join those who oppose this line of argumentation. There are, in fact, a number of compelling arguments against it: The notion of selection is inappropriate in this context, expectant parents should not be used as a means for societal goals and, finally, if people oppose liberal abortion rules, they should do so openly and directly [8].

Having said this, I want to admit that I feel a vague sympathy for the criticism raised against NIPT. But how can one reject the common arguments against NIPT and still feel somewhat uneasy about this new prenatal testing method? Is there any rational ground for this discomfort? I think so.

Content

Reasons for using NIPT

In order to see more clearly here, it is helpful to take a closer look at the reasons that speak in favor of using NIPT first. For some parents-to-be, it is clear that they will be unwilling to have a child with trisomy 21. (From the beginning on, the test covered more conditions. For the sake of simplicity, I shall concentrate on trisomy 21 as the most controversial condition.) They take the test in order to have an abortion if the result is positive (for numbers of termination rates after a positive trisomy 21 test see [9]). On the other side, for some parents-to-be, abortion is no option at all. Nevertheless, they take the test for being prepared if their child is affected. In both cases, the test is a useful tool for living an autonomous life. From the perspective of such couples, there is no room for any feeling of discomfort caused by the test. On the contrary, the test turns out to be a welcomed advancement in medical technology.

Not all parents-to-be fall neatly into one of the two groups just mentioned. A recent study by Birko et al. on preferences of Canadian pregnant women, their partners, and health professionals regarding NIPT use and access, for example, shows that there are parents-to-be who initially do not have a clear and unambiguous position on what to do in case of a positive test result [10]. The authors report that 14.3% of the women and 15.2% of partners were "unsure" how they would use a positive test result for Down's syndrome. Apparently, those parents-to-be neither have an irrevocable attitude towards abortion, nor have they seriously considered the possibility of living a life with a disabled child before. It seems as if they choose to perform prenatal testing simply because it is available. Maybe not taking it would mean not having done 'everything possible' in the course of pregnancy – and this may feel like a neglect to them. It is a fact that is hard to deny that the mere accessibility of technologies can create pressures to use them. I understand that counseling services are widely available and that these services are intended to help expectant parents to consider whether and why they would like to take advantage of prenatal testing. Still, it is hard to resist the appeal of an existing technology and not just take it for granted, especially if this technology has the prospect of proving that the unborn child is doing well. After all, this is what all parents wish to hear.

To be sure, even if expectant parents do not initially have a clear idea of what to do in the event of a positive test result, a test can be very helpful. It offers them the opportunity to deal with alternative courses of action and to carefully weigh up which one is the most appropriate for them. A test, then, helps the parents to lead a self-determined life. Again, the test proves to be a beneficial medical technology and there is hardly room for any feeling of discomfort. In sum, it seems as if prenatal testing including NIPT should definitely be welcomed as a useful medical advancement.

Life and death decisions

From the beginning on, prenatal testing has made decisions about life and death necessary. For many fetal disorders and defects there were – and still are – no therapeutic approaches. Of course, parents-to-be always have the option to continue pregnancy despite a positive test result. However, the termination of a pregnancy was – and still is – an option, too. It would, therefore, be naive to deny

the life-and-death character of prenatal testing. To be sure, this is not an argument against prenatal testing. Sometimes we have to make tough decisions in life. But it is also true that we are sometimes not prepared to make such decisions. The only way to avoid decision-making in such situations is to circumvent getting into them in the first place. This is, of course, not always possible. Think, for example, about life-sustaining treatments in hopeless situations. In the absence of a patient will, relatives sometimes have to make the difficult decision as to whether or not to continue treatment. Once the situation is there, they cannot reject making a decision.

With prenatal predictive testing and diagnosis, the situation is slightly different. Expectant parents do have a choice. After counseling, they can decide against taking a test. However, such a decision comes at a price. Parents-to-be have to maintain that not using advanced medical technologies was the right thing to do. As mentioned above, technologies often create pressures and not using them becomes a matter that demands justification – to yourself and to others. However, using them throws parents-to-be into a situation in which a difficult decision suddenly becomes unavoidable.

Imagine the case of a couple that already has a child. This couple may fear that having a second child with Down's syndrome will inevitably mean that they will not have enough time for their first child. Regardless of whether this fear is justified, they may think that they have a moral obligation to their firstborn child that they will no longer be able to live up to once the second child is born. On the other side, they may equally feel obligated towards their unborn child. An abortion may seem morally wrong to them, especially if the reason for it is a positive test result for trisomy 21. This is the typical form of classical dilemma: a situation in which two (or more) courses of action seem equally morally wrong.

I am not concerned here with the question of whether the situation just described is really a moral dilemma. Some will argue that the life of the unborn child undoubtedly matters morally more than any restrictions that may be placed on the child already born. Others will disagree and refer to the net sum of expected happiness or some other measure they deem morally relevant. The truth is that either point of view or variant thereof can refer to an elaborate ethical theory and can legitimately claim that it is an accepted position in our pluralistic society. So, if the parents do not consider either point of view convincing, it cannot be denied that the decision they face does have the structure of a dilemma. Still, one could argue that it is not the test that leads to the dilemma, but rather the fact that the unborn child is affected by trisomy 21. Of course, this is true in a way. However, it is the test that forces the expectant parents to make a decision. If they hadn't known about the finding, they would not have had any need to act. It would just have happened. For them, the test does have a dilemma-generating effect.

Of course, everyone is free not to take the test. As already mentioned, counseling services are widely available, and these services are intended to help expectant parents to consider whether and why they would like to take advantage of prenatal testing. However, as also mentioned, it can be hard to resist the appeal of an existing technology. The more widespread a technology is and the easier it is to access it, the more difficult it is to reject it, and the faster one gets into a decision-making situation that is morally overwhelming. And even the preliminary question of whether one wants to take the test or not can present itself as a dilemma: On the one hand there is the moral obligation to do everything possible for an undisturbed course of pregnancy, on the other hand there is the possibility of excessive moral demands. The increasingly easy availability of PD – notably NIPT – thus leads to a kind of second-order dilemma. I think this latter fact can adequately be described by the term "moral ambivalence".

Summary and outlook: dealing with moral ambivalence

What does all this mean in terms of the discomfort some feel at the introduction of ever better methods of prenatal testing, including NIPT? First, it means that for many people, NIPT is a beneficial medical technology for it can help to live a more self-determined life. Second, it means that counselling is paramount and should empower expectant parents to decide whether they want to use prenatal testing. In particular, not using prenatal tests should not be viewed as requiring special justification (unless therapeutic means are available). Third, we should recognize that easy availability can undermine this decision-making process and throw people into a moral dilemma. Fourth, we must acknowledge both the benefits and the burdens of modern technologies, as well as the moral ambivalence they inevitably create: They sometimes force us to make decisions that we do not want to make. Finally, policy regulations need to find ways for dealing with this moral ambivalence and, at the same time, respect the individual choices of expectant parents. This is especially difficult.

With regard to the recent decision of the German G-BA on whether NIPT should be included in the catalog of services of the statutory health insurance, Christoph

Rehmann-Sutter and Christina Schües maintained that the regulation is both paradoxical and flexible. They continue to argue that "the model of the G-BA could be a socio-politically and ultimately also ethically defensible pragmatic solution, exactly because of its paradoxes and its inherent flexibility." [11, 386]. This, in turn, can be interpreted as an attempt to come to terms with moral ambivalence.

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