TEST (Trivent Ethics in Science and Technology Imprint)
Heading Towards Humans Again: Aspects of
Bioethics in the New Age of Science
Ed. Miroslav Radenković
Available online at http://trivent-publishing.eu

Is There a Moral Reproductive Behaviour in the Context of Prenatal Diagnosis and Care?

Luboslava Kostova

Ethical Studies Department, Institute of Philosophy and Sociology – BAS, Bulgaria

Abstract

This article aims to explore the meaning of concepts such as gender and moral reproductive behavior in the context of prenatal diagnosis and care. It will discuss making a reproductive decision in a time when the difference between nature and technology is blurry, when even moral responsibility is considered both medical and technological, a time of free choice, when the question arises: do we have a choice at all? This paper presents statistical data on the reasons for undergoing prenatal testing and the reproductive choices made by parents. All of the decisions are conceptualized in the history of gender and the medicalization of reproduction as a monolith process, which rather than unifying women in a joint project, divides, condemns and regulates them. Their reactions and responses as users, consumers, and, above all, as subjects of medical discourse and practice are barely audible. Finally, this paper will show how the very existence of prenatal genetic testing transforms social dimensions of pregnancy, motherhood, and parenthood.

DOI: 10.22618/TP.AEBIO.20214.231009

IS THERE A MORAL REPRODUCTIVE BEHAVIOUR IN THE CONTEXT OF PRENATAL DIAGNOSIS AND CARE?

Luboslava Kostova[1]

INTRODUCTION

Prenatal genetic testing and screening during pregnancy are free and non-mandatory options for women. However, they are almost immediately accepted by every pregnant woman as something good, useful and obligatory in the sense of responsible parenthood and as a source of excellent prenatal care. When the offer of testing is made, the parents` opportunity to reject it is almost inexistent. It is nearly impossible to choose not to choose because this means that you are irresponsible, overly religious or out of date, "crazy" or just a "gypsy" – which is the most common offence in the Bulgarian reproductive discourse. Gravitating towards the concept of moral reproductive behaviour, we gravitate towards the concept of gendered moral responsibility. Mothers are the main actors and their basic role as givers and caretakers is used in constructing this kind of biosocial normality. The choice is theirs, as well as the responsibility and the shame in case of rejecting testing and eventually giving birth to a sick or disabled child. There is a basic consensus that an illness or disability is wrong, something that burdens and not enriches the life of the family. In the context of prenatal testing and screening, the selective abortion of an impaired foetus in case of positive test result and diagnosis is considered not only as the only

[1] Ethical Studies Department, Institute of Philosophy and Sociology – BAS.

option, but also as a responsible and reasonable option, as a right of choice.

Current debates in Poland show this construction very clearly. "The governing right-wing Law and Justice party (PiS) to approve draft legislation that would ban pregnancy terminations in the case of foetuses with congenital birth defects. The worst-case scenario that could come true has come true. It is a devastating sentence that will destroy the lives of many women and families," said Kamila Ferenc, a lawyer who works with an NGO helping women denied abortion.[2] Is life with birth defects always a devastating sentence or is it only our perception, prejudice or our imagination's fail? Who has the right to interpret the reproductive power of a woman's body, the woman herself or the whole society, wombed in her body – state, church, men, and finally her own unborn children. According to Barbara Catz Rothman, what is considered to be a goal in good prenatal care is "not just the making of babies, but the making of mothers that midwives see as the miracle of birth."[3] Therefore, does much knowledge bring great sadness? What can be a good pregnancy outcome and what is the essential basis for wholesomeness or integrity reconsidered today as moral responsibility?

There are at least two ways to understand the midwives' valuing a pregnancy as "good" when the outcome is "bad." The first reflects their view of life. If life is about accomplishing things, then pregnancies resulting in dead babies are pointless. But if life is about living, and we have only limited time to live, then days spent in joyous anticipation are good days, and days spent in grief are bad days. Therefore, the prenatal diagnosis of conditions that cause death simply moves days from the good to the bad side of the ledger for women. A second way of understanding this – closely related to the first – is to postulate that pregnancy itself has a particular meaning and value in a woman's life, and that for women who want to become mothers, a good pregnancy and good birth are good things to have. Consider the following: in our practice, we had a child with a disorder that was not compatible with life.

---

[2] "Poland rules abortion due to foetal defects unconstitutional," *The Guardian* (2020), www.theguardian.com/world/2020/oct/22/poland-rules-abortion-due-to-foetal-defects-unconstitutional?CMP=share_btn_fb&fbclid=IwAR2d_qvzM_iZUM5CN0j8B4H2xf-I1H9QMeZx9YT709Q9ljQGqCPBXu2VrfU (accessed November 17, 2020).

[3] Barbara Katz Rothman, "Spoiling the pregnancy. Prenatal diagnosis in the Netherlands," in *Birth by design* (London: Routledge, 2001).

It did not have a *middenrif* (diaphragm). The intestines were placed upwards, while the heart was in the wrong place. The mother had a good pregnancy, a difficult delivery, but she looks back on it very positively. The child lived for a couple of hours. Of course, the parents were in grief for the child, but they also had very positive feelings toward the child. I heard several pregnant women talk about it, saying condescendingly, "They could have seen it [the disorder] in an echo" (i.e., an ultrasound), which is true. "They should have done an echo, then they could have known."

This is the general view on the issue: something that is best to be known in advance. Theoretically, however, the women who talked about this mother did not know her. This woman was delighted that she did not know anything in advance because an ultrasound would not have changed it. Yes, she would probably have had a hospital birth and three thousand echoes and pressure. However, she now has the memory of a good pregnancy and a positive experience of her delivery. The outcome would have been the same in both cases."[4]

THE MEANING OF GENDER

To explore the meaning of gender, we have to clarify its existing definitions. According to one of them, gender is a social construct, a social role and social expectation for proper behaviour, rather than a biological destiny. This is a position, which plays a significant role in the deconspiration and demystifying of the structures of power in the social world and also has an obvious weakness, provoked by the concept`s overexposure. The mutual connection between nature and culture is a fact of great significance to the understanding of the human situation: we are neither natural nor cultural beings, but both their synthesis: that allows us to survive.[5]

According to the other theory, sex is a natural, biological construct, something which fits the social order in a restricted and limited way: "It is almost impossible to transform from a man into a woman."[6] The disadvantages of that theory come from two main points: first, it generalizes and reduces the individual's personality only to its biology

[4] Ibidem.
[5] T. Eagleton, *The idea of culture* (Hoboken: Wiley, 2000), 131.
[6] Peter Berger, *Invitation to sociology. A Humanistic Perspective* (London: Anchor, 1999), 15.

and second, it attributes social power dimensions and current social inequalities to pure biology (as a destiny). What is typical between these two theories of understanding gender is that they recognize its significance and presence in almost every area of human existence because gender is a structure that influences social and cultural practices.

This article will put the concept of gender in relation to the medicalization of the reproduction process and its direct influence on the prospective parents' decisions during the offer of prenatal diagnosis. The practice of prenatal diagnosis during pregnancy gives parents information about their foetus' health, so in case of detected anomalies such as Down syndrome, they have to decide whether to continue the pregnancy or not. This moment of choice has at least two faces. On the one hand, it is voluntary and free from the interference of physicians and the state. On the other hand, including prenatal genetic testing in national screening programs makes them routine and standard decisions. Converting prenatal diagnosis into a popular mass-decision is legitimated by the ideas of risk and responsibility, health and illness, good and evil, from life worthy and unworthy of living. We become witnesses to tremendous transformations in what we consider to be responsible reproductive behaviour. The scope of testing increases because it is defined as a parents' right, not as an obligation. So the practice of prenatal diagnosis as a part of the genetic testing itself reveals its main characteristics through the control of reproduction.

Reproduction is a substantial and frequently latent part of biopolitical processes. It takes part in developing national policies and also has global dimensions: these aspects of Foucault's works are an object of growing attention in the field of feminist bioethics studies and in disability studies.[7]

Prenatal genetic testing (both invasive and non-invasive procedures) possesses three main biopolitical characteristics, which directly influence the capacity of free and autonomous choice:

- They are free to all parents, mothers to be, who want to use them;
- They treat all pregnancies as risky;
- They assume different discourses in the heart of which are future parents, especially the future mother – a subject of choice and an

[7] Penelope Deutscher, „The Inversion of Exceptionality: Foucault, Agamben, and 'Reproductive Rights'," *South Atlantic Quarterly* 107 (2008): 55-70.

object of governance in the same capacity of choice of taking or not prenatal testing.

THE MEDICALIZATION OF REPRODUCTION

The process of medicalization radically transforms reproduction from actual experience and capacity for autonomy, affecting women's bodies and reproductive functions to means of social control. From an intimate and private sphere, reproduction turns to a delicate and specific interaction between gender, sexuality, politics, economics, biotechnology and ethical dilemmas. The process of medicalization of reproduction reveals global changes, provoked by the status of biomedicine as a legitimate source of truth about the body. In the nineteenth century, building the national state was accompanied by the care of the national population and it gives different roles to men and women and different consequences for each of them.

The new demographic discourse was concerned with both increasing the number of national citizens and improving their overall "quality" in terms of health, productivity, and reproduction. Within this discourse, men's citizenship came to be defined largely in terms of their contributions as disciplined and conscientious soldiers and productive and compliant workers. Women, on the other hand, were assigned the primary responsibility for reproducing and ensuring the health and vigor of these "stalwart sons" of the nation.[8]

Over time, the ideological bond between women and motherhood and between women's citizenship and the quality of their reproductive contribution to the national body became increasingly tight. The new concern with the quantity and quality of national populations was accompanied by the "discovery" of children and their migration from the ideological margins to the center of concern in family life.[9]

By the latter part of the nineteenth century, these newly devised statistical and survey techniques were revealing declining fertility and

[8] Kalpana Ram and Margaret Jolly, *Maternities and Modernities: Colonial and Postcolonial Experiences in Asia and the Pacific* (Cambridge: Cambridge University Press, 1998).
[9] Phillipe Aries, *Centuries of Childhood* (London: Jonathan Cape, 1962); Jacques Donzelot, *The Policing of Families* (New York: Pantheon, 1979).

alarmingly high rates of infant and child mortality in nation after nation across Europe and North America.[10]

More generally, the high rates of infant and child deaths, as well as the declining birth rates, uncovered by the new methods of statistical analysis, were widely read as an abdication on the part of women to do their duty as citizens, either by not reproducing in sufficiently large numbers or by contributing to the premature death of their children through ignorance and the pursuit of irrational childbirth and child-rearing practices. In either case, the stage was set for a series of interventions whose objective was to medicalize motherhood, that is, to replace existing maternal understandings and practices with novel ones based on science and medicine. This was a project in which medicine and its auxiliary professions, as well as education, the law, and later on, the mass media, all played pivotal roles. Yet across the board, it was women who were assigned the core responsibility for learning and following the canons of scientific hygiene and medicine to ensure the successful birth, survival, and health of their children.[11]

"Good mothers" were those who did so, "bad mothers" those who did not. And since all women were expected to reproduce, their contributions to society increasingly came to be gauged by their "successes and failures as mothers."[12]

Medicalized definitions and categories thus had a powerful role to play in reconfiguring gender roles and meanings in the nineteenth and twentieth centuries. Ultimately, however, rather than unifying women in a joint project of scientific reproduction, they offered a new (and constantly mutating) set of tools for dividing, condemning, and regulating them.[13]

Either way, their reactions and responses as users, consumers, and, above all, as subjects of medical discourse and practice are barely audible.

---

[10] Leon Blum, *At the Breast: Ideologies of Breastfeeding and Motherhood in the Contemporary United States* (Boston: Beacon Press, 1999); J. Cole, *The Power of Large Numbers: Population, Politics, and Gender in Nineteenth Century France* (Ithaca and London: Cornell University Press, 2000), 15.

[11] Rima Apple, *Mothers and Medicine: A Social History of Infant Feeding, 1890–1950* (London and Madison: University of Wisconsin Press, 1987).

[12] Joshua Cole, *The Power of Large Numbers*, 15.

[13] Jacqueline Litt, *Medicalized Motherhood: Perspectives from the Lives of African-American and Jewish Women* (New Brunswick, N.J., and London: Rutgers University Press, 2000).

However, a rapidly growing number of feminist-informed ethnographic studies persuasively argue the inadequacy of such approaches and underscores both the scholarly and practical benefits of paying close attention to women's embodied experiences as they attempt to interpret and assign meaning to an ever-expanding array of reproductive technologies and practices.[14]

Current studies suggest that significant cultural differences between the scope and applications of different biomedical techniques and methods in the field of reproduction. "More than any other area of medical practice, the organization and provision of maternity care is a highly charged mix of medical science, cultural ideas and structural forces."[15]

So one of the problems which feminist bioethics deals with is the identification of the woman only as a mother and valuating her duty to care and to serve. The woman is the biological sex, who becomes pregnant, gives birth and raises the children. The new reproductive technologies make it possible to distinguish sexuality from reproduction. The sexual act becomes unnecessary for the human's reproduction. According to feminist argumentation, personal life and experience rather than abstract, moral reasoning is at the core of moral decisions and actions. The area of research of reproductive practices is located between public and private domain where the women's reproductive choices have been made. The concept of individual choice, even made as a choice of concrete medical behaviour and services, is always a part of some greater structural space. In the context of reproduction, these are the discourses of gynaecology, midwifery, demography and the idea of rights.

LIMITS OF CHOICE IN THE DECISION-MAKING PROCESS DURING PRENATAL GENETIC TESTING

Prenatal genetic testing is a part of biotechnological development and its integration into the reproduction medicalization process. In a way, biotechnologies are not only a means of increasing the control of human life but rather a tool to decrease the amount of suffering in it. According

[14] Margaret Lock and Patricia Kaufert, ed., *Pragmatic Women and Body Politics* (Cambridge: Cambridge University Press, 1998).
[15] Raymond De Vries., ed., *Birth by Design: Pregnancy, Maternity Care, and Midwifery in North America and Europe* (New York: Routledge, 2001).

to Freud, suffering has at least three sources: the power of nature, the weakness of the body and the insufficiency of regulations in family, state and society affairs.[16]

These assumptions lead up to the fact that every technology or practice of decreasing the suffering has to be accepted as an appropriate one. The person's choice is to define the limits of such interruption and this is the main ethical question: what will be its scope? The practice of prenatal diagnosis is not only a value-free application of some technology and free exercise of informed and rational choice. Its own existence influences the choice, making it impossible to refuse it. The choice, provoked by the information derived from the prenatal testing, is, nevertheless, action. Alternatives like not choosing, accepting things as they are, refusing such information are defined as a form of irresponsibility. So, on one side, the choice of prenatal testing has medical aspects, and on the other –moral ones, because the decision not to choose has to be justified.[17]

Variety of choices implies more significant responsibilities and technology demands and receives answers through people's choices. Because of the biotechnological implications, our knowledge and imagination related to the hidden foetus increases. The price of this knowledge reformulates the concept of parental care into quality control. In the past, when these tests did not exist, mothers used to interrupt pregnancy because of their situation and life plans and not due to the expected quality of life of the unborn child. When a mother is provided with such biomedical information, this transforms her into a moral pioneer who has to decide whether to allow her child into the world.[18]

THE DECISION FOR PRENATAL GENETIC TESTING

The choice of pregnant women to accept or refuse prenatal testing, to continue or to terminate the wanted pregnancy, emphasizes the meaning of disease and disability to life. To do prenatal testing means to be ready to accept a considerable amount of ethical dilemmas and personal risks

[16] Zigmund Freud, *Civilization and its Discontents* (London: Hogarth, 1975), 57-146.
[17] Mishelle Callon and Vololona Rabeharisoa, "Gino's Lesson on Humanity: Genetics, Mutual Entanglements and the Sociologist's Role," *Economy and Society* 33 (2004): 1-27.
[18] Rayna Rapp, *Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America* (London: Routledge, 1999), 3.

connected to such a decision. Reasons for accepting prenatal testing could be defined as purely medical, but the realization of such a decision is highly subjective. Research in the field of "risk" has shown significant differences between objective and subjective perception of risk because the latter depends on personality, level of information and scale of values, especially the value of good. As much as the idea of good is of value for a person, they will want to protect it, even from the minor harms and risks. Furthermore, what is important here is that every component of the prenatal testing (invasive and non-invasive) procedures could be a base for a dilemmatic situation.

The purpose of testing is to provide future parents with information about foetal health and detect potential anomalies indirectly so that future parents can be reassured of their child's good health condition. Most medical practices make a synthesis between diagnosis and therapy. A good diagnosis defines successful treatment and vice versa. In the implementation of prenatal testing, this connection is very controversial. They do not function as means of therapy because there is no cure for most of the detected anomalies. In fact, prenatal testing gives information, not therapy. Basically, because of this information, parents become responsible for the life or the death of their child and its eventual suffering if they decide to continue the pregnancy despite the detected disability.

The link between diagnosis, therapy and recovery is broken so the person's mind becomes a source of intense pain, confusion and anxiety. Overcoming this emotional state of shock is a task of great importance and considerable effort. Suffering has to be integrated into person's life and sense of authenticity. Separating the diagnosis from the therapy creates substantial moral conflicts and dilemmas because it happens during pregnancy. Moreover, pregnancy is an intimate experience between the mother and the child (foetus). Through prenatal genetic testing, the right to life of a child (foetus) is opposed to the mother's right of choice.[19]

The parental choice could be separated into two sides: deciding on whether doing prenatal testing at all, and what to do in case of a detected anomaly. Even though most test results are good and indicate the future

[19] Marianne Leuzinger-Bohleber, Eva Engels M., Tsiantis, J., ed., *The Janus Face of Prenatal Diagnostics – a European study bridging ethics, psychoanalysis and medicine* (London: Karnac Books, 2008).

child's health (97% of results), in the cases of a detected anomaly, the situation changes and so does the whole pregnancy. According to data collected by an EDIG study, the main factors for undergoing prenatal testing are maternal age and the results from the triple screen, which is a test for risk indication. The decision for testing is made quickly after a discussion with the physician and the partner with some cross-cultural differences. In Israel, for example, pregnant women make the decision by themselves, while in Greece, the role and authority of the physician is dominating. According to data collected in Germany, only 4% of the population would not undergo prenatal testing and this justifies the practice as a common decision during pregnancy.

Empirical profile of participants in prenatal genetic testing (EDIG, 2008)

Table 1. Reasons for undergoing prenatal testing

Reasons	Germany	Italy	Israel	Greece
Age	61.3 %	68.6 %	48 %	54.6 %
Genetic	8.3 %	3.6 %	15 %	8.8 %
Psychological	7.5 %	2.4 %	0.8 %	2.4 %
Risk assessment test result	13.3 %	12.1 %	23.4 %	17.6 %
Others	9.7 %	12.9 %	11.9 %	16.6 %

Table 2. How has the decision for prenatal testing been made?

Ways	Germany	Israel	Greece	Italy
Discuss only with my physician	18.7 %	14.2 %	28.8 %	16.9 %
Discuss with my partner	68.7 %	62.5 %	60.4 %	71. 2 %
Discuss with relatives	1.5 %	0 %	0.9 %	0.8 %
Discuss with both physician and partner	44 %	35 %	47 %	36 %
Discuss with physician, partner and relatives	12.5 %	10.6 %	7.2 %	5.9 %

Table 3. What kind of choice have you made?

Answers	Germany	Israel	Greece	Italy
Quick	74. 9 %	81.8 %	81.4 %	71.8 %
Complicated	16.5 %	12.9 %	4.7 %	25.4 %

Answers	Germany	Israel	Greece	Italy
Difficult	19.8 %	19. 5 %	18.6 %	13.6 %

Table 4. Is the prenatal testing-decision just yours?

Answers	Germany	Israel	Greece	Italy
It is my decision	16.4 %	27.7 %	11.7 %	9.3 %
It is our decision (me and my partner)	57 %	61.6 %	38.7 %	61.9 %
It is my physician's decision	1.8 %	0.9 %	1.8 %	0.8 %
It is our decision (me and my physician)	11.9 %	10.7 %	25.2 %	5.9 %
It is our decision (me, my partner and my physician)	25.1%	21.4 %	41.4 %	22.9 %

This empirical data illustrates that subtle, but important differences exist between different countries and that the same biomedical practices are accepted elsewhere in different, contextual ways.

THE DECISION AGAINST PRENATAL GENETIC TESTING

The decision against prenatal genetic testing could also be a part of the ethical dilemma. The very existence of the opportunity to test prenatally changes the moral and social implications of disability, even in its later appearance. For example, if prospective parents (namely the future mother) refuse to undergo such testing for Tay-Sacks disease and their baby has that condition, their birth will not be accepted as a tragic state of the art, but rather as a result of conscious and wilful ignorance.

There is a discreet but significant difference between sympathy in the case of a tragic, accidental life event compared to something avoidable. Such testing changes the shape of human solidarity, turning reproduction into an area of individual responsibility. The possibility to explain suffering or accident by chance is very restricted. The concept of individual choice and responsibility in the context of prenatal genetic testing changes not only the total amount of children born with disabilities but also the individual's perceptions of the role of suffering in our lives, transforming it into a rational calculation. The concept of

choice is a factor of great importance to the distribution and scope of prenatal testing.[20]

This choice, however, is located into a structurally- defined area of technological development, and it functions by itself rather than as a proof of individual freedom and autonomy. Moreover, this right of choice restricts the right of life, which becomes a subject of selection. In this context, the very structure of non-invasive procedures like the so-called risk-assessment triple functions not only as a way of optimizing prenatal testing, but as a normative artefact. The incorporative normativity influences our space for choice and our actions, when they are based on selective criteria. It embodies the connection between technical availability for anomalies' identification with the normative desire to prevent births of disabled children. This desire is driven by one of the basic principles in medical practice: the principle to avoid harm. For example, the desire to prevent the birth of a child with Down's syndrome is incorporated in the same methods used for its detection. So when the triple test is offered to the pregnant woman in maternity care services, this is a good example of an incorporative normativity, because the offer begins to function by itself, independently of the woman's decision whether to undergo testing or not.[21]

Primarily because of the provided information, the pregnant woman is responsible for making a choice. Even when her decision is not to undergo testing, it has already been an incorporated decision. Thereby, the increase of options leads to a decrease in the capacity to act independently. Every part of the decision-making process is rooted in the concept of benevolence for the child's sake – even the choice of selected abortion in the cases of detected foetal anomaly.

It is worth mentioning that the options for choice express a wrong dichotomy, located in the very heart of the medical model of reproduction: the choice between the desire for a healthy child and an opportunity of the woman to exercise her own autonomy not only to her body but also to her identity as a whole. This dichotomy is a modification

[20] Cathrine Mills, "Resisting Biopolitics, Resisting Freedom: Prenatal Testing and Choice," in *Resisting Biopolitics: Philosophical, Political and Performative Strategies*, ed. Wilmer, Stephen & Zukauskaite, Audrone (London: Routledge. 2015), 19.

[21] Marcus Popkema and Hans Harbers, "The Cultural Politics of Prenatal Screening," in *Inside the Politics of Technology: Agency and Normativity in the Co-Production of Technology and Society* (Amsterdam: Amsterdam University Press, 2005), 238.

of the Cartesian dualistic view of body and soul distinction and about the need to rationalize and discipline the latter.

PRENATAL GENETIC TESTING IMPLICATIONS: FOR PREGNANCY, MOTHERHOOD AND PARENTHOOD

In her article "How is technology changing the meaning of motherhood in Western Europe?" Lori B. Andrews expresses the opinion that the new biomedical technologies free and enslave women at the same in an almost invisible manner – using women's own convictions and perceptions. According to Andrews, the risks connected with the growth of the new reproductive technologies and practices are related to unsuitable experiments with women; unstable legal bias, regulating its use; diminishing the meaning of motherhood to "production, in the optimal case, of healthy children"; transforming reproduction to the production process with its own commercial and rational aims.[22]

The pregnancy of a woman is a crucial period, transforming its meaning: from private experience to an object of public control and attention to her decisions and way of life. The womb of the mother transforms into a semi-public territory and the woman's right of autonomy is regarded partly.[23]

In the light of prenatal testing and screening, women have to bear the physical and psychological consequences. In some cases of detected genetic anomalies, the information has a double effect – it reveals the health status not only of the foetus, but also of the mother, and changes not only the perception of the foetus, but also the very self-perception of the mother. Women are more inclined to worry about their test results and to feel guilty in cases of detected mutation. A Swedish survey about the attitudes to prenatal testing reveals that autonomy is more valued by women than by men.[24] 82% of women think that the decision for testing has to be made together with their partners as opposed to 20% of men. 40% of men think that specialists should make the decision. The decision

[22] Lorry Andrews, "How is Technology Changing Meaning of Motherhood," in *Women's Reproductive Rights*, ed. Idiakez, I. and Widdows, H. (Palgrave Macmillan, 2006), 124-140.
[23] Carol Barnett, "The forgotten and the neglected," *Golden Gate University Law Review* 863 (1993): 886– 887.
[24] Berit Sjogren, "Future use and development of prenatal diagnosis, consumers attitudes," *Prenatal Diagnosis* 12 (1992): 1-8.

to refuse testing is more important for women and, unfortunately, is the only form of autonomy, which they can make.

The growing use of prenatal testing is based on the conviction that women have an obligation to guarantee the health of their children. This obligation is often mixed with a sense of guilt:

- When a woman refuses testing and gives birth to a sick child;
- When a woman is obliged to inform her partner about the possibility of defective genes, so to promote his reproductive choice and freedom;
- When a woman undergoes testing and gives birth to a sick child, despite the bad results;
- When a woman undergoes testing and gives birth to a sick child, despite the good results (these are so-called false positive and false negative results).
- When a woman undergoes testing and makes a selective abortion.

Therefore, the very existence and use of such testing influences not only the individual choice, but also the social expectations and perceptions of pregnancy and motherhood. Apart from the fact that genetic disorders are rare, the pregnancy is perceived not as a natural state, but as a territory of risk and pathology. Besides, women are prone to underestimate these risks. This picture reveals the high degree of medicalization and trust in medical technology and authorities in developed countries. The necessity of medicalization is not biological but rather social, so pregnant women are expected to care about what they eat, what they drink, how they sleep, what they feel, how they live by appropriate medical standards for all these activities.[25]

The decision-making process during prenatal genetic testing is a good example of an amalgam between structural (macro) and individual (micro) factors. For medical specialists, the information about the use of prenatal testing is based on professional, legal and ethical norms and guides. From a medical point of view, the important evidence is based on concrete medical facts, statistical information about the detected anomaly and so on. There is a power and informational asymmetry

[25] Rebecca Kukla, *Mass Hysteria: Medicine, Culture, and Mothers' Bodies* (Lanham MD: Rowman and Littlefield., 2005).

between the medics and pregnant women. Pregnant women have to act according to the given information and their emotional balance to cope with it.

The concept of free, individual choice is nevertheless seen as a moral-neutral kind of it. However, the choice is never moral-neutral, especially when it is within the defined limits of someone's life and context. The very process of decision-making on an individual level has its roots in the woman`s reproductive history and visions of future, the so-called imaginary level. This process generates knowledge of the situation. According to the ethical theory, maybe the most appropriate way to conceptualize the practice of prenatal diagnosis is by the methods and framework of ethics of care with its accent on individual narrative and situation.

In the frames of the bioethical discourse, the experience is not only the reason for the emergence of bioethical problems, but also their solution. The moral challenge of the decision-making process on its emotional level has two important faces: relations and emotions. These are the essential accents of the situation as opposed to too normative and abstract ethical theories. This distance leads to a specific kind of ethical conflict, released in three directions, including prenatal testing in national screening programs produces social stigma to concrete disabilities.[26] Pregnant women are so involved in their own situation that they do not realize the morally problematic effects of testing at all, and due to this, the decision-making process is defined rather fragmentally.[27]

Medical specialists with their specific knowledge can see some of the morally problematic tendencies of testing, but their professional place in the structure (health care, maternity care, genetic consultation) creates inner rationality, which complicates their ability to criticize or to change these problematic issues. With its technology and social practice, prenatal diagnosis and testing produce normative effects.[28]

---

[26] Joan Rothschild, *The Dream of the Perfect Child* (Indiana University Press, Bloomington, 2005).

[27] Lucash Kovasc, "Taking Risk in Striving for Certainty. Discrepancies in the Moral Deliberations of Counsellors and Pregnant Women Undergoing PND," in *Ethical Dilemmas in Prenatal Diagnosis*, ed. Tamara Fischmann, Elisabeth Hildt (New York: Springer, 2011), 34.

[28] Hans Harbers and Marcus Popkema, "The Cultural Politics of Prenatal Screening," in *Inside the Politics of Technology: Agency and Normativity in the Co-Production of Technology and Society* (Amsterdam: Amsterdam University Press, 2005), 229-257.

The process of decision-making is the hardest in cases of detected anomalies and a positive diagnosis. At this moment, testing changes its meaning from an instrument of security and control to appeal to a woman's responsibility and consciousness, legitimating the choice of selective abortion. If an offer to test is made, usually during the visit to the maternity care, the pregnant woman cannot make the decision.[29] So the routinization of testing creates specific ethical controversy, insensitive to individual experience and circumstances.

Finally, compared to universal ethical norms, the value of individual narrative can also be under question. The emphasis of individual narrative reduces ethics to the calculation of subjective assessments of the situation and the significance of individual desires. This subjectivity can be morally problematic for a stable bias of moral choices and decisions.

BEYOND MORALITY OR SOME REMARKS ON CHOICE

So the main question of this article remains – is it possible to speak of morality in the context of reproduction, is there a space for real autonomy and integrated and fully understanding of the meaning of pregnancy and birth? Are there any means to empower absolute autonomy for pregnant women and in fact not limit its existence? I consider the role of midwives to be crucial in prenatal and postnatal care, seeing them as guides and supporters for mothers-to-be. I do not believe in the discourse of rights or bans, but I believe in imagination and personal transformation that can bring for the majority of us a sense of common shared values in the understanding of what life is about and. Every one of us, every living being on Earth has the most powerful weapon in their chest – the center of love that reminds us of the meaning of being right here and right now. Our only choice should be not to disturb it, neither by technology nor by the failures of our imagination.

[29] Eva M. Engels, "Experience and Ethics: Ethical and Methodological Reflections on the Integration of the EDIG Study in the Ethical Landscape," in *The Janus Face of Prenatal Diagnostics*, ed. Leuziger-Bohleber M., Engels E.-M., Tsiantis J. (London: Karnac Books, 2008).

CONCLUSION

Individual freedom is a leading principle and moral value in the governance of reproduction due to commercialization and technologization.[30]

On the one side, procreative liberty is not restricted neither by the state, nor by the "important others." The routine use of prenatal testing is evident in the most frequent choices pregnant women make. In the narrative of prenatal testing, norms are the health, the quality of life, the idea of a good life – life without suffering. It is not the disability itself that legitimizes the necessity of testing but the simple fact that anomaly threatens prosperity and the good life. Hence the biological concept of normality is equal to the idea of a good life. The practice of prenatal testing begins to function as a moral genetic code on an individual level – as a desire for normality and on a biopolitical, structural level, as a routinization of concrete, reproductive choices. On the other hand, morality is reduced to the value of genetic health in the frames and restrictions of an individual situation. The current biopolitics of reproduction operates through concepts of risk, insecurity, and individual responsibility, transforming natural states such as pregnancy into a challenge.

REFERENCES

Andrews, L. "How is Technology Changing Meaning of Motherhood." In *Women's Reproductive Rights*, ed. Idiakez, I. and Widdows, H. London: Palgrave Macmillan, 2006.

Apple, R. *Mothers and Medicine: A Social History of Infant Feeding, 1890–1950*. London and Madison: University of Wisconsin Press, 1987.

Aries, P. *Centuries of Childhood*. London: Jonathan Cape, 1962.

Barnett, C. B. "The forgotten and the neglected." *Golden Gate University Law Review* 863 (1993): 886-887.

Berger, P. *Invitation to sociology. A Humanistic Perspective*. London: Anchor, 1999.

Blum, L. *At the Breast: Ideologies of Breastfeeding and Motherhood in the Contemporary United States*. Boston: Beacon Press, 1999.

[30] Catherine Waldby and Melinda Cooper, "The Biopolitics of Reproduction," *Australian Feminist Studies* (2008): 57-73.

Callon, M. and V. Rabeharisoa. "Gino's Lesson on Humanity: Genetics, Mutual Entanglements and the Sociologist's Role." *Economy and Society* 33 (2004): 1-27.

Cole, J. *The Power of Large Numbers: Population, Politics, and Gender in Nineteenth Century France*. Ithaca and London: Cornell University Press, 2000.

De Vries, R., and Benoit C., van Teijlingen E. and Wrede S., eds. *Birth by Design: Pregnancy, Maternity Care, and Midwifery in North America and Europe*. New York: Routledge, 2001.

Deutscher, P. "The Inversion of Exceptionality: Foucault, Agamben, and 'Reproductive Rights'." *South Atlantic Quarterly* 107 (2008): 55-70.

Donzelot, J. *The Policing of Families*. New York: Pantheon, 1979.

Eagleton, T. *The idea of culture*. Hoboken: Wiley, 2000.

Engels, E-M. "Experience and Ethics: Ethical and Methodological Reflections on the Integration of the EDIG Study in the Ethical Landscape." In *The Janus Face of Prenatal Diagnostics*, ed Leuziger-Bohleber M., Engels E.-M., Tsiantis J. London: Karnac, 2008.

Freud, S. *Civilization and its Discontents*. London: Hogarth 1975.

Kovasc, L. "Taking Risk in Striving for Certainty. Discrepancies in the Moral Deliberations of Counsellors and Pregnant Women Undergoing PND." In *Ethical Dilemmas in Prenatal Diagnosis*, ed. Tamara Fischmann, Elisabeth Hildt. New York: Springer, 2011.

Kukla, R. *Mass Hysteria: Medicine, Culture, and Mothers' Bodies*. Lanham MD: Rowman and Littlefield, 2005.

Leuzinger-Bohleber, M., and Engels E-M., Tsiantis J., eds. *The Janus Face of Prenatal Diagnostics – a European study bridging ethics, psychoanalysis and medicine*. London: Karnac Books, 2008.

Litt, J. *Medicalized Motherhood: Perspectives from the Lives of African-American and Jewish Women*. New Brunswick, N.J., and London: Rutgers University Press, 2000.

Lock, M., and P. Kaufert, eds. *Pragmatic Women and Body Politics*. Cambridge: Cambridge University Press, 1998.

Mills, C. "Forthcoming. Resisting Biopolitics, Resisting Freedom: Prenatal Testing and Choice." In *Resisting Biopolitics: Philosophical, Political and Performative Strategies*, ed. Wilmer, Stephen and Zukauskaite, Audrone. London: Routledge, 2015.

Popkema, M., and H. Harbers. *The Cultural Politics of Prenatal Screening. In: Inside the Politics of Technology: Agency and Normativity in the Co-Production of Technology and Society*. Amsterdam University Press, 2005.

Ram, K., and M. Jolly. *Maternities and Modernities: Colonial and Postcolonial Experiences in Asia and the Pacific*. Cambridge: Cambridge University Press, 1998.

Rapp, R. *Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America*. London: Routledge, 1999.

Rothman, B.K. "Spoiling the pregnancy. Prenatal diagnosis in the Netherlands." In *Birth by design*. London: Routledge, 2001

Rothschild, J. *The Dream of the Perfect Child*. Indiana University Press, Bloomington, 2005.

Sjogren, B. "Future use and development of prenatal diagnosis, consumers attitudes." *Prenatal Diagnosis* 12 (1992): 1-8.

Waldby, C., and M. Cooper. "The Biopolitics of Reproduction." *Australian Feminist Studies* 23(55) (2008): 57-73.

Internet reference link:

"Poland rules abortion due to foetal defects unconstitutional," *The Guardian*. 2020. www.theguardian.com/world/2020/oct/22/poland-rules-abortion-due-to-foetal-defects-unconstitutional?CMP=share_btn_fb&fbclid=IwAR2d_qvzM_iZUM5CN0j8B4H2xf-I1H9QMeZx9YT709Q9ljQGqCPBXu2VrfU.