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Право ребенка на пренатальной стадии развития на получение педиатрической паллиативной помощи

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Резюме

Статья посвящена вопросам о сущности, природе и объеме гарантий права ребенка на пренатальной стадии развития на педиатрическую паллиативную помощь, в целом комплекса прав такого ребенка как пациента. Авторы подчеркивают способность ребенка на пренатальной стадии развития (с определенного возраста) чувствовать боль и страдать от нее, определяя право ребенка на дородовом этапе на защиту от боли. Авторы объясняют, почему право ребенка на пренатальной стадии развития на получение паллиативной медицинской помощи (при ее необходимости) подлежит юридическому признанию, правовой охране и защите.

Ключевые слова: *право ребенка на пренатальной стадии развития на получение педиатрической паллиативной помощи, ребенок на пренатальной стадии развития, паллиативная помощь, права пациентов, боль, страдания*

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A child's right to receive pediatric palliative care at prenatal stage

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Abstract

This paper is aimed at outlining the essence, nature as well as range of child's guarantees for receiving pediatric palliative care at prenatal stage including common scope of the rights for such patients. It is emphasized that a child at prenatal stage (starting from certain age) is able to feel pain sensation and suffer from it, thereby underlying its right for palliative care. It is underscored as to why a child's right at prenatal stage for pediatric palliative care (if necessary) is subject to legal recognition and legal protection.

Key words: *a child's right to receive pediatric palliative care at prenatal stage, a child at prenatal stage, palliative care, patients' rights, pain, distress*

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Author's contribution

Authors contributed equally to this article.

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Introduction / Введение

Among the above-mentioned rights of the little patient, special complexity for interpretation and justification is attributed to the right of the child at the prenatal stage to palliative medical care [1], which is illustrated by the known maxim: "If the person can not be cured it does not mean that aid can not be rendered".

The issue of the right of such a child to palliative medical care theoretically and, especially, practically is not studied.

It can not be said that the right of the child at the prenatal stage to palliative medical care is absolutely ignored by scientists. But from the constitutional and legal, medical and legal, and bioethical points of view, the specified right is almost not studied and not described.

Besides, according to Anita Catlin and Brian Carter, though it is extremely important that the development and vitality of the fetus are to be discussed with families, the prenatal palliative care hardly appeared the subject of public discussions [2].

The foregoing predetermines the need for scientific research and discussion of this complex of questions.

Essence of the right of the child at the prenatal stage to palliative medical care (in case of need) / Сущность права ребенка на пренатальном этапе на паллиативную медицинскую помощь (в случае необходимости)

Pregnancy cases complicated by fatal anomalies of the human fetus bring up a number of complicated problematic issues – both for obstetricians and for pediatricians. Some expected progress in prenatal diagnostics, even today, create the conditions for exception of the need for late induced abortion. The alternative in the form of possible perinatal palliative care relieves parents and doctors of induced abortion [3].

In the preface to the Charter for the Rights of the Dying Child, the authors, Franca Benini and Roberta Vecchi emphasized that dying is not an obstacle for observance of human rights. On the contrary, fragility and complexity of the condition of the child increases their value and does not leave an opportunity for refusal [4].

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According to article 27 of Law of Iceland No. 74/1997 dd. 28.05.1997 (edited in 2014) "On the rights of patients" [5], "all possible actions are to be done *to provide the sick child with the opportunity to develop and enjoy life*, despite the illness and medical treatment as far as the condition of the child allows…".

In the field of rendering pediatric palliative care, it is traditional to consider that children can pass from the healthy to unhealthy state according to the following four possible scenarios [6]:

– the child has potentially curable disease, but the treatment does not give the expected positive results;

– it is expected that intensive therapy can prolong or improve life, but probably premature death will occur;

– a progressing disease of the child which does not respond to treatment in modern conditions is diagnosed;

– the child has non-progressing disease, but there is a threat of premature death because of the general weakness of the organism and complications, such, as, for example, respiratory infections.

The essence of the right of the child at the prenatal stage to palliative medical care (in case of need) is that to such a child even in the conditions of the medical forecast of the child's frailty (during some foreseeable period of time including the time after the birth) or weak viability, the necessary pediatric palliative care is to be provided [7], focused on reduction of the child's sufferings, including physical (painful), to the possible extent.

That is, in other words, if we know that the child has weak chances to live for more than several days or weeks after the birth or even to be born, it can not be the basis for refusal in medical care and, especially, – the basis for devitalization of the child (accepting that there can be (and it happens quite often) a mistake or another defect of the diagnosis [8]), but it is presumed as the basis (and the reasonable requirement) to create all the necessary conditions in order that the child would live the life (even short, even if the child is not born alive) in compliance with the ideas of normal human existence (without heavy, especially, – intolerable, sufferings), the ideas of human dignity.

It is not about artificial extension of the process of dying by means of use of disproportionate and obviously excess, unjustified measures of medical character only prolonging the strongest sufferings of the little patient without hope to cure the child or to rescue the child from inevitable fast death. It is about recognition of human dignity of the child at the prenatal stage and creation of the conditions for proper life during the period provided (with the stopped or softened factors of sufferings).

It is conventional that the pediatric palliative care is directed neither on acceleration of death, nor on extension of sufferings of the child, it is directed on assistance to the child and the members of the child's family in adoption of the most optimum decisions on spending the time which they have together, and also assumes support of their hopes for treatment, extension of life or improvement of the quality of life [9]. And this approach quite reasonably can be and must be applied also to the child at the prenatal stage of development.

Application of pediatric palliative care to the children at the prenatal stage is closely connected with application of the same care to newborns.

As Stephen R. Leuthner notes, "more and more growing number of scientific publications devoted to neonatal period supports application of palliative care to newborns. Three main categories or symptoms at which possibility of application of palliative care is considered and discussed with families are allocated: 1) the newborns born with the state at the viability limit, 2) the newborns with innate anomalies which are considered incompatible with long life, and 3) the newborns with incurable diseases with no reaction to vigorous life-supporting medical treatment, or the newborns for whom the proceeding treatment can prolong sufferings [2] … Can the same categories be used in fetal palliative care? … The way to treat the decision-making process in providing palliative care at birth, is defined by the three factors: 1) definiteness of the diagnosis, 2) definiteness of the forecast, and 3) role of this forecast for future parents. These three factors are to be considered before development of any plan of fetal palliative care. In order to allow the future parents to make a deliberate decision, they need to consult with neonatologists and other pediatrician specialists to understand the diagnosis and the forecast. Only then, the family can realize the importance of this forecast for their family and their future child. The process of fetal consultation with neonatologists or other experts in pediatric medicine is crucial for development of these plans … First, the degree of accuracy of the diagnosis or forecast has to be defined. Secondly, it has to be defined, whether this situation is such when the value of this forecast allows the doctor and the parent to provide palliative care in the best interests of the newborn" [10].

Stephen R. Leuthner specifies that "despite existence of restrictions in diagnostics at the prenatal stage, some prenatal tests can easily and precisely define the diagnosis. The prenatal diagnosis has to correspond to one of the three levels of accuracy. 1) At the first level, it is authentically known that the diagnosis is fatal. In other words, the diagnosis and the forecast are accurate … If the diagnosis is a certain fatal anomaly at which providing any intensive therapy can be considered irresponsible, the palliative care has to be a recommended option, there is no need in the vigorous treatment test for the child. Diagnostic accuracy of the fatal state allows perinatal palliative care to become one more option, as an alternative to artificial termination of pregnancy, possibly, even the desired option for observance of the best interests of care of the newborn if the termination of pregnancy did not happen. 2) At the second level, even if there is a confidence in some diseases found as the result of diagnostic process which threaten the fetal, the basic final diagnosis is not clear. 3) At the third level, even if there is a confidence in

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the diagnosis, the forecast is ambiguous. At the last two levels, the research of accuracy of the forecast helps to make the decision irrespective of whether palliative care at birth is the acceptable option. If the obvious diagnosis is unattainable, but the fatal forecast is exact, palliative care at childbirth can be offered. When the forecast reaches the level of clarity, palliative care as option becomes care standard even if the diagnostic reason is not clear. As the forecast becomes less certain, research of the best interests of the child becomes more and more difficult" [10].

Why is the right of the child at the prenatal stage to palliative medical care subject to legal recognition and legal protection (in case of need)? / Почему право ребенка на пренатальном этапе на паллиативную медицинскую помощь подлежит юридическому признанию и правовой защите(в случае необходимости)?

Determinants of obligation of legal recognition by the state and legal protection of the right of the child at the prenatal stage to palliative medical care (if necessary):

1) proof of the ability of the child at the prenatal stage (from a certain age) to feel pain and to suffer from it, that determines the right of the child at the prenatal stage to protection against pain;

2) the child at the prenatal stage is an independent living human being with own [11] legal personhood which is subject to recognition by the state.

Ability of the child at the prenatal stage (from a certain age) to feel pain and to suffer from it, determining the right of the child at the prenatal stage to protection against pain / Способность ребенка на пренатальном этапе (с определенного возраста) чувствовать боль и страдать от нее, определяющая право ребенка на пренатальном этапе на защиту от боли

The most important component of palliative medical care is regulating pain, reduction or stopping pain syndromes [7, 12, 13].

Pain is one of the cruel, psychoinjuring symptoms of a considerable number of diseases. It causes to patients the strongest sufferings. Especially pain is attributable to oncological and some other diseases [14, 15]. Besides, pain is the biggest source of sufferings for families of such patients [16].

Today, there is no standard, exact, and comprehensive definition of the concept of "pain", and equally of the concepts preconditioned by pain and human sufferings represented in it. It, in general, is an extremely complex challenge – to formulate such a definition which would be relevant, in a necessary and sufficient extent, full and detailed.

Office of Legal Counsel of the U.S. Department of Justice in the research concerning what is included in the concept of pain which can be caused within the act, according to the criminal legislation of the USA, classified as tortures, came to the conclusion: in order that the act was classified as causing tortures, it has to cause such pain which is hard to tolerate. Physical pain in this case has to be equivalent in the intensity to the pain accompanying a serious physical trauma, such as deprivation of the body organ, malfunctioning of the body or even death. Severe pain is determined, as a rule, as such pain, which the person who feels it, can not tolerate [17].

In 1968, Margo McCaffery formulated the bioethical definition of pain which became classical: "What the patient calls pain, is actually pain; it exists always when the patient says that it exists"[18].

We will give our author's definition of the concept of "pain" (in medico-legal and bioethical meaning), *Pain* is expressed painful disturbing (vehement and unpleasant, hard to tolerate, defiant sufferings) or injuring physical sensor feelings and emotions of the person, which: 1) can be ordinary (simple in presentation) or integrated, and also single, repeating, or lasting, 2) are caused or connected with valid, imaginary, or really menacing (reasonably anticipated) damage of tissue (tissues) or an organ (organs) of the human body, 3) possess special sensor characteristics and described in the terms of such damage, and also the psycho-emotional impressions of these feelings interfaced to them and their deep mental and spiritual and moral experiences. Pain attracts sufferings of the person, it is integrally connected with human sufferings and, in itself, is the form, the core, and presentation of sufferings. Pain encroaches on the dignity of the person undergoing it, it is destructive for human dignity. Intolerable pain "dehumanizes" the person, deforms consciousness of the person. The feeling of pain is always very much subjective, as a result – existence of pain is extremely difficult (on the verge of impossibility) to be confirmed by the third persons. Pain is polylateral (many-sided) and intersectional.

It is clear, that in the case with the child at the prenatal stage of development, some other criteria of pain are necessary.

But here, it is important that according to the Vice-President and the Research Director of the Charlotte Lozier Institute, Doctor David A. Prentis, the modern medicine proved that the child at the prenatal stage of development, at least, in 20 weeks after fertilization and even earlier, is capable to feel pain (and at the moment of abortion the child feels intolerable pain and sufferings) [19].

Along with the process of development of understanding the concept of pain, there is also development in this sphere of the measures taken at the legislative level for the purpose of providing more essential legal protection of the persons who need it. So, for example, such measures can include (for example, in the USA) the provisions accustomed by some states recognizing that the human fetus can feel a certain pain (including abortion pain).

On May 13, 2015, the House of Representatives of the Congress of the United States of America adopted *the Pain-Capable Unborn Children Protection Act* (as of 04.10.2017 is under consideration in the Senate of the USA Congress) [20]. This law makes changes to the

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federal criminal code, criminalizing commitment (by any person), including attempts of commitment, abortions if the probable age after fertilization of the fetus makes 20 weeks and more. Sanction in the form of a penalty and imprisonment for up to five years of imprisonment, or both of these sanctions are applied. Exceptions for abortions are provided: 1) those which are necessary for rescue of life of the pregnant woman, or 2) when pregnancy is the result of rape or incests. The doctor who carries out or tries to execute abortion as the specified exception, has to conform to the established requirements.

Not only the name of this projected law but also its text are indicative. According to clauses 1, 2, 6, 11, and 12 of the specified act, "Pain receptors (nociceptors) are present throughout the unborn child's entire body and nerves link these receptors to the brain's thalamus and subcortical plate by no later than 20 weeks after fertilization. By 8 weeks after fertilization, the unborn child reacts to touch. After 20 weeks, the unborn child reacts to stimuli that would be recognized as painful if applied to an adult human, for example, by recoiling … Recent medical research and analysis, especially since 2007, provides strong evidence for the conclusion that a functioning cortex is not necessary to experience pain … There is substantial medical evidence that an unborn child is capable of experiencing pain at least by 20 weeks after fertilization, if not earlier … It is the purpose of the Congress to assert a compelling governmental interest in protecting the lives of unborn children from the stage at which substantial medical evidence indicates that they are capable of feeling pain"[20].

According to the declaration in *the Pain-Capable Unborn Children Protection Act of the State of Louisiana (USA)*, pain receptors (nociceptors) are present throughout the unborn child's entire body and nerves link these receptors to the brain's thalamus and subcortical plate by no later than twenty weeks. The child at the age of 8 weeks already reacts to touches. After 20 weeks the unborn child reacts to irritants which in relation to the adult would be reasonably defined as painful. The unborn child can feel pain at this age in spite of the fact that the child's brain still does not function adequately yet. Therefore, there are necessary and sufficient medical proofs of that the unborn child is capable to feel pain starting with the age of 20 weeks after conception (subparagraphs of "a", "b", "f" and "k", clause B, § 1299.30.1 of *the Louisiana Revised Statutes* [21]). Analogous or similar provisions are fixed in *the Pain-Capable Unborn Children Protection Act of the State of Idaho* (USA**)** (points 1, 2, 6 and 10, article 18-503, Chapter 5, Title 18 of the *Idaho Statutes* [22]), in *the Wisconsin Statutes* [23] (point 3, article 253.107, Chapter 253 of "Maternal and child health"), in laws of some other states of the USA. Names of these laws are self-characteristic. Similar projected laws are at the stage of consideration today in a number of the states of the USA [24].

Ignoring of pain syndromes and other sufferings of the child at the prenatal stage caused by the child's disease, leaving of such child to die in tortures (from pain, asthma, dehydration, etc.) represent deliberate, extremely cruel treatment of this child (it is similar to tortures). The child feels sufferings, which the child underwent. Including abortion at the term, at least, starting with 20 weeks (even from 8 weeks) of gestational age of the child which causes terrible sufferings prior the child's death. That is, besides the right to life, the rights of the little patient to recognition and protection of human dignity, to protection from pain are violated in a very grave way.

The child at the prenatal stage is an independent living human being with own legal personhood which is subject to recognition by the state / Ребенок на пренатальном этапе — это независимый живой человек с собственной юридической личностью, который подлежит признанию государством

It is known that there are two main approaches to the definition of relationship between the pregnant woman and the child in her womb.

According to the first approach, the woman and the child together are defined as one person, and the human fetus is positioned as part of the woman's body (as, for example, a liver). This approach is ideologically motivated and very objurgatory from the legal point of view as the human fetus possesses own physiology and is different from maternal genetic code, the fetus possesses a certain legal personhood, at the prenatal stage already, and leaving, at birth, the mother's body – gets more legal personhood. Positioning of the fetus of the person as owned by the mother unreasonably, depreciates the fetus, represents ideologically motivated refusal to the child at the prenatal stage in the rights and dignity, without strong legislative and actual bases.

According to the second approach, the human fetus and the mother are considered and positioned as two independents, in a certain measure, autonomous (though biologically connected at this stage of life) human beings having human rights in full. This approach finds a significant amount of references – as legal (in details stated by us in the Report provided below), and actual, first of all – resulting from medical practice.

In obstetrics, the human fetus (at least, the wanted child) even earlier was perceived as "co-patient", however, now, with exponential development of opportunities of pre-natal diagnostics and pre-natal therapeutic manipulations, the situation has significantly changed and continues to change.

This model considers the fetus and the mother as two separate patients and considers pregnancy as complex correlation between the rights and legitimate interests of the child at the prenatal stage and the mother.

And, this approach can even produce and encourage the position which is equitable to the best interests of the

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fetus (the child at the prenatal stage of development) and contradicting the best interests of the woman.

Success of all forms of therapy of the fetus (except for blood transfusion) is not always advanced, however the probability of treatment of the same problems after the child's birth is even lower. And it even more actualizes the need of articulating and recognition of the rights of the patient (in this case – to palliative medical care) in relation to the child at the prenatal stage of development.

One more complex legal problem defining the need of definition of the fetus as a separate patient is the question of possibility of refusal of the pregnant woman during pregnancy from treatment the need in which is caused by the interests of the child who is in her womb. The doctor in such situation has to take health of both patients who are biologically connected into account. Respectively, there is a serious ethical and legal problem in that case when the pregnant woman refuses the treatment prescribed to the fetus as when the condition of the fetus does not cause any harm the mother's health, any treatment of the fetus will create a certain degree of risk to her without any direct therapeutic effect on her, and the basic ethical medical principles of benefaction and not infliction of harm enter the conflict. There is also more fundamental issue about, whether doctors or the state have the right to assume decision-making in such cases and to carry out intervention for the purpose of ensuring interests of the second patient – the fetus.

It should be noted that the point of view that the considered problem of a mutual contradiction of the rights of the pregnant mother and her child is hypertrophied is repeatedly expressed. For example, the former chief surgeon of the Health Service of the USA, Charles Everett Koop, testified that for his 36 years' practice in pediatric surgery he did not record any case when a reasonable need of abortion for the sake of the mother's life rescue objectively took place [25].

It is advisable to address to reference jurisprudence.

According to the Judgement of the Constitutional Court of Spain No. 53/1985 dd. 11.04.1985, "*pregnancy results into life of the individual, independent in relation to the mother (third party), though being in her*" (subparagraph of "b" of clause 5).

The position was accurately expressed in the Judgement of the Federal Constitutional Court of Germany dd. 28.05.1993 [26]: "*In the case with the child at the prenatal stage we deal with individual life with genetically determined identity which is inseparable and unique*" (paragraph 146).

According to the Judgement of the European Court of Human Rights dd. 26.05.2011 in the case of "R.R. versus Poland" [27], the rights of the child at the prenatal stage and the rights of the child's mother are inseparably linked, and it is necessary to find balance between them at their conflict (§ 186).

The specified conflict needs separate constitutional and legal, medico-legal and bioethical research.

The decision of the District of Columbia Court of Appeals (USA) dd. 16.06.1987 No. 87-609 [26], and the case itself, concerning which this decision was issued, is indicative as just in this case, actually, the fetus was defined by the decisions of the relevant judicial instances as a separate patient, and the fetus' interests tried to be provided thus as it was possible.

It should be noted that, further, the decision nevertheless was appealed and revised, which does not belittle research interest in the considered precedent and its value.

The child's mother, since teenage age, had had leukemia, had a number of surgeries, treatments, and chemotherapy. At the time of pregnancy, her disease was in the condition of remission for three years. At pregnancy term approximately of twenty five weeks tumor in the child's mother's lung was found, and her state was defined as terminal.

At the twenty sixth week of pregnancy, the mother of the child was taken to the hospital it was discussed with her and her family about the possibility of radiation therapy and chemotherapy for reducing her pain and maintenance of pregnancy. There with doctors noted that chances of the child for survival would be higher at the twenty eighth week of pregnancy. The following day, the mother of the child was put into controlled sleep in order that she had an opportunity to breathe, and the administration of the hospital applied to the Superior Court of the District of Columbia for the official permission to carry out Cesarean section as the condition of the patient worsened, and the treating medical personnel doubted about non-surgical treatment as the patient could not survive, and the chances for the survival of the child were small. The administration of the medical institution came to a conclusion about the need to check such decision in the Superior Court of the District of Columbia.

The Superior Court of the District of Columbia appointed the lawyer for the mother and for the fetus. The District of Columbia was authorized to interfere with the activity connected with the fetus on the basis of the principle *of "parens patriae"* (assuming, in brief, the opportunity in certain cases of the state to act as the child's parent).

Before mother of the child was put into sleep, she specified that she was ready to sacrifice her life to save the fetus life, if the fetus reaches the age of twenty eight weeks. Thus possibility of the surgery at an earlier gestational age was not discussed. At the same time, the fetus at that time already started suffering from the lack of oxygen that increased the possibility of various diseases.

The Superior Court of the District of Columbia found that the fetus was viable, and that the District of Columbia is interested in protection of the potential life of the fetus, having decided, respectively, that Cesarean section is to be performed.

After the decision of the Superior Court of the District of Columbia the mother of the child was brought to consciousness and informed about that. The mother gave

her consent to the surgery, though there was a chance of her death as the result of it, however when another doctor came to confirm her decision, she refused the surgery without explanations.

The Superior Court of the District of Columbia received an appeal, and by results of the hearing the court suspended carrying out the surgery, specifying, at the same time, that the fetus would get more chances, maybe not guaranteed, if the child is born before inevitable death of the mother as in case of death of the mother before the surgery the child would die together with her.

In this case it was necessary to consider the balance between delicate survival interests of the fetus and the condition of the mother.

The District of Columbia Court of Appeals also made a decision about the need of carrying out Cesarean section, having specified thus that they understand probability of reduction, by the decision, of the mother's for several hours. This appeals court, having considered all the arguments, came to the conclusion that Cesarean section can not significantly affect the condition of the child's mother as at best the remained duration of her life would make two days in artificial sleep, and the complications connected with such operation could not change significantly such forecast, and the child would get chances of a survival, despite probability to be born disabled. In their resolution, the District of Columbia Court of Appeals also noted the interests of the state in ensuring protection of a new potential life [28].

Thus, arising in certain situations (we emphasize – in a very small share of cases), the conflict between the rights of the child at the prenatal stage to life and to health protection and the same rights of his mother – in case of the threat to the life of the child's mother owing to critical medical problems with the condition and the health of the fetus, and also owing to the condition of her health in connection with pregnancy – raises a number of difficult questions, but does not depreciate human dignity of the child at the prenatal stage of life and development at all and does not cancel the child's fundamental rights to life, health protection, development, and human dignity.

On the other hand, the considered judgment confirmed that the child is, in a certain measure, an independent subject even at the prenatal stage of development, having the right to medical care and pediatric palliative care.

Conclusion / Заключение

Today, in the Russian Federation and many other states in the fields of medical science and practice, and in legislation, legal science, and human rights sphere as well, it is widespread and dominating to have the point of view which denies the child's legal personhood at the prenatal stage of development does not accept and ignore the child's human dignity. One of the most ignored rights of the child at the prenatal stage is the child's rights to medical care, health protection, and, in case of need, to palliative medical care. This complex of the rights of the patient which, in our opinion, are to be admitted as the child's at the prenatal stage of development, today, is practically not discussed in the Russian research and practical medical literature.

However, it is to be admitted and provided, be subject to protection the right of the child at the prenatal stage for receiving pediatric palliative care in case of need.

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