

ETHICAL CONSIDERATIONS FOR OFFERING NON-INVASIVE PRENATAL TESTS WITHIN A PUBLIC HEALTHCARE SYSTEM: A RULE UTILITARIAN PERSPECTIVE

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Abstract

Non-invasive prenatal testing (NIPT) appeals to the general obstetrical population due to its reliability and safety in fetal aneuploidy screening. However, it often attracts ethical concerns when offered via publicly funded healthcare systems. Using moral reasoning, this paper makes rule utilitarian arguments to address the ethical question: How can NIPT be ethically offered to the general obstetric population via a public healthcare system for the detection of fetal aneuploidy? Three moral arguments were constructed deductively, upon which three governing “rules” are based. According to rule utilitarianism, policies that consider and conform to these rules should lead to maximization of utility for the greatest number of people. This paper provides a moral foundation for formulating policies that govern the roles of NIPT in fetal aneuploidy screening programs and may, therefore, have implications for many people, including pregnant women, the disabled, and society as a whole.

Keywords

Moral theory, rule utilitarianism, non-invasive prenatal testing, aneuploidy, screening

Introduction

Cell-free fetal DNA (cfDNA) was discovered in maternal blood in 1997.¹ With technological advances, clinical screening for fetal aneuploidy by non-invasive prenatal testing (NIPT) became feasible and matured over time.^{2,3} Nowadays, NIPT can be used to screen for three common trisomy conditions, namely Patau syndrome (trisomy 13; relative frequency of 1.4 in 10,000), Edwards syndrome (trisomy 18; 2.3 in 10,000), and Down’s syndrome (trisomy 21; 1 in 500).^{4,5} There is currently no cure for these three conditions of trisomy.

As a prenatal screening test, NIPT is available in many developed countries, such as the USA, Western Europe, and China.⁶ Nonetheless, it remains a self-financed prenatal screening test. In Canada, for example, NIPT is not publicly funded in general, but in certain circumstances may be provided as a “second level contingent test” to women at risk for trisomy 13, 18, and 21.^{7,8} In America, NIPT is offered as a direct-to-consumer test via commercial laboratories or individual practitioners.⁹ Pregnant women who wish to test for fetal aneuploidy must self-finance or use insurance coverage. In the Netherlands, NIPT has been offered since April 2017 to

low-risk pregnant women, who previously had to go abroad for the test.^{10,11} In Hong Kong, NIPT is mostly offered by the private healthcare sector, costing approximately HKD 5,000 per test.¹² A local study revealed that despite its relatively high cost as a screening test, NIPT appeals to pregnant women because of its safety (in comparison with other invasive testing modalities, such as amniocentesis) as well as result accuracy and reliability.¹³ Pregnant women commonly believe that NIPT provides early access to fetal information, thereby providing a certain level of reassurance regarding fetal health.

The clinical superiority and societal utility of NIPT makes it an attractive prenatal screening modality for health policymakers, and many countries show keen interest in offering NIPT ethically within a public healthcare system. While Hospital Authority (the largest government-funded healthcare provider in Hong Kong) actively plans for a territory-wide provision of the test, the question of how to implement NIPT is not only morally important but also central to relevant policies. During health policy formulation, conclusions that are based on moral theories can stand up to public scrutiny as to why terms within the policies are thus constructed. Healthcare resources are limited, and one may never exclude that when a policy claims to be justified by certain ethical principles (such as those concerned with equality); others may disagree by asking why one principle ultimately takes precedence over others. For the benefits of social solidarity, healthcare policymakers are required to consider the moral aspects of each policy (including NIPT-related policies).

Some clinical practitioners may argue that ethical questions can be completely addressed by merely referencing various ethical statements from international professional bodies.^{14–18} Indeed, professional societies or health institutions may “prescribe” or “stipulate” guidance on what ought to be done—or is expected to be done—by conferring a degree of “obligations” to certain parties (frequently professionals, such as physicians and nurses). However, applying general ethical principles may at times fail to adequately respond to the public’s inquiry with respect to the morality underlying the policies that govern the offering of NIPT. By contrast, a systematic analysis based on moral theories with deep-rooted origins in philosophy may provide a stronger base for soundly constructed arguments for or against ethics-related policy allegations in society. Therefore, this paper responds to the urgent need of policymakers (both local and worldwide) by proposing and answering a key question related to the welfare of pregnant women and society, which is on the basis of rule utilitarianism: how can NIPT be ethically offered to the general obstetric population via a public (publicly funded) healthcare system for the detection of fetal aneuploidy?

To address this ethical question, we shall first begin with a short literature review that outlines the current landscape of the relevant moral debate, thereby highlighting the unique knowledge gap that this paper attempts to address. Then, we shall give an account of the ethical position, along with the significance and scope of the present moral discussion. Central to the philosophical views of rule utilitarianism, the concept of utility will then be interpreted in the context of antenatal screening. The philosophical concern as to why NIPT should be offered with an aim to promote reproductive autonomy will be addressed, and by doing so, the principle of utility can be satisfied. Three moral arguments are then proposed, from which certain governing “rules” that are of moral importance are derived as a response to the ethical question.

This paper argues that using these derived rules in guiding the policy formulation process will enable the ethical offering of NIPT within a public healthcare system. For clarity, we shall use the term “non-invasive prenatal testing (NIPT)” in this paper to refer to the screening tests that analyze the fetal genome based on cfDNA in maternal blood.⁴ This definition is consistent with the definition of NIPT in a medical context. The word “non-invasive” refers to the way by which the cfDNA sample is obtained.

Ethics of NIPT Application in Detecting Fetal Anomalies: A Short Review

Using the relevant terms (including “ethics,” “considerations,” “morality,” “NIPT,” “non-invasive prenatal test,” “screening,” and “fetal aneuploidy”) and the Boolean operators “AND” and/or “OR” where appropriate as the connector, the scope of the electronic search was maximized across four major healthcare databases: EMBASE, CINAHL, MEDLINE, and PubMed.

A total of sixty studies were found, five of which provide important ethical insights into the debates regarding NIPT application in antenatal care.^{19,9,10,20,8} Historically, arguments concerning the ethics of NIPT varied considerably when different aspects of morality were evaluated against various sociocultural contexts with different foci of ethical concerns.²¹⁻²⁴ Summarizing this entire spectrum of views is not the primary aim of this paper, as it is not intended to be an integrated literature review. Nonetheless, a general overview of some arguments of relevance to this paper is needed to outline the foundational landscape around which the contemporary moral discussion of NIPT application revolves. Two contrasting schools of thoughts are evident when discussing the morality of offering NIPT as a prenatal screening test in a public healthcare system.

Arguments in favor of using NIPT to screen for fetal anomalies are largely beneficence-based and derived from a deductive approach. Proponents are mostly consequentialists who appeal to the two-fold benefits of NIPT to the welfare of children and the psychological well-being of prospective parents and families.^{25,26} Since the emergence of genomic-based technologies in prenatal testing, the notion of offering genetic tests to prevent the birth of an affected child has been widely proposed in the literature. The traditional belief is that some fetal anomalies, such as those arising from mutations that randomly result from a naturalistic course of gene interactions, are not preventable by measures during the prenatal or perinatal stages. Thus, offering a screening test is morally justified if the test ultimately leads to fewer persons who must bear life-long physical and/or psychological suffering due to congenital conditions. Proponents also believe that their argument makes sense, particularly for medical conditions that are characterized by severe or significant disabilities and continuous non-palliative pain.²⁷ By their interpretation, the severity of a genetic condition should be sufficiently great such that non-existence may be seen legitimate in the best interests of an affected child. In a similar vein, the concept of minimizing “suffering” is applied to pregnant women, as well as couples. The psychological or mental well-being of the prospective parents is of concern here. Studies point out that the negative implications of having an affected child are multi-dimensional, yet they may not stem from the child’s suffering *per se*.²⁸⁻³² Mothers may subject themselves to anger and grief by attributing their failures in preventing

the congenital condition(s) from occurring, although—in a strict scientific sense—congenital diseases are beyond the control of the mother. The perceived obligations of parenthood may also burden mothers by worrying about failure in providing adequate or ideal care to support an affected child. As a result, this type of moral discussion often concludes that offering NIPT to screen for fetal anomalies is ethical because (1) it helps prevent the birth of children whose lives are likely to be severely and negatively affected by congenital conditions and (2) it protects the mother from the possibility of having psychological distress that may impair her own mental health.

Apart from the above beneficence-based school of thought, arguments against offering NIPT in the healthcare system originate from two groups of people, one that is inclined to a deontological line of thinking^{33,34,10} and the other disability rights advocates. Arguments from the former tend to be constructed on the premise that the life of a fetus is sacred.³⁵ Since the conditions that NIPT screens for are rarely treatable, offering NIPT is nothing more but to hint at the choice of selective abortion for pregnant women if an affected fetus is found. Because abortion sacrifices the sacred life of a fetus and NIPT provides the basis upon which pregnant women may decide to terminate pregnancy, offering NIPT is morally wrong. These arguments have been criticized because their proposed linkage between NIPT and selective abortion could only be justified if NIPT had been offered to encourage women to terminate affected pregnancies. However, a positive result from NIPT should not only be interpreted as a single reproductive choice—abortion is possible but not necessary. Furthermore, bioethics literature does not seem to have a consensus on the moral status of a fetus in the context of reproductive ethics. Supporters who argue from a deontological perspective are also challenged for their views on whether abortion is equivalent to murder if the moral standing of an unborn fetus is not equivalent to that of an adult. Certain ethics studies assign a lower moral status to the unborn fetus when the fetus is at an early stage of neurobiological, psychological, and cognitive development.³⁶ As a result, the deontological-based opposition against offering NIPT to pregnant women receives relatively little support in the literature.

As for disability rights advocates, concerns regarding the discriminatory and/or stigmatizing messages that are “implied” or “inseparable” from prenatal screening tests often form the basis of their arguments against offering NIPT in a public healthcare system.³⁷⁻⁴⁰ These advocates ask: if certain screening tests are offered for reproductive choices, then why is the screening scope subjectively set for specific genetic conditions but not for others? These kinds of questions initially arose for Down’s syndrome, when it was being tested as part of a prenatal care program in the past.⁴¹ Their concerns were intensified when NIPT presented itself as a new screening technology with greater accuracy for detecting trisomy. The following direct quote regarding Down’s syndrome appears to fuel their argument: “[B]ut whatever is done, the survivors continue in a state of permanent dependence that imposes a severe burden on their families and on existing forms of social organization.”⁴² To disability rights advocates, this quote is ethically problematic for its underlying notion that people with Down’s syndrome are considered a “burden” on the rest of the society. These advocates then constructed a slippery slope statement that highlights the undesirable societal impacts of the introduction of NIPT. They argue that when NIPT screens and attains its aim to reduce the birth of children affected by a certain genetic condition, people who are living with that condition will be marginalized in terms of

social resource allocation. They deduced this consequence from the fact that social resource allocation is negatively influenced when the affected population represents a minority in society and is hence less visible and less vocal.⁴³ Considering that rule utilitarian appeals to empiricism, the disability rights critique may not hold true, particularly when empirical evidence disputes that their predicted consequences are occurring.⁴⁴ Studies revealed that pregnant women who choose selective abortion for an affected fetus after a positive NIPT result frequently choose out of good will to prevent a life that is medically known to present with severe suffering.⁴⁵ Another common reason that selective abortion is chosen is that pregnant women perceive themselves as incapable of providing the best conditions to care for a child with disability.⁴⁶ Researches highlight that the decision-making process of pregnant women in the face of an affected pregnancy is complex and not simply based on the reason that the fetus is not as healthy as one desires or expects.^{47,48}

Following this overview of existing literature, diverse publications were seen in relation to the morality of applying NIPT for different purposes and in different sociocultural contexts. Most studies adopted a generic approach in examining the problem, mostly grounding their views on a selected set of principles in bioethics, such as the principle of justice. Nonetheless, conclusions derived from the selected principles may sometimes conflict with one another. Through the lens of rule utilitarianism, the use of an established normative theory in the analytical framework may allow for a systematic analysis based on a set of philosophical beliefs. Unfortunately, the current body of literature regarding the ethics of NIPT is not often constructed via this approach.

Ethical Position, Significance, and Scope of Moral Discussion

Like other technologies in the field of reproductive genetics, the limitless application and indiscriminate use of NIPT may lead to ethical concerns regarding the long-term impacts on the general welfare of society. Some examples that frequently attract moral debate include the morality of sex selection via NIPT to fulfill the expectations of a cultural group or social norms and the morality of selecting desired traits by NIPT at the expense of fetal lives. Thus, deriving certain rules that are congruous with rule utilitarian values via moral discussion is important for offering NIPT in an ethical way that maximizes utility under a public healthcare system.

We approached the ethical question from a rule utilitarian perspective due to two considerations. First, any plausible moral theory that justifies offering NIPT under a public healthcare system must consider the principle of beneficence, that is, the welfare of pregnant women in society. Rule utilitarianism values utility, and hence its consequentialist reasoning is helpful in the formulation of healthcare policies. The application of rule utilitarianism for our ethical question is thus appropriate in this context.

Second, rule utilitarianism demands an objective assessment of the consequences of offering NIPT to pregnant women.⁴⁹ Thus, whether NIPT is offered in an ethical way under a public healthcare system depends on whether the principle of utility has been satisfied. Rule utilitarianism enables us to consider the morality of offering NIPT to pregnant women in terms of the goal of promoting welfare. It also requires us to make an impartial choice that favors good outcomes. Rule utilitarianism emphasizes

that if certain rules devised to maximize utility are conformed to, the social utility of NIPT can be maximized in the long run.⁵⁰

Areas that are not within the intended scope of the present moral discussion include the morality of interventions that pregnant women employ based on the results of NIPT, whether it is ethical for a pregnant woman with a positive NIPT result to terminate her pregnancy and the moral status or standing of a fetus and its associated rights.

Interpretations of the “Utility” in the Context of Antenatal Screening

Two lines of thought are morally important when the societal utility of NIPT appears central to rule utilitarian-based arguments. When NIPT is offered under a public health-oriented screening program, the aim of NIPT is likely the reduction of morbidity and mortality of certain congenital genetic diseases in the population.^{25,23,24} Thus, the societal utility of NIPT can be evaluated, in a sense, by several quantitative measures, such as the termination rates of affected fetuses subsequent to a positive NIPT result. This line of thinking, which positions NIPT as an instrument (means) to lessen the overall burden of disease on society, may be ethically problematic, even from a rule utilitarian perspective. Considering the circumstances in which an extreme application of economic models can quantify the societal utility of NIPT—whether pleasure (or happiness) can be maximized for the greatest number of people in society—remains doubtful. Suppose that an economic model assesses the societal utility of NIPT in terms of the benefits derived from the abortion of an affected fetus after the test. In this model, it is assumed that if a woman does not abort the affected fetus, the screening test is regarded as bringing zero societal benefit. On the contrary, the screening test will be considered to have great societal utility if the abortion that follows a positive result ultimately leads to savings in public expenditure on the provision of costly medical care to the seriously affected child, decreases in the utilization of expensive health services and treatment modalities for children with trisomy, reduction in family expenditure on taking care of an affected child, and the increased maternal output that would otherwise be lost due to parenting an affected child. In the long run, society may become less inclusive to the disabled, discouraging those traits that are deemed less productive in economic terms. Discrimination and stigmatization for persons living with trisomy will be intensified. Women who choose to give birth to an affected child may be perceived as burdening the societal healthcare resources. Not only parents but also families with an affected child may face great societal pressure for their “irresponsible” reproductive choices (although these choices are meaningful to the parents at least). Similar concerns over the use of such monetary-centered models in evaluating the societal utility of NIPT were raised in the bioethics literature.⁵¹ After all, as rule utilitarian, we are convinced that in the aforementioned circumstance there could hardly be a maximization of pleasure and happiness for the greatest number of people in the long run.

The ethical pitfall in offering NIPT as a public health instrument can be prevented if the aim of NIPT is to promote meaningful reproductive choices by pregnant women. This gives rise to the second line of thought that we are arguing for in this paragraph. That is, for NIPT offered in the antenatal context, the societal utility of NIPT should be evaluated by the pleasure and happiness of the affected pregnant

women themselves. Priaulx⁵² offers an inspiring philosophical view in his article titled “Rethinking Progenitive Conflict: Why Reproductive Autonomy Matters.” The article offers a detailed philosophical account on the social values of reproductive autonomy. We wish to highlight a few points raised in the article to support our interpretation of utility. The social values of reproductive autonomy can be justified by three ideological tenets: the significance of (1) reproduction, (2) respecting human needs, and (3) respecting bodily integrity. Basically, a woman owns her body and no one is in a better position than her to determine what her pregnancy means in terms of self-definition and sense of self in relation to society. Pregnant women are the best situated to determine in what ways reproductive choice is meaningful. A woman who functions as a member in society and parent in the family should be respected for her welfare and interests in knowing critical information regarding fetal aneuploidy. With such a philosophical view in mind, the societal utility of offering NIPT as a screening test for fetal aneuploidy distinguishes itself from the utility of antenatal tests (such as screening for hypertension or rhesus status) that promote the health of the mother and fetus. Societal utility, as it relates to the subsequent arguments in this paper, should not be viewed in relation to economic interests in a quantitative dimension (as certain politicians and pragmatists may favor this approach). Instead, the contextual understanding of societal utility herein should factor in the value of humanity in a civilized society and thus consider the classical interpretation of utility offered by Jeremy Bentham and John Stuart Mill—that is, the pleasure and happiness of pregnant women in the context of reproductive autonomy (or freedom).

Argument Concerning Informed Choice Prior to the Test

This argument contains two central premises (one factual and one normative). Evidence from the literature will be provided to strengthen each premise. Following that, the concluding statement of this argument will form one of the three derived rules.

Firstly, NIPT provides pregnant women with valid and reliable information regarding fetal aneuploidy. A recent high-quality, meta-analysis indicated that NIPT shows highly accurate performance as a prenatal screening tool in the detection of trisomy 13, 18, and 21 for different obstetrical populations.⁵³ The sensitivity and specificity of detecting each trisomy are 99% and 99.92% for Down’s syndrome, 96.8% and 99.85% for Edwards syndrome, and 92.1% and 99.8% for Patau syndrome, respectively. A negative NIPT result was also highly reliable for the exclusion of these conditions.⁵⁴ Studies also suggested that false positive results are substantially lower than those achieved with a combined ultrasound and biochemical screening. NIPT can yield accurate and reliable results as early as the tenth week of pregnancy. Furthermore, the results are readily available within seven days.⁵⁵ Therefore, we argue that information from a NIPT enables reproductive choices and facilitates the decision-making process.^{22,56,57} Early screening provides pregnant women with additional time to consider other confirmatory prenatal tests or reproductive interventions. They can also enjoy a longer period of decision making following a positive test result. For those who will not consider abortion of an affected fetus, a positive NIPT result may be sufficiently informative even without confirmatory testing. In other words, these women are enabled to make their own meaningful reproductive decisions. They have access to early monitoring for fetal development and can consult relevant professionals

(midwives, obstetricians, and genetic counselors) to address their concerns. This helps them be in a better position to make a well-reasoned decision in the event of a positive result. The women would also be able to prepare for the birth of a disabled child and thus improve care.

Based on the above discussion, the first premise (as a factual claim) can be established, i.e., NIPT provides pregnant women with valid and reliable information about the presence (or absence) of fetal aneuploidy during early pregnancy (from the tenth week of gestation). The availability of a fetus' genetic information greatly facilitates decision making regarding reproductive choices. Therefore, offering NIPT leads to positive impacts on the welfare of pregnant women.

Another premise (a normative claim) is that in the context of reproductive autonomy, the decision to take any prenatal screening test (including NIPT) should be an informed choice because a pregnant woman has the right not to know about fetal aneuploidy, even if it exists. This premise is grounded in the following evidence: to start with, informed choice is often defined as a choice that is based on relevant knowledge, consistent with the decision maker's values, and behaviorally implemented.^{57,58} Often in reproductive ethics literature, an informed choice of whether or not to take a prenatal test is thought to be crucial in the context of enhancing reproductive autonomy.^{9,17,18} The need for an informed choice acknowledges the fact that pregnant women have the right not to know. Pregnant women should be made aware that they may be confronted with several unanticipated choices and decisions with the NIPT results. They may wish to avoid the test, if the possibility of these consequences were made known.¹⁰ To make an informed choice, a pregnant woman needs to understand the scope, limits, and purpose of NIPT, as well as its potential risks and implications.⁵⁹ A qualitative study found that reproductive choices and autonomy are compromised if a woman does not engage in an NIPT with an informed choice.¹⁰ Some women may feel regretful to be informed of a positive result for a wanted pregnancy. Some think that if they had not been informed of fetal aneuploidy, then the reproductive choices would be paradoxically "easier" and not morally difficult. After all, an informed choice of whether to undergo NIPT should be made by women to protect themselves from the abovementioned negative consequences that affect reproductive autonomy.

Therefore, the concluding statement of this argument and hence the first derived rule would be that a pregnant woman who makes an informed choice of undergoing NIPT should be offered the test because, as a valid and reliable prenatal screening tool, NIPT provides crucial information that enables her to make autonomous reproductive choices.

Argument Concerning Genetic Counseling

There are three premises in this argument. The first premise is that offering NIPT for prenatal screening of fetal aneuploidy may provide several benefits to pregnant women. Firstly, a negative result may reduce maternal anxiety over fetal health.⁹ NIPT may also reduce the need for invasive follow-up tests (such as amniocentesis and chorionic villus sampling), which have a 0.1–0.2% risk of miscarriage;^{9,11} it may also help women decide if they wish to pursue further invasive tests.⁶⁰ Moreover, NIPT reduces the likelihood of unanticipated births of children with aneuploidy⁶¹ and allows women to prepare for an affected child.⁶⁰ If a woman decides to terminate

her pregnancy, terminating the pregnancy at an earlier time is less physically risky and less emotionally traumatic.⁶² Furthermore, NIPT does not have an upper limit for gestational age. Women who present late for their first prenatal visit may still be able to take the test. Such women may otherwise only be able to assess screening modalities with lower sensitivity and specificity rates.⁶³ Undergoing NIPT, compared with amniocentesis or chorionic villus sampling, is associated with a significantly reduced fear of pain and discomfort.⁶⁴ NIPT can be offered in more settings than can invasive testing, making it more available to women. Moreover, a sample of maternal blood can be drawn by a nurse, whereas chorionic villus sampling or amniocentesis require the skills of a specialist physician.^{65,66}

Despite that the mentioned utility of NIPT enhances reproductive autonomy, potential risks may also be present under several circumstances.^{61,18} False reassurance may result from false-negative test results, although reproductive geneticists generally believe that the likelihood of a false-negative NIPT result is technically rare. On the other hand, false positive outcomes (a likelihood of approximately 0.1%) are possible due to placental mosaicism, obesity of test recipients, presence of a maternal tumor, and/or the influence of ethnicity, such as Afro-Caribbean descent. Some worries may also arise from incidental findings that are of unclear clinical significance.

The benefits and potential risks of NIPT are well recognized in the literature on ethical and policy considerations of the test.^{10,8} In general, ethicists acknowledge the listed benefits and potential risks and agree that NIPT demonstrates a superior and favorable utility profile as a prenatal screening test.⁹ Various professional societies, such as the American College of Obstetricians and Gynecologists (ACOG), the International Society for Prenatal Diagnosis (ISPD), and the National Society of Genetic Counselors (NSGC), favor the adoption of NIPT for prenatal screening in the healthcare system. They unanimously agree that the benefits (i.e., the utility) of NIPT outweigh the involved risks for pregnant women.⁶⁷

The second premise is that, from a rule utilitarian perspective, the offering of a prenatal screening test is ethically justified when the way in which it is offered can result in the maximization of utility with minimal associated risks. This premise follows the views of rule utilitarianism that a morally right action is the one that produces the most favorable balance of good over evil, everyone considered. Applied to the context of prenatal screening, the rule utilitarian view of whether NIPT is offered in an ethical way within the public healthcare system depends on how the maximization of good (benefits of NIPT) and reduction of associated risks can be achieved. The ethical framework of UNESCO (the United Nations Educational, Scientific and Cultural Organization) shares similar views with rule utilitarianism and specifies that for a prenatal testing offer to be ethically justified, the advantages (utility) should outweigh the disadvantages.¹⁷ Therefore, in addition to the well-argued and favorable utility profile of NIPT, there is a need for a third premise to help fulfill the rule utilitarian views on the ethical offering of NIPT within a public healthcare system.

The third premise argues that non-directive genetic counseling before and after NIPT may maximize the positive outcomes with a reduction in unwanted risks, maximizing the net benefits to pregnant women. Research on the ethics of prenatal testing suggest including information in pre-test genetic counseling, as it is important

for pregnant women to make autonomous reproductive choices to maximize the utility of NIPT.^{68,18} This information should include the nature (as a non-mandatory prenatal screening test), aim (to enhance reproductive autonomy), and validity of the test, complete information about the tested disorders (including names and general characteristics), possible treatments in case of positive findings, possible unexpected (or unclear) findings of the test, and the kinds of test-outcomes. Pre-test genetic counseling should emphasize that NIPT is not intended for use as an unlimited scope for genome analysis of a fetus. Studies point out that identifying traits with low medical morbidity or uncertain clinical significance may undermine reproductive autonomy.⁶⁹ Post-test counseling, by contrast, should be non-directive. High-quality and non-biased information should be offered by trained professionals and should serve to provide options and correct misunderstandings. The norms, values, and attitudes of women towards having a child with a disability should be adequately explored.^{70,8}

Therefore, in this argument, the second derived rule is that NIPT should be offered based on a favorable utility profile for which non-directive genetic counseling should be conducted during the pre and post-test periods.

Argument Concerning Testing Fee

Three premises set the basis of this argument. The first premise argues that free-of-charge NIPT may not bring the greatest utility to pregnant women. Charging test recipients a small amount is instead shown to be more appropriate because ill-considered testing may compromise utility. Free-of-charge NIPT may seem to benefit the greatest number of women but does not necessarily lead to the greatest social utility. The literature has raised concerns over the negative ethical implications of ill-considered testing, particularly on the original aim of NIPT in enhancing reproductive autonomy.¹⁰ It was found that asking women to pay for prenatal screening increases the chances that a truly informed choice was made prior to the test.⁷¹

The second premise, as a normative claim, emphasizes that in addition to a favorable utility profile of NIPT, rule utilitarianism also demands that the greatest number of pregnant women should benefit from the offering of the test. Some may argue that however small the NIPT fee is, it is inevitable that less financially capable women will be marginalized. Such a hypothetical circumstance logically leads to the conclusion that to bring maximum utility, unlimited access to the test is required with the local government (i.e., taxpayers) bearing this needed social cost for the provision of basic prenatal care. Nonetheless, it should be noted that rule utilitarianism values utility as much as it values the number of beneficiaries. Considering the greatest utility of NIPT is to promote reproductive autonomy; a hasty decision to take the test due to its free-of-charge nature is likely to bring the opposite effect. Therefore, rule utilitarianism argues that government subsidies for the less financially capable women may be necessary as a safety net to secure a larger base of beneficiaries.

The third premise suggests that government subsidies for the less financially capable women may help in securing a larger base of beneficiaries if NIPT is offered under the public healthcare system. Reproductive health is a collective responsibility, for which some studies on the ethics of NIPT-related health policies argue that the government should play a role in to facilitate reproductive health at a population-wide

level.^{9,72} If a government has a role and responsibilities in the reproductive health of its citizens, then it should enable the greatest number of women who can benefit from NIPT; thus, rule utilitarianism supports the provision of government subsidies for the less financially capable groups to undergo NIPT.

To conclude this argument, the third rule is derived, wherein rule utilitarianism favors the offering of NIPT at a small fee and that government subsidies should be provided for the less financially capable groups to enable the greatest number of beneficiaries.

Counterarguments for the Routinization of NIPT

Based on a rule utilitarian line of deductive thinking, consequences are what matters when determining morality over how NIPT is offered. By the three arguments previously discussed, one may pose a morally important question about why NIPT is not routinized as part of the current antenatal screening program. This proposition seems intuitively true in that routinization is more likely to guarantee the greatest number of beneficiaries if the societal utility of NIPT has been adequately argued from the philosophical aspect and found to sufficiently satisfy the principle of utility. Nonetheless, as rule utilitarian, we are conservative as to whether the routinization of NIPT would result in the maximization of societal utility. There is evidence in the literature that leads one to argue that the ultimate aim of NIPT—promoting reproductive autonomy—may not be fulfilled when the test is routinized. Antenatal ultrasonography is a good example of this;^{73,74} it was offered with the primary intention to assess gestational age, detect structural anomalies, and monitor the general development of the fetus. It then became normalized in the context of reproductive medicine, and, rather unexpectedly, society gradually viewed it as an opportunity to promote fetal-maternal bonding because the mother can visualize the fetus through ultrasonography.^{75,76} Ethical problems then arise when parents are eager to visualize non-medical traits, such as for the hidden purpose of sex selection to meet sociocultural norms and expectations. From empirical experience, the routinization of ultrasonography—serving as a good analogy for NIPT as it is also associated with minimal clinical risks for the detection of fetal anomalies—unpredictably undermined women’s informed consent.^{77,78} It cannot be excluded that women’s autonomous reproductive choice may be compromised by subtle pressures from their partners, families, and society based on ultrasonography test results.

If NIPT becomes a routine test, women may face increasing difficulties in refusing it for fear that declining a screening test with low risk of miscarriage can hardly be justified.⁷⁹ Some women may be worried that they will be judged by society as irrational or irresponsible parents-to-be.⁷⁹ Eventually the trust of pregnant women in public healthcare services and opinions from professionals may lead women to undergo NIPT without fully understanding the purposes of the test because NIPT following routinization will likely be perceived as “another standard check-up during antenatal consultations.” Even healthcare professionals may find it less important to inform pregnant women of the purposes, aims, possible consequences, uncommon findings, and significance before the test. Whether a woman is truly informed regarding NIPT and the impacts on her subsequent decision making on reproduction will hardly be ensured. Some women may then be wholly unprepared for adverse

findings. The circumstances discussed above may not lead to a positive impact on the reproductive choices and autonomy of pregnant women. Therefore, when routinizing NIPT, the societal utility of NIPT may not be as much as the current proposed option in which a woman retains the full right to choose whether she wishes to have this optional (non-mandatory) test or not. Several studies have also raised ethical concerns over the effect of NIPT routinization in the literature.^{80,81}

Conclusion

By grounding arguments in rule utilitarianism, this paper has merits regarding its novelty. It derives important policy insights using a philosophical and theory-based approach of moral reasoning to solve a contemporary moral issue. Relevant healthcare policies that govern the roles of NIPT in fetal aneuploidy screening programs at a population level should give due consideration to the derived rules. Policymakers should recognize that the ethical offering of NIPT within a public healthcare system may have implications for the welfare of many people, including pregnant women, the disabled, and society as a whole.

As a prenatal screening modality, NIPT shows a favorable utility profile. If it is offered ethically in terms of rule utilitarianism, maximized social utility could be brought to the greatest number of pregnant women via the public healthcare system. Three rules are derived from the moral discussion addressing the proposed ethical question. When healthcare policymakers conform to these rules, it is believed that the social utility of NIPT can be maximized in the long run.

In summary, the derived rules are (1) a pregnant woman who makes an informed choice of undertaking NIPT should be offered the test because, as a valid and reliable prenatal screening tool, NIPT provides crucial information that enables her to make autonomous reproductive choices; (2) NIPT should be offered based on a favorable utility profile for which non-directive genetic counseling should be conducted at the pre and post-test periods; and (3) rule utilitarianism favors the offering of NIPT at a small fee and with government subsidies offered for less financially capable women to enable the greatest number of beneficiaries.

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