

- отсутствие системы стимулирования волонтеров к участию в таких исследованиях;
- несоответствие отечественных стандартов (включая финансовые) проведения исследований мировым образцам.

Более детальное изучение структуры биоэтических представлений ученых-медиков показывает, что общее положительное отношение к биоэтической экспертизе и понимание важности решения этических проблем не отражает внутренних противоречий системы «исследователь – испытуемый – социум» и системы «методология биоэтики – практика этической экспертизы». Наличие такого противоречия создает не только дополнительные «риски» возможного нарушения прав пациентов-испытуемых, но и может вызывать сомнения в достоверности полученных научных данных. Для гармонизации указанных противоречий может быть полезной (из данных нашего опыта как членов локальной комиссии по биоэтике) следующая последовательность подготовки исследователя-медика к прохождению этической экспертизы в локальных комиссиях: предварительная консультация по процедуре (СОП), текущие консультации по выявлению конкретных этических проблем и способов их решений в конкретном исследовании; анализ взаимосвязи всех аспектов (научных, этических) данного исследования в диалоге с назначенным экспертом–консультантом от локальной комиссии; итоговая защита протокола (во время заседания локальной комиссии) и т.д. Указанный подход, по нашему мнению, позволяет:

- контролировать «методическое» качество процедуры этической экспертизы и корректировать ее процедуру;
- формировать компетенции соискателей как будущих членов локальных этических комиссий;
- выявлять и систематизировать характерные особенности этических проблем по различным медицинским специальностям.

Особое место при подготовке исследователей к проведению этической экспертизы должна занимать процедура оформления *информированного согласия*. Это связано с проблемой, которую Ф. Фукуяма в книге «Наше постчеловеческое будущее» выразил следующей сентенцией: «...В сообществе исследователей, работающих в биомедицине, есть много талантливых, целеустремленных, энергичных, порядочных и вдумчивых людей, но их интересы не обязательно соответствуют интересам общества. Ученым во многом движет честолюбие, а зачастую и денежная заинтересованность в каких-то конкретных технологиях или медикаментах...». И эта проблема остается даже при гармонизации всех правил оформления информированного согласия. Речь идет о разном понимании такой процедуры со стороны исследователя и со стороны пациента. Основная причина возможного «непонимания» (и, соответственно, неполного соответствия условий биомедицинского исследования критериям информированного согласия) – в различии «языков» исследователя, с одной стороны, и испытуемого, с другой. В основе языка исследователя лежат такие понятия, как цель исследования, методы и объекты исследования, метод математической обработки данных и т. д. – все то, что составляет методологический аппарат научного исследования. Несмотря на наличие врачебной этики (в виде клятвы Гиппократова или ее современных вариантов), этот понятийный аппарат часто доминирует в сознании исследователя. Язык испытуемого – это другое измерение: индивидуальная польза, облегчение страданий или дискомфорта, желание получить какие-то дополнительные преимущества (эстетические, физиологические) от участия в исследовании, нравственное желание принести пользу другим людям. Эти разные подходы гармонизировать, объединить, или хотя бы сблизить.

Процедура этической экспертизы проектов и результатов биомедицинских исследований должна включать в себя не только этико-научный анализ (по стандартным критериям) представленных материалов, но и методологический и дидактический контроль уровня понимания исследователями сущности этической экспертизы. Отсутствие единства между формальными требованиями (критериями) к протоколам и пониманием исследователем моральной сущности биоэтической экспертизы может привести к негативным последствиям, к излишней бюрократизации биомедицинского исследования, а также затруднит процесс внедрения методологических принципов и стандартов доказательной медицины, частью которой, по нашему мнению, можно считать и принципы «доказательной» биоэтической экспертизы.

Все перечисленные вопросы обнажают круг задач обновления биоэтической экспертизы и стимулируют практические решения центральной Комиссии по биоэтике НАМН Украины.

BIOETHICAL DILEMMA IN CASE OF FETAL ABNORMALITIES

БИОЭТИЧЕСКАЯ ДИЛЕММА ПРИ АНОМАЛИИ РАЗВИТИЯ ПЛОДА

V. Chiriac, I. Banari
В. Курияк, И. П. Банарь

*The State University of Medicine and Pharmacy «Nicolae Testemitanu»,
 Chisinau, Republic of Moldova
 vladlena.chiriac@yahoo.com*
*Государственный университет медицины и фармации им. Николая Тестемицану,
 г. Кишинев, Республика Молдова*

The 21st century medicine comes with major improvements in prenatal screening due to growing sophistication and use of technology that can detect a physical or genetic abnormality, but also with considerable improvements in

medical care, which means that even extremely premature babies or very ill ones now have better chances to survive and to make a good recovery. However, it can be difficult to predict the outcomes with great accuracy, whether the baby will die shortly after birth, will completely recover or will develop disabilities. This means that the family or the woman herself and the doctors often have to make a decision regarding the pregnancy, whether to keep it or terminate it, which can be very emotionally demanding for all the participants involved in the decision-making process. It is well known that the issue of abortion for fetal abnormality has become probably the most contentious of those raised in debates that involve abortion in recent times.

Медицина XXI в. внесла огромный вклад в область перинатальной диагностики. Благодаря использованию новейших технологий, стало возможным не только обнаружение физических и генетических аномалий плода, но и значительно улучшилось качество оказания медицинской помощи. Это означает, что даже у недоношенных и очень больных детей шансы на выживание стали гораздо лучше, чем в прошлом веке. Однако очень сложно сделать точный прогноз в том или ином случае – умрет ли ребенок вскоре после рождения, выздоровеет или останется инвалидом. Это означает, что перед женщиной, ее семьей, а также перед врачами, нередко стоит непростой выбор – сохранить или прервать беременность? Такое решение может быть крайне сложным и эмоционально истощающим для всех участников его принятия. Поэтому одним из самых спорных в ходе дискуссий на тему аборта стал в последнее время вопрос об аборте по причине аномалии развития плода.

Keywords: medicine, ethics, fetal abnormalities, termination of pregnancy, abortion, decision making, eugenics.

Ключевые слова: медицина, этика, аномалии развития плода, прерывание беременности, аборт, принятие решений, евгеника.

The 21st century medicine comes with major improvements in prenatal screening due to growing sophistication and use of technology that can detect a physical or genetic abnormality, but also with considerable improvements in medical care, which means that even extremely premature babies or very ill ones now have better chances to survive and to make a good recovery. However, it can be difficult to predict the outcomes with great accuracy, whether the baby will die shortly after birth, will completely recover or will develop disabilities. This means that the family or the woman herself and the doctors often have to make a decision regarding the pregnancy, whether to keep it or terminate it, which can be very emotionally demanding for all the participants involved in the decision-making process. It is well known that the issue of abortion for fetal abnormality has become probably the most contentious of those raised in debates that involve abortion in recent times.

In the Republic of Moldova abortions are lawful during the first 12 weeks of gestation upon request and until 21 weeks for medical reasons, one of these being where there is a risk of fetal abnormality. It currently has become a source of some controversy. Statistics show that in the Republic of Moldova that in 2017 7841 abortions were performed upon request up to 12 weeks, 681 on medical grounds until 21 weeks and 184 within 13 and 21 weeks. There are people who argue that the existing law regarding abortion on fetal abnormality grounds is eugenic in this respect and encourages discrimination against disabled people. Thus, the impression was created that the abortion of a malformed fetus is especially elitist and unjust, and comes as an attack against the most vulnerable, offending disabled people and sending them a message that they are inferior and less valuable than the able bodied [4].

Defined properly, eugenics is a set of beliefs and practices that aim to improve the genetic quality of human population by manipulating the genetic inheritance through the control and shaping of human reproduction. Thus, it aims to improve the qualities of the species rather than of an individual. Some societies and governments have attempted to apply this doctrine in practice. The most notable example was provided by the Nazi party in Germany, which supported human geneticists in their eugenic research in return for practical support for the party's race policies [5, p. 79–80].

In current practice, I see the termination of pregnancy on fetal abnormality grounds discriminatory in another way: basically it institutionalizes killing of fetuses with malformations regarded to be severe, but not of fetuses with perceived minor ones. This is discrimination against fetuses with disability, which is also a form of eugenics. So when a professional practice (or law) only allows termination of pregnancy when there is fetal abnormality, this discriminates against abnormal fetuses. While pregnancy termination may not be mandatory, its effect is eugenic anyway. On the other hand, many people would object that current practice is not eugenic because the intention of it is to offer choice regarding continuing a pregnancy with a major abnormality, and not to promote a healthier population [2, p. 166].

In this context, it is hard to say that abortion, when there is evidence of fetal abnormality, makes a part of a social strategy to reduce the number of disabled people in society, because the decision to end the pregnancy or to proceed with it is ultimately the woman's, not her doctor's, nor anybody else's. And if the woman herself or together with her family choose to do so, it is not hard to understand why, as the discovery of a fetal abnormality changes her expectations about what her future family will be like, so such an attitude to her pregnancy does not make any social statement about the abnormality or about disabled people in general, but rather about herself and what she is ready to cope with and what she wants, since she will have to live with the consequences of this decision. So, in conclusion, it is not a matter of eugenics, but rather a matter of women's control over their lives and future. [4]

Emotions play an important part in the moral decision making process, which makes it not just a matter of detached rationality in this regard. However, decisions often have to be made by parents and medical staff, frequently in stressful

circumstances and with very little time to consider the clinical options, so I find it essential that any discussion of ethical issues should seek firstly to be impartial, dispassionate and have practical relevance to the decision makers, equally acknowledging the great personal significance and, consequently, the strong feelings of those who are involved. In general, parents are considered to have the moral authority to make decisions regarding their future child, but sometimes they might not wish to make decisions that would result in the death of their baby, preferring the doctors to make such a decision on their behalf.

In this regard, I think it is a matter of duty that health care professionals have to give attention to the emotional distress the pregnant woman might be experiencing and to provide emotional support when needed in relation to screening, confirmatory testing, giving bad news, making abortion decisions or making management decisions after birth. The ethical principle of autonomy creates a duty of the doctor to help the pregnant woman make informed management decisions based on her values and goals. Thus, a recommendation for a particular approach to management is sometimes ethically justifiable on the basis of an analysis of the risks and benefits to the mother and fetus [3, p. 22–23].

So, the healthcare professionals have to make every effort to convey relevant medical information to the parents and to provide them with proper counseling. During the counseling process, there is a set of key prognostic questions that parents are likely to ask after the diagnosis of a congenital malformation:

1. How certain can practitioners be about the diagnosis?
2. What are the chances of survival past the new-born period if treatments are provided?
3. If life-sustaining treatment is provided, how long is the child likely to survive?
4. What long-term health problems and impairments are the newborns about to experience, if they survive? What are the possible outcomes?
5. What are the treatments that would be required to keep the newborn alive and how burdensome would these be for the child and the family?

However, doctors' command of medical knowledge does not make them able to predict the future health of the baby with 100 % accuracy and it doesn't give them any moral authority to decide on the baby's or parents' best interests. This is why all the participants in decision making should strive to reach an agreement and every effort should be made to secure the consensus with the parties.

It is sometimes argued that there is a tendency among medical professionals of encouraging women to abort an abnormal pregnancy. But is that an assumption that they value the lives of normal children above the lives of those with disability? This question is arguable and I think this happens because they tend to see abortion on grounds of fetal abnormality in the context of preventing an illness. Some people could find this objectionable, but I think that such objections are irrational, because, as long as it doesn't harm the women's autonomy and their right to make decisions according to their conscience, the doctors, as members that are also involved in critical care decision making, have to fully right to hold deeply personal views about moral status of the fetus.

There is one important question that should concern all those involved in decision making process, regarding the value of life of the fetus: weather is it equal to that of an adult person with self-conscience or not? And if not, how does it influence critical care decision? Does it support the statement that humans have different value (or moral status) at different stages of development?

The doctrine of the "sanctity of life" is saying that taking the human life is absolutely wrong, as all humans are of equal value and should be treated with the same respect. Some people interpret this as an absolute right to life, in both moral and legal aspects. This absolutist position is often defended in religious terms, and one influential line of argument in this respect is that man is made in the image of God, and only God may take life. The "sanctity of life" concept can be contrasted with the "quality of life" view, that does not recognize an absolute right to life nor a duty to preserve it, but rather judges whether is a life worth preserving in terms of its quality.

According to the last view, regarding the quality of life, there are people who would see a life with a severe physical or mental impairment not worth living. But there are many severe disabled people that report they are fine with their lives and they do not regard their life less valuable than the lives of the others. Judgements on quality of life may rather reveal prejudices and conclusions based on preconceptions in a society where at the moment disability tend to be seen as an expression of identity [3, p. 11–14].

Getting back to the moral status of the fetus, there are a lot of debates over this subject. For example, some people hold that the human embryo from the biological moment of conception has the same moral status as a born living human person. They place importance upon the formation of one (or more) new individuals with unique genetic identities at the point of fertilization. For other people, the relevant threshold relates to the earliest appearance of structures needed for the central nervous system to function. Others argue that in moral terms a more developed nervous system should be the focus of concern, such as the emergence of the first components of the central nervous system, and developments in the brain that allow sustained awareness. Some philosophers consider that the point of birth is highly significant, as a new and in many senses independent being has been brought into existence. Others contend that full moral status is only reached when an individual possesses self-consciousness [3, p. 13–14]. As this does not appear to develop until some months after birth, on this view not only the embryo and fetus, but also the newborn baby and the young infant, lack the moral status of a fully self-conscious person. Central to this position is the claim that it is the capacity for self-consciousness and self-valuing that gives humans their unique status as moral agents.

But Is actually the aborted embryo or fetus a human being?

This question is probably the most important single question in the entire controversy that concerns abortion. This question must be treated with care, because in fact there are two questions which should not be confused. There is the factual question settled by biology and the other is a philosophical or theological question, and one's answer to it depends on the whole world-view and sense of values of a person.

The factual question is: in the reproductive process, at what point does the human individual originate?

This question which refers to biology is the easier one to answer. Life proceeds from life, and human life from human life, in a continuous process. New individuals emerge from existing individuals. Relative to parents, the individuality of the offspring must be admitted to beginning at conception. The sperm and the ovum, before the fertilization, obviously can be considered as belonging to those from whom they derive. But once the conception process takes place, there starts to exist a cell which cannot be identified with either parent. The fertilized ovum is something derived from two sources and the duality of the sperm and ovum are continuous with the duality of the two parents. Thus, the proper demarcation between parents and offspring is conception, and so the new individual begins with conception. From this point of view, then, it is certain that the embryo from conception until birth is a living, human individual.

The philosophical or theological question is quite distinct: should we treat all living human individuals as persons, or should we accept a concept of person that will exclude some who are in fact humans, alive, and individuals, but who do not meet certain additional criteria we incorporate in the idea of "person"? Generally, the person is considered to be the subject of rights, and so once it is admitted that a person exists, there will be a very broad consensus that the embryo has at least at first sight the right to continued life, since this right is more fundamental than any other.

In conclusion, facts are relevant but never decisive, and a mere declaration of a restrictive definition of personhood is not an argument but merely begs more questions [1, p. 273–274].

REFERENCES

1. *Germain, G.* Abortion. The Myths, The Realities, and the Arguments. – New York and Cleveland: Corpus books, 1970. – 559 p.
2. *Savulescu J.* Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion// Journal of Medical Ethics. – 2001. – № 27(3). – P. 165–171; Critical care decisions in fetal and neonatal medicine: ethical issues//Nuffield Council on Bioethics 2006. URL: www.nuffieldbioethics.org. 276 p. *Furedi A.* Abortion for fetal abnormality: ethical issues// available on www.prochoiceforum.org.uk.
3. Genetic screening ethical issues//Nuffield Council on Bioethics 1993. URL: www.nuffieldbioethics.org. 130 p.

БИОМЕДИЦИНСКАЯ ЭТИКА В КОНТЕКСТЕ ЦЕННОСТНО-НОРМАТИВНЫХ ТРАНСФОРМАЦИЙ СОВРЕМЕННОГО ОБЩЕСТВА

BIOMEDICAL ETHICS IN THE CONTEXT OF VALUE AND NORMATIVE TRANSFORMATIONS OF MODERN SOCIETY

Е. А. Коваль¹, А. А. Сычев², Н. В. Жадунова²

E. Koval¹, A. Sychev², N. Zhadunova²

¹*Средне-Волжский институт (филиал) Всероссийского государственного университета юстиции
(РПА Минюста России), г. Саранск, Российская Федерация*

²*Национальный исследовательский Мордовский государственный университет*

им. Н. П. Огарева, г. Саранск, Российская Федерация

nwifesc@yandex.ru, sychevaa@mail.ru, zhadunovan@mail.ru

¹*Middle-Volga Institute (branch) of Russian State University of Justice
(MOJ Russia RPA) in Saransk, Russian Federation*

²*Ogarev Mordovia State University, Saransk, Russian Federation*

Нормы современной биомедицинской этики принципиально отличаются от нормативных положений медицинской деонтологии, основанной на идеях Гиппократов. Если в деонтологической модели отношений «врач – пациент» последний находится в зависимости от врача, то модель, предлагаемая современной биомедицинской этикой, переворачивает эти отношения. В этой модели, основанной на идеях прав человека, справедливости, автономии, пациент приобретает большой объем прав, однако инерционно возлагает ответственность за свое состояние на врача, фактически оказывающего медицинские услуги. Это порождает ряд практических проблем, в частности, дискредитацию профессионального статуса врача, избыточную нормативную регуляцию его деятельности, дисбаланс прав и обязанностей пациента. Для их решения может потребоваться дальнейшая трансформация нормативных оснований биомедицинской этики.