ETHICAL ISSUES OF THE THERAPY OF PREMATURE INFANTS

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Currently preterm births are the leading causes of newborn mortality in developed countries. There is growing concern in the medical community about the moral and ethical implications of therapeutic care for these patients. The article raises the problem of joint decision-making by neonatologists and parents on the treatment of premature newborns. Including the question of who is most qualified to make decisions regarding the initiation, termination or withdrawal of life-sustaining treatment for preterm infants. The rest of the life of surviving premature newborns may be associated with inconvenience and suffering in everyday life, and understanding of responsibility for the life of the patient and the child greatly complicates the decision. Another important issue is the relationship between intensive care nurses and parents in caring for premature newborns. The article describes the life experience and ethical and moral problems that medical personnel face during caring for premature newborns.

Keywords: premature infants, neonatologists, paternalism, intensive care

Author contribution: Kazanova AM — analysis of the research data, review of publications on the topic of the article, manuscript writing; Zyryanov SK — manuscript editing.

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Received: 06.02.2023 **Accepted:** 04.04.2023 **Published online:** 30.06.2023

DOI: 10.24075/medet.2023.012

ЭТИЧЕСКИЕ АСПЕКТЫ ТЕРАПИИ НЕДОНОШЕННЫХ НОВОРОЖДЕННЫХ

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В настоящее время преждевременные роды являются основной причиной смертности новорожденных в развитых странах. В медицинском сообществе растет озабоченность по поводу моральных и этических последствий терапевтической помощи данным пациентам. В статье поднимается проблема о совместном принятии решений врачей-неонатологов и родителей о проведении терапии недоношенным новорожденным. В том числе и вопрос о том, кто имеет наибольшую квалификацию, чтобы принимать решения в отношении инициирования, прекращения или отказа от поддерживающего жизнь лечения недоношенных новорожденных. Дальнейшая жизнь выживших недоношенных новорожденных может быть связана с неудобствами и страданиями в повседневной жизни, а понимание ответственности за жизнь пациента и ребенка значительно затрудняет принятие решения. Важным также является вопрос об отношениях между медицинскими сестрами отделений интенсивной терапии и родителями при уходе за недоношенными новорожденными. В статье описывается жизненный опыт и этические и моральные проблемы, с которыми сталкивается медицинский персонал при выхаживании недоношенных новорожденных.

Ключевые слова: недоношенные новорожденные, врачи-неонатологи, патернализм, интенсивная терапия

Вклад авторов: А. М. Казанова — анализ научного материала, обзор публикаций по теме статьи, написание текста статьи; С. К. Зырянов — редактирование статьи.

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Статья поступила: 06.02.2023 **Статья принята к печати:** 04.04.2023 **Опубликована онлайн:** 30.06.2023

DOI: 10.24075/medet.2023.012

According to the Ministry of Health, over 100 thousand preterm neonates are born in Russia annually. Survival of this group of patients is 97% [1]. Despite that, preterm birth is the main reason for neonatal mortality (during the first 4 weeks of life) in developed countries. In Russia, they nurse neonates who were born at 22 weeks and have a body mass of over 500 g and body length of over 25 cm as per standards established by the World Health Organization [2].

In Russia, the rate of preterm birth is about 6%. In Europe and the U.S., it is slightly higher and constitutes 10–13%. This is due to widespread introduction of novel assisted reproductive technologies, higher number of multiple births, expanded indications for preterm birth, and growing number of single premature deliveries, when birth is either induced or when Caesarean section is performed [3]. Maternal concomitant diseases (gestational diabetes, hypertension and diabetes) and a lack of qualitative perinatal care required to support full-term pregnancy produce a large effect on preterm birth.

Very early preterm labor (22–27 weeks), early preterm labor (28–30 weeks), preterm labor (31–33 weeks) and late preterm labor (34–36 weeks) are differentiated taking into account gestational age [4]. Prematurity is determined based on neonatal body weight: up to 1,000 g for extremely low body weight (ELBW); 1,001 to 1,500 g for very low body weight (VLBW); and 1,501 to 2,500 g for low body weight (LBW) [4]. Modern medicine has made remarkable clinical and technical progress, which would allow an unprecedented increase of survival rates among premature children. The current viability threshold depends on the physiological development of the lungs, which occurs approximately at gestational weeks 22–24 [5]. Unfortunately, infants with the lowest threshold still have no

absolute survival rates, whereas some of those who survive can have severe disorders and disabilities.

In Russia, current survival of children with body mass of less than 1,000 g is 85%, the number reaches 90% in perinatal centers [1]. There is an opinion that this was facilitated by experimental methods of treatment without ethically approved clinical trials or without informed consent of parents or legal representatives. But if those prematurely born survived in 100% of cases and if intensive therapy did not produce physical, mental or cognitive adverse effects or complications, this area of medicine would fail to be developed. However, there exist numerous short-term and long-term issues, which should be taken into account prior to intensive care of neonates with ELBW and LBW or its withdrawal.

Despite dramatic improvement of fetal mortality rates during the last decades, premature neonates belong to the group of high risk of infectious complications, including respiratory distress-syndrome, bronchopulmonary dysplasia, apnea, necrotizing enterocolitis, patent ductus arteriosus and anemia of prematurity [6]. Immature immune system increases a risk of pneumonia, sepsis, meningitis and urinary tract infections to protect from viruses, bacteria and other pathogens [7].

Thus, neonatologists believe that intensive therapy is an essential condition of survival of neonates with ELBW and LBW with gestational age of less than 29 weeks. Nevertheless, a doctor can't warrant full recovery of these patients only because the neonates can survive. Interruption and withdrawal of intensive treatment for neonates should be discussed not by neonatologists only, but also by parents or legal representatives, rehabilitologists, other pediatricians and representatives of the community.

There is growing concern about moral and ethical consequences of complex and technological aid provided to children with ELBW at neonatal intensive care units in developed countries [5,7]. Nurses who take care of seriously ill patients stay at the bedside daily, and foster neonates with severe complications that require complex and frequently painful treatment.

They have to communicate with families, who are often upset and depressed because of the condition of their neonates, and come across ethical and moral problems daily while taking care of premature neonates with ELBW and LBW [3]. Despite this, daily 'live' experience of perception by nurses of their collision with various moral and ethical dilemmas receives minimal attention and is described in a small number of articles [5,7].

The nurses participating in the trial by *Webb S.* openly discussed their experience of solving moral and ethical issues they came across. They reported that they often had troubles with their moral sense, especially when they unconsciously tried to protect neonates from pain and unnecessary discomfort. Despite moral and ethical issues, the nurses still remained loyal to what they did. According to the results, the participants had to deal with ethical principles such as beneficence, non-harm, social justice and parents' autonomy. Decisions taken by parents of neonates could possibly be the most complex problem faced by nurses of an intensive care unit. Some participants announced that families were not always properly informed by neonatologists of a very bad prognosis for therapy outcomes and had hopes for impossible wonder. According to a nurse, parents were asked to take decisions they were not capable of. It is especially difficult for parents to take decisions due to such factors as incapacity to foresee a long-term prognosis and outcomes, young age and minimal death-related experience, as they always hoped for wonder and were in stress when the child was hospitalized.

One of the most important issues was remote treatment outcomes that influenced a patient's quality of life. For instance, the issue of whether premature children can complete primary school and take care of themselves in the future. Unlike the majority of neonatologists and nurses, the major part of the population considers the issues central while discussing the need to provide intensive therapy to premature neonates [8]. It is most frequently associated with the need for life support by parents and society. Parents should also take into account how children with possible cognitive or physical disturbances can influence the family life and other children.

Some healthcare representatives believe themselves to be the best alternative to protect and take decisions on behalf of a preterm newborn [8]. Neonatologist-newborn relationship is definitely paternalism (doctor-patient relationship when a patient totally relies on qualification and experience of a treating physician). But is this pure paternalism? Does a doctor have a scientific interest while taking decisions on conflicting issues? That's why neonatologists and nurses have to take joint decisions about intensive therapy with parents or legal representatives.

According to a modern study by Fauchère et al, it is assumed that a paternalistic attitude can mean that neonatologists do not supply parents with complete information about their premature newborn's condition just not to disturb them. However, there is a risk that it is done to exclude parents from taking decisions.

But what would doctors tell parents? Will they inform of various risks of health worsening [9]? Will they inform of the autism risk due to long-term treatment in couveuse [10]? How would they submit the data? Will they exaggerate the expected favorable outcome [11]? According to Fauchère et al., doctors who take part in participation could have their own personal values. They also state that cultural values could influence the attitude towards patients and indicate at various results in the involved German- and French-speaking countries. The differences could have an influence on whether the intensive therapy was initiated, suspended or withheld. The differences were registered in other researches as well [6,11,12].

The study discusses whether premature children with ELBW should be treated with other neonates and elder children. Significantly more doctors (82%) than nurses (57%) announced that the same ethical principles should be applied. However, replies to the questions can't be definitive as we don't know how those interviewed raised the issue. If we understand the principle, according to which equal cases should be considered equally, and if the need should determine our actions, it is easily to agree that premature children with ELBW and LBW should be treated just like other children are. The age itself means nothing for prioritization.

Tolerability of certain therapy in various patients of the same age with similar diagnosis should be taken into account. Patient A can have a much better treatment outcome than Patient B who is very weak, has several concomitant diseases and can fail to survive a potential surgery. In this case, if a doctor decides that the surgery can do more harm than benefit to patient B, we should not carry out the procedure. So, equal cases are not always really equal due to concomitant medical differences. Thus, equal attitude is not always possible.

If we apply the judgement to intensive therapy of premature neonates with ELBW and LBW and compare it with therapy obtained by neonates or children, significant differences will be registered. If the prognosis is very pessimistic in relation to survival and quality of life of premature infants, the doctors can refuse from life-sustaining therapy.

The study by Fauchère et al. has shown that nurses were less willing to use too aggressive treatment as compared to neonatologists. It could be because they felt that this could not be in the best interests of the patients. It is noted in the study that parents or legal representatives should participate in taking decisions though doctors and nurses can have different views on the therapy course. The parents' interests are applied to the entire family and go beyond intensive therapy obtained by their premature infant.

Doctors can neglect the use of a family-oriented approach in such cases. Nevertheless, discussion of ideas, hopes and preferences of families preceded by informing parents of what their child can come across in the future should be an important step in the process of common decision-making. Family care is an essential condition to submit adequate data and promote sincere joint participation in taking decisions. Doctors and nurses in the intensive care units should follow the family-oriented models when they inform parents or legal representatives of potential treatment outcomes for premature neonates with ELBW and LBW. Joint evidence-based decision should be made without a paternalistic effect and effect of personal values of neonatologists. Families and legal representatives should be well-informed and obtain data in an honest but clear way, as this is important for taking joint decisions.

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