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Artificial termination of pregnancy in the risk of having an intellectually disabled child (within ethics of social consequences)

Abstract

Article deals with the problem of termination of pregnancy when the prenatal diagnosis proves the genetically impaired development of foetus. Author focuses on the solution of this issue within ethics of social consequences which represents a form of non-utilitarian consequentialism.

Analysis of given issue is addressed especially through the value of human dignity and humanity which function as an axiological fundaments of this ethical theory. Article includes the consideration of circumstances which can happen in this conflicting situation, particularly it addresses the fact that impaired fetal development may lead into various levels of intellectual disability of newborn child and it also discusses whether it would be in accordance with humanity and human dignity to bring such a child into existence.

Keywords: intellectual disability, ethics of social consequences, humanity, human dignity

INTRODUCTION

his article deals with the situation of parents when they find out that their foetus (unborn child) has certain genetic defect. Such genetically impaired development will result in a birth of child with intellectual disability. What should they do in such situation? Should the pregnancy continue or do they have a moral right to terminate the pregnancy and thus prevent this child to be born? Main aim of this article is to answer these questions and specifically to determine whether parents have moral right to prevent their child to be born. I think about this complicated situation within the ethics of social consequences.¹

Deeper analysis and especially critique of this theory focusing on the principle of maximization is offered by Kalajtzidis (6, 8). Ethics of social consequences represents methodological basis also for Komenská. She works with this theory within medical ethics. "Ethics of social

Moral right to life is in this ethical theory reflected through the value of human dignity and humanity. These values represent a concretization of moral right to life. I use same method in my further reflections; it means that in answering the question "Do the parents have moral right to prevent their child with intellectual disability to be born?" I consider if such decision and consequently termination of pregnancy is in accordance with the value of human dignity and humanity. For this, I consider as necessary to deal with the question of justifiability of abortion within the ethics of social consequences.

ARTIFICIAL TERMINATION OF PREGNANCY AND DIGNITY

Artificial termination of pregnancy is in this ethical theory directly connected with the value of life of foetus and so firstly it is important to answer the question whether the foetus has certain value. If this is not so and the foetus is not valuable, abortion would not be a problem because there would not be a destruction of valuable being.

In this ethical theory, value of life is ontologically conditioned and gradual. It is reflected within value of dignity that has several aspects, but in this case the first aspect- ontological is of most importance. All living entities and all life forms have certain value of dignity. Based on this, also a foetus (despite its genetically impaired development) as a particular life form has certain dignity and deserves respect and esteem from other moral agents. This value of dignity depends on the stage of fetal development, which means that the foetus dignity in the first trimester is lower than his dignity in the second or third trimester. It signifies that with ongoing development of foetus, the value of dignity which is attributed to this form of life increases too.

End of the first trimester (approximately 12 week) represents an important milestone in the fetal development. In this period of time, foetus starts to resemble human being and it means he fulfills basic morphological (physiological similarity) and functional features (existence of brain and brain activity) of human being. During further development of foetus, his value of dignity slowly moves towards the basic value of human dignity which is attributed to child in the moment of birth. "Therefore, until the moment of birth the foetus is only a potential human being and level of his dignity corresponds to this fact" (2).²

On the ground of this, artificial termination of pregnancy is not connected with the termination of life of human being. It is a termination of foetus life, or in other words, termination of potential human being's life. Gluchman claims that by the

consequences is not a theory of health care ethics but its authors often react to the contemporary issues of medical and bioethical discussions. Its normative basis is situated around primary values connected with the core of this ethics; the concept of life. Concretely, these values are values of dignity, humanity, and moral law" (10). These values represent an inspiration in formulation of concept of health and disease in ethics of social consequences which is based on holistic understanding of health (9).

² In ethics of social consequences, foetus in whatever stage of pregnancy is not a human being but he is a particular form of life with certain value of dignity. In the moment of birth he becomes a member of *Homo sapiens* species that represents the highest developmental form of life (so far). In this moment foetus becomes a human being and he is attributed a human dignity.

end of first trimester the foetus has not yet developed all basic morphological and functional features of human being, so we should not speak about the termination of human life (2).³ On this basis, I can conclude that there is not a violation of human dignity happening, but it is a violation of dignity attributed to this life form, it means to foetus. Moreover, it is important to add that the level of foetus dignity is several times lower than value of dignity of pregnant woman. Based on this fact, it is possible to understand the termination of pregnancy in the first trimester as right, because the value of human dignity of pregnant woman is higher that dignity of foetus on the ground of stage of his development.

However, the situation changes when we think about the abortion later in pregnancy. Artificial termination of pregnancy after 12 weeks is allowed only on basis of detection of genetic defects of foetus, which are usually detected in the beginning of second trimester (or even later) through the results of prenatal diagnosis. Gluchman highlights this situation too. "Even after the first trimester there can be a situation that the foetus in variety of reasons ceases to develop normally and it may lead to severe developmental and genetic disorders of foetus, which in extreme cases may entail a substantial developmental and genetic deformities or even the death of foetus" (2).

In this situation, the moral evaluation of action will be more difficult. This difficulty is connected with the stage of fetal development. Such foetus at later stage of pregnancy has already developed the basic features of human being and it means that abortion would violate the level of foetus dignity in more significant way than abortion in the first trimester of pregnancy.

Foetus increasingly resembles human being and based on his development his dignity increases too. Here lies the main problem of evaluation of potential abortion within ethics of social consequences. It takes into account a particular situation of pregnant woman and it emphasizes that it is necessary to focus on situation and life expectations of human foetus. According to Gluchman, in situation in which the life of pregnant woman is endangered and there is no chance for foetus to survive or there is a high risk of child's death shortly after birth, then the parents have right to decide what to do (2).

In other words, although the woman is in higher stage of pregnancy (dignity of foetus increases in dependence on his ongoing development), based on the developmental and genetic defects of foetus which threaten the life of pregnant woman and will presumably lead to foetus death, or death of newborn child shortly after the birth, in accordance with ethics of social consequences, the pregnant woman (both parents) has right to decide what to do. Despite the fact that termination of pregnancy in later periods is connected with greater extent of violation of foetus dignity, the decision for the abortion and related higher foetus dignity violation

³ In accordance with law nb. 73/1986 on termination of pregnancy, pregnancy can be artificially terminated at latest till to 12 weeks (3).

can be ethically and morally considered as right because such an action bring the prevalence of positive social consequences over negative social consequences (2).⁴

Among these positive social consequences belong for example the rescue of woman's life, termination of foetus suffering, or more precisely the prevention of suffering of newborn child who would die shortly after birth. In my opinion, such action is right (but not moral) and it is in accordance with the human dignity of pregnant woman which is higher that dignity of foetus.

Another possible situation which can happen is the situation of pregnant woman whose foetus develops with serious genetic defects but these defects do not threaten her life and also child after birth will be able to survive. Result of genetically impaired development will be some of the more serious levels of intellectual disability.

This woman has already exceeded the first trimester of pregnancy and like in the previous case the foetus has already developed basic morphological and functional features of human being. How should we evaluate the artificial termination of pregnancy in this case? Although foetus starts to resemble human being and based on his stage of development value of his dignity increases, it is necessary to remind again that level of his dignity is still lower than dignity of pregnant woman.

If we agree with abortion, there would be, like in previous case, more serious violation of foetus dignity. In my opinion, also in this case the parents have right to decide what to do with their unborn child, whether to terminate or proceed in gestation. The life of woman is not in danger, so there is not a direct conflict between the protection of woman's life and protection of fetal life. Both of them will survive woman as well as her foetus and also a newborn child will be able to live after birth.

Reflection on possible solution of such difficult situation should be based on particular circumstances in which the woman or couple is. It is needful to concentrate on the foetus conditions and his perspectives in life. I realize that it is never possible to specify exactly how seriously disabled the child will be after his birth. Well, let's at least hypothetically think about the situation where the genetically impaired fetal development will lead to the birth of child with more severe levels of intellectual disability.

These levels of intellectual disability are characterized by delays in development of understanding, in development of self-care activities, there is prevalence of non-verbal expressions in communication, typical is inability to control own emotions, problems with immobility, constant requests for attention, care and others (13). Individuals with more severe levels of intellectual disability are not able to realize the moral situation in society, to decide autonomously about their actions and to be responsible for their actions and its consequences.

⁴ The same attitude can be found also in valid legislation. Genetic defects of foetus represent a possible reason for artificial termination of pregnancy in period after 12 weeks of pregnancy (3).

Couple should all these matters take into account in deciding on how to solve their situation and pregnancy. More serious levels of intellectual disability may represent a certain suffering for foetus in question, also for couple and whole family that must adapt to new life with new terms. Such a disability may be also an economic burden for family because of needful regular medical checks, certain specialized instruments and tools which are necessary to meet the specific needs of individuals with these levels of intellectual disability. Couple also need to think about their ability of everyday care of child with this level of disability and whether they are ready to devote the majority part of their life in behalf of improvement, or at least preservation of certain quality of life of their child with intellectual disability.

All these matters (and many others) the parents should consider during their decision making process. On the ground of serious developmental and genetic defects of foetus that will lead to birth of child with more severe levels of intellectual disability, I hold the view that even the life of woman and child after birth are not threaten, the parents should have moral right to prevent this child to be born.

Such a decision and consecutive termination of pregnancy is in my opinion right, or more precisely morally justifiable. I think that termination of pregnancy in this case results in the prevalence of positive social consequences. Of course, there would be termination of foetus life that is connected with violation of his dignity which I consider to be negative social consequence resulting from this decision. Among positive social consequences of this decision belongs the prevention of suffering which child after birth and also during further life would face, as well as the prevention of suffering experienced by parents. Such parents' decision would avoid the increased economic burden on their family resulting from child's disability and also care that should be devoted to this child may be distributed among all other children in family.

During decision-making process, it is possible to take into account the fact pointed out by Singer (11). When the parents decide to terminate this pregnancy, they may have another child later without intellectual disability. When this couple is able to conceive a child without intellectual disability, their decision would bring even greater prevalence of positive social consequences. Of course, one pregnancy would be terminated, but later they would have another child without disability which in my opinion includes higher prevalence of positive social consequences, as in the case of life-long care of a child with severe level of intellectual disability.

In connection to this, I consider as important to emphasize that even the parents should have moral right to prevent their child with more severe levels of intellectual disability to be born, it is not their moral duty. Even their decision in favour of termination of pregnancy brings the prevalence of positive social consequences and such action would be right, or morally acceptable, particular decision itself should remain the matter of parents as moral agents who are directly involved in this ethically conflicting situation.

The third possible situation which can occur is the case, when the parents discover that their foetus develops with certain genetic defects, but it does not threaten the

woman's life and enables his birth and further life. Hypothetically, suppose it is known that this genetically impaired development of foetus will bring the birth of a child with mild intellectual disability.

Similarly, like in the previous cases, we speak about the foetus in later stage of his development. He has developed basic morphological and functional features of human being that means that the level of his dignity is higher than dignity of foetus in the beginning of pregnancy. But again, this dignity of foetus is still lower than dignity of pregnant woman. The question remains the same. Do the parents have moral right to prevent their child with mild intellectual disability to be born? Likewise in previous cases, also now I hold the view that parents and other people directly involved should have right to decide what to do in such situation. Parents as moral agents should be able to make autonomous and responsible decision with consideration of all circumstances involved.

In comparison with previous case, where the child with severe level of intellectual disability would be born, in this case the result of genetically impaired development is the mild intellectual disability which makes possible for individual to live valuable life. Although such individual will be probably partly dependent on help and support of parents, relatives and friends during life I think that his life may be valuable and of good quality. He is able to establish relations with other people, to act and bring positive social consequences to himself, to relatives and to whole society. As I have already mention, these situations are only hypothetical cases, as it is known that during the pregnancy it is impossible for the physicians to discover the exact situation of foetus and subsequently, how the situation will be when the child is born. It is impossible to state exactly the seriousness of intellectual disability, as well as it is impossible to suppose the abilities, skills and sorrows of future life of child with intellectual disability.

Based on this, it is very difficult to answer clearly on given question, whether the parents have moral right to prevent their child with mild intellectual disability to be born. As it has been mentioned above, parents as moral agents should be able to consider the consequences of particular decision and they should be able to bear a responsibility for their decision and action. In my opinion, after in-depth consideration about all positive and negative social consequences resulting from their decision, the parents have moral right to avoid the birth of child with mild intellectual disability. Such an action could be in ethics of social consequences identified as morally justifiable.

ARTIFICIAL TERMINATION OF PREGNANCY AND HUMANITY

Now I consider as important to analyze my basic question through the reflection on value of humanity. It means that I am trying to find out, whether the moral right to prevent the child with intellectual disability to be born is in accordance with value of humanity within ethics of social consequences. Humanity can be characterized as behaviour and action aiming to protection, support and development of human life (2). $^{\scriptscriptstyle 5}$

Ethics of social consequences distinguishes between humanity as a natural-biological feature and humanity as a moral feature. Humanity as a natural-biological feature is behaviour and action aiming to protection, support and development of life of our relatives, or in other words it is humanity on the basis of biologically determined social relations to relatives. Humanity as moral feature represents moral surplus value of behaviour and action of moral agent towards the unknown people. In this case, biological determination of social relations does not play a role in the moral agent's action. Gluchman understands such action as a manifestation of morality and it is result of cultural evolution and moral development of human being (1, 2).

Gluchman points to one interesting thing in connection to people with intellectual disability. Specifically human behaviour which is not based on biological or natural conditions, but only on moral basis is our behaviour towards the various disabled forms of human life and its protection and towards the unknown people. Such actions should result in protection and maintenance of their life, property, physical and mental integrity, their goals and purposes supporting and protecting their life (2).

On the ground of these opinions I conclude, that maintenance and development of life of people with intellectual disability is understood as moral surplus value, as it is specific action typical only for human beings. When the moral agents behave in human way towards their intellectually disabled relatives, or towards unknown people with intellectual disability, it is a manifestation of humanity as moral feature. On the basis of these opinions, it should be logical to conclude, that also parents who know that their foetus has a genetic defects and their child will be intellectually disabled, should behave in human way to this foetus and it means to take care of him, develop and protect this disabled form of life.

Similarly as I have emphasized on previous pages, I think that also in reflections about given topic within the value of humanity it is necessary to focus on particular circumstances, in our case on particular levels of intellectual disability which help us to think about it in more detail. It means that it is impossible to generalize, but it is necessary to think about particular levels of intellectual disability, because life with it is specific, includes different situations, possibilities but also limitations resulting from the specifics of individual levels. It is valid also in my attempt to answer the question whether it is human to continue in pregnancy or it is more human to terminate the pregnancy.

In investigation of possible answers to this question I focus on three situations which I have already presented above in the text. First situation is based on the genetically impaired development of foetus, which endanger the life of pregnant

⁵ Humanity in this ethical theory and especially in medical ethics is more discussed by Kalajtzidis and Gluchman (7).

woman and there is a high probability, that when the pregnancy will continue, child will die shortly after birth.

In this case, the most important fact is that this genetically impaired development of foetus threatens the life of woman. Protection of own life is understood as basic manifestation of humanity as a natural-biological feature (2). If we firstly do not protect our own life, it would not be possible to protect, promote and develop the lives of our relatives and also lives of strangers. Pregnant woman as moral agent has a special moral obligation to protect her own life to be able to behave in human way to her relatives (partner, children, and parents).

Based on this I believe, that in this particular case it would be in accordance with humanity if the woman (couple) decide for termination of pregnancy. Life or pregnant woman is at risk and in my opinion it is a significant reason so she has a moral right to prevent her child with serious intellectual disability to be born. It is the only chance to save her own life and by this to be able to realize humanity towards her relatives as well as unknown people in the future. This situation, on the ground of threat to woman's life permits the termination of pregnancy and this decision and subsequent action may be considered as human action.

Second situation includes the issue of termination of pregnancy in the case, when the genetically impaired development of foetus does not threaten the life of pregnant woman. When the pregnancy will continue, child after birth will survive, but through the prenatal diagnosis we may hypothetically presuppose that he will have some of the more severe levels of intellectual disability.

It is a little bit different situation like in former case. Life of woman is not at risk, as well as the foetus deformations will not lead to death shortly after birth. Child will survive, but he will have severe intellectual disability. On the ground of these circumstances it is very difficult to think if the termination of pregnancy could be consistent with humanity, as there is not a risk of death of woman or child.

In reflection on this question it is necessary to focus again on the life expectations of the child after birth. Is such a life with severe intellectual disability full-value or is it only a biological living of this organism? Suppose that more severe levels of intellectual disability are so heavy that development of such a child is limited, this individual would suffer almost whole life, and he would be dependent on the care of his parents also in the most fundamental everyday activities. This means that such a life could be define only as a biological living and not the living of high-class and full-value life. This situation is reflected also in ethics of social consequences. It inclines to the attitude that effort to protect, maintain and develop human life should not glide into the inhumanity and striving to preserve this life at any cost (2). Because of this, mentioned ethical theory distinguishes certain basic criteria belong a) biological (morphological and functional features of man); b) social (ability of speech, communication, maintenance of social contacts and interpersonal relations, individual's mobility, ability to care of self, moral judgement, planning

of future); c) mental criteria (consciousness, self-awareness, abstract thinking, free will, moral reasoning) (2).

Minimal criteria that are needful for distinction between real human life and biological existence of organism are represented by the presence of features fulfilling at least some of the social and mental criteria. "If human life does not contain any of social and mental features and abilities, it is only biological living of human organism and based on this we may treat him in the effort to preserve and maintain it" (2). So when we want to consider somebody as human being, there should be morphological and some of the social or mental criteria fulfilled.

Are some of necessary criteria fulfilled when speaking about the people with more severe levels of intellectual disability? By more severe levels of intellectual disability I understand moderate, severe and profound levels of intellectual disability. In reflection whether the individuals with these levels of disability fulfill at least some of needful criteria of human life it is needed to deal particularly with each of these levels.

If we think about the moderate level of intellectual disability, it is important to note that these individuals can communicate although their verbal speech is poor and badly articulated. They are able to acquire ordinary habits and skills, especially connected with the self-care. Their thinking is on the level of preschool children (14). It can be concluded that abilities of these individuals are significantly limited, but despite this fact they fulfil at least some of the necessary criteria of human life, for example ability of speech and communication, ability to self-care, consciousness. I believe that these individuals have life which resembles human life at least in minimal way and when we want to treat them in human way, we should protect and maintain their life.

Individuals with severe levels of intellectual disability in majority cases have comprehension usually limited to the understanding of basic relations and their thinking is approximately on the level of toddler. Speech is also limited; they can learn several verbal expressions but there may be inaccurate use of it. Their learning requires lifelong effort, by which they can manage to fulfill at least basic self-caring activities (14). On the ground of these characteristics, it is possible to deduce that individuals with this level of disability fulfill at least some of the basic criteria, which are in ethics of social consequences necessary for differentiation of real human life from biological existence of organism. Among these criteria belong the ability of speech and communication (although it is limited), they manage to take care of themselves to some extent and to be aware of situation around them. Based on this I believe that their life is not only a biological living organism, but it should be considered as human life worthy to live and to be protected, maintained and developed.

Profound level of intellectual disability represents significant limitation of individual's abilities and skills. Cognitive abilities of these people are almost undeveloped, they are at maximum able to differentiate known and unknown objects and react through the expression of emotions. They do not have fundamentals of

speech and they are totally dependent on the care of other people. They are usually placed in social care houses (14).

On the basis of these characteristics, I conclude that there are serious limitations in all important abilities that are necessary for fulfilment of basic criteria of human life. These individuals are not able to speak, to communicate and subsequently to establish and maintain social contacts and interpersonal relations, they are very often immobile, they need day-long care, they are not able to think about their future as in majority of cases they are not aware of the present time and even their existence.

Concerning profound levels of intellectual disability, it is possible to state the absence of necessary social and mental criteria of human life. In majority of cases it is better to speak only about their biological living of organism. In accordance with the ethics of social consequences, I think that when the content of human life does not at least in minimal way resemble human life, but it is only a biological existence of organism, protection, care and maintenance of such a life is not a moral value, because this life exists only in its natural-biological form and on the ground of it we should treat it (2).

Lešková Bláhová agrees with this approach. She claims that effort to protect human life should not change into the non-human action with main aim to preserve human life (which resembles more only a biological living organism and there is no assumption that this condition could change in future) at any cost (4, 5). In this case, human action would be to provide adequate health care which does not exclude a possibility of natural death. In connection to this, I agree with the Gluchman's opinion: "It is important to realize the widen dimension of the term humanity and do not reduce humanity only on the protection of life or preservation of any life at any cost" (2).

What does it mean in connection to my main question? When prenatal diagnosis proves that child will be born with profound level of intellectual disability, in my opinion it would be human for parents to decide for termination of pregnancy. By such action they will prevent the birth of child whose life (because of its profound disability) would not resemble human life, but it would be only a biological existence of organism.

In my opinion, the birth of this child would bring more suffering to child, his parents and relatives. In accordance with ethics of social consequences I hold the view that these parents have moral right to avoid the birth of this child. Artificial termination of pregnancy in such case would be considered as morally justifiable, as the level of foetus dignity is lower than dignity of pregnant woman.

It would be also regarded as human action, because by termination of pregnancy we would prevent the birth of child whose life would be at most biological living organism and not a full-value life. On the ground of this decision we would preclude the suffering of this child, parents and other relatives. Of course, I realize that abortion includes certain suffering and qualms of the parents, but I think that it is of lower extent than the suffering of child with profound intellectual disability.

The third possible situation which is necessary to reflect on, is the situation when genetically impaired development of foetus does not threaten the woman's life but it will result in birth of child with mild intellectual disability. Would be the termination of this pregnancy considered as human action too?

When I want to answer this question it is needful to think if the people with mild intellectual disability fulfil at least some of the fundamental criteria of human life. People with mild intellectual disability are in majority cases able to speak and communicate in everyday life, although their speech develops later. They manage to care of themselves and master various practical house-hold activities. Important for them is the education that should be directed towards the development of practical skills which can be used in their everyday life. There can be problems with theoretical work in the school, but despite it majority of these individuals are able to live alone as adults, to work, to establish and maintain good interpersonal relationships and to be a profitable member of society (12). Some of the people with mild intellectual disability have adequate cognitive and intellectual abilities so they are moral agents. Based on this I can deduce that majority of them fulfill some of necessary criteria of high-grade and full value life.⁶ These individuals fulfil some (not necessary all) social criteria, for example ability of speech and communication, maintenance of social contacts and interpersonal relations, planning of future and in majority cases also moral judgement. Among accomplished mental criteria in majority cases belong the consciousness, self-awareness and in some cases also free will.

I believe that concerning the people with mild intellectual disability we may speak about really human life and not only about biological existence of organism. It is confirmed by the ethics of social consequences. "Also in majority of minor genetic or mental disorders, there is a real chance that such individual will fulfill at least in minimal way these qualitative parameters of human life. Therefore, the care of them should be considered as a manifestation of humanity, and not only as natural-biological feature of human being which is common also for some members of animal world, but as a moral feature occurring only within human species" (2).

Based on this I conclude, that termination of pregnancy because of mild intellectual disability of future child should be considered as inhuman action. The life of people with mild intellectual disability may be valuable, qualitative, as they are able to establish social relations, to work, to have a family and friends, in other words to live a life very similar to ours.

⁶ I use the expression "majority of them" because it is not possible to generalize when speaking about the abilities of people with mild intellectual disability. There are various differences and specifics among these individuals. That is the reason of my rejection of generalization and I point to the fact that these statements are valid for majority (but not for all) individuals with mild intellectual disability.

CONCLUSIONS

In conclusion I want to emphasize that moral evaluation of artificial termination of pregnancy and reflection whether it is in accordance with the value of humanity and human dignity is a specific matter. It requires the perception of all aspects and particular situations which may occur, as for example the threat to life and value of human dignity of pregnant woman, also the life expectations and dignity of foetus. It is needful to think about life of child in the case the couple decide not to terminate the pregnancy. All these aspects are important in consideration of positive as well as negative social consequences resulting from their decision and subsequent continuation or termination of pregnancy. Anyway, I think that couple (parents) should have moral right to decide about the birth of their child with intellectual disability. It includes also a right to prevent such child to be born in dependence on the level of intellectual disability and following consequences.

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