ORIGINAL ARTICLE

CONTENTS

Protection of children's rights to access palliative medical services: Legal problems

Oleksandr M. Shevchuk[1], **Anatolii M. Shevchuk**[2], **Olena O. Holovash**[1], **Oleksandr O. Mykhailenko**[3], **Arina O. Ivanytsia**[2]

[1]YAROSLAV MUDRYI NATIONAL LAW UNIVERSITY, KHARKIV, UKRAINE
[2]NATIONAL PIROGOV MEMORIAL MEDICAL UNIVERSITY, VINNYTSIA, UKRAINE
[3]PRINCE VOLODYMYR THE GREAT IAPM EDUCATIONAL AND RESEARCH INSTITUTE OF LAW, KYIV, UKRAINE

ABSTRACT

Aim: To identify legal issues in protecting children's rights to palliative care in Ukraine, to propose basic guarantees of their rights, and to note trends in foreign practice.

Materials and Methods: The study is based on its theoretical and empirical basis, the system of methods of scientific knowledge. The theoretical basis includes scientific articles, expert analysis of legislation and international organizations.

Results: The implementation of children's right to palliative care can be classified as universal and special. In the implementation of this right, children often face inadequate representation of their interests and shortcomings in the provision of medical services to them. As a result, the right of children to quality medical care when receiving palliative care, the right of children to receive palliative care at home, the right of the child to consent to receiving palliative care, the right of children to confidentiality and protection of personal data when receiving palliative care, and the right of children to privacy in this area are violated.

Conclusions: Accessibility of children's rights to palliative medical care is an important aspect of ensuring the implementation of one of the fundamental, inalienable human rights to life and health as the highest social values.

KEY WORDS: palliative medical services, children's rights, legal regulation

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INTRODUCTION

Ukraine, having signed the Association Agreement between Ukraine and the EU in 2014, chose the European integration vector of its development, which provides for the gradual adaptation of norms, requirements, and approximation to European standards in the healthcare system through the implementation of its systemic reform [1]. The national healthcare systems of many countries around the world are facing new, more serious challenges that determine the quality of life of the population. One of these challenges is the constant increase in the number of incurable child patients who need palliative care. Thus, the Resolution of the Parliamentary Assembly of the Council of Europe of January 28, 2009, No. 1649 (paragraph 4), notes that an increasing number of social groups of the population (seriously ill, chronically ill, patients requiring individual care) at the final stages of their lives are unable to obtain proper legal protection of rights guaranteed by the state, to realize and satisfy their basic needs for medical care due to the significant costs of obtaining them. The Constitution of Ukraine, as a participant in international relations, provides for obligations to ensure the safety and quality of life of its citizens (Articles 3, 49), including the rights to health care and medical care. In particular, the protection of the rights of patients to medical care for incurable diseases [2], especially children. Children with incurable and debilitating diseases suffer from pain, but are often not provided with palliative care [3]. The number of such children-patients will grow, both in the world [4] and in Ukraine.

AIM

The aim of the study was to identify problems in the implementation of children's rights to palliative care in Ukraine, and on this basis to propose methods of legal provision of guarantees of such children's rights.

MATERIALS AND METHODS

The methodological basis of the study is a set of methods and techniques of scientific knowledge.

Table 1. The components of a children’s right to palliative care

Component	Description
Medical	Children’s right to symptomatic therapy, children›s right to prevention and treatment of chronic pain syndrome, children›s right to drug therapy, right to effective pain relief
Social	Children’s right to provide social services of palliative care
Spiritual and psychological support	The right of children to spiritual and psychological support from their family and other caregivers

Table 2. The main ones principles of children’s rights to palliative care

Component Number	Description
1	The principle of accessibility of palliative care for children
2	The principle of planning palliative care for children
3	The principle of continuity and continuity of palliative care for children
4	The principle of choosing a place of treatment when providing palliative care to children (with parental consent)
5	The principle of choosing the place of death when providing palliative care in children
6	The principle of ethical and humane treatment of the children-Patient and his family members, other persons caring for the children-Patient, 7 days a week

Table 3. The main violations of children’s rights when receiving palliative care

Component Number	Description
1	Inaccessibility of palliative care (the vast majority of terminally ill children cannot receive it in the required volume)
2	Unavailability and insufficiency of medicinal narcotic drugs and other painkillers in the required quantities
3	Non-compliance of children’s palliative care departments with international norms and standards for material and technical resources
4	Lack of qualified health workers for palliative care of children
5	Underfunding of the palliative care system for children from state sources
6	Children’s representatives do not take their interests personally
7	Medical intervention on children under duress
8	Provision of unjustified medical care to children without appropriate indications

In particular, the following methods were used in the work: formal-dogmatic, systemic, semantic, epistemological and axiological, sociological, comparative-legal, statistical, systemic, and structural analysis. The comprehensiveness of the study of this article is ensured by a systematic approach, which made it possible to consider and analyze the problems of implementing children’s rights to palliative care, in the unity of their content, essence, and legal form. The application of scientific methods allowed the authors to achieve the goal of the article, substantiate the conclusions of the study, and suggest ways to optimize legislation on the implementation of children’s rights to palliative care

ETHICS

No animals or human subjects were used in this study.

RESULTS

Children’s rights in the healthcare sector are divided into two groups. The first (universal) are inherent to both children and adults. The other group (specific) belongs only to children and is supported by guarantees of their legal status [5]. Among the latter category of children’s rights are children’s rights to palliative medical care [6-9]. National legislation provides for definitions of the category “palliative care” for all categories of patients. Thus, at the legislative level, it is stipulated that palliative care is a set of measures aimed at improving the quality of life of patients of all age categories and their family members who are faced with problems associated with life-threatening diseases. This complex involves measures to prevent and alleviate the patient’s suffering through early identification and assessment of symptoms, pain relief, and overcoming other physical, psychosocial, and spiritual problems. (Article 35 – 4) [10].

Palliative care for children is divided into general and specialized palliative care. Palliative care for children (patients aged from birth to 18 years) is provided in accordance with the provisions of sections I - IV and paragraph 1 of section III of the Procedure for the Provision of Palliative Care [11]. When organizing the provision of palliative care to pediatric patients, preference is given to organizational forms that allow for the provision of palliative care at home with the involvement of family members or legal representatives of the child, subject to the informed consent of such patients [11]. During the stay of a pediatric patient in a health care facility providing palliative care, the child's right to stay with family members is ensured [11]. Palliative care for children is provided in Ukraine at the expense of the state budget.

The right of children to palliative care is also provided for in international legislation. Thus, international legislation indicates that the right of children to treatment of illnesses and restoration of health (Article 24 of the Convention on the Rights of the Child) and directs political, civil, economic, social and cultural rights of children (who have not reached the age of 18 [12]). Children, including adolescents, have the same rights as adults: "the right to protect their own health to the extent that disease prevention and treatment allow, in order to achieve the highest possible level of health", which is reflected in the Declaration on Policy on Ensuring Patient Rights in Europe (paragraph 1.6, part 1) [13]; the right to treatment only subject to the patient's consent, which he has given voluntarily on the basis of relevant information (Article 5 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine) [14], the right to protection from torture, inhuman or degrading treatment or punishment (Article 3 of the Convention for the Protection of Human Rights and Fundamental Freedoms) [15] and others.

The main components of children's rights to palliative care are given below in Table 1 [7, 8, 11].

Palliative care for children is based on the same principles as palliative care for adults, but the principles under study also have their own specifics [16]. The main principles of implementing the right of children to palliative care are given below in Table 2 [4, 6, 11].

The main violations of the rights of minors who need palliative care have been identified in Table 3 [3, 7, 8, 17-19].

In the human rights framework, children's rights to receive and access palliative care are vital and must first be protected. This is due to the specific nature of the treatment, their vulnerability, the need for further protection and care and includes providing support to the child and his family. It should be noted that effective legal regulation of the implementation of children's right to palliative care should be aimed at improving their quality of life. Realization of this right for children also includes support for optimal child development, formal education, stimulation of development in order to enable the child at any age to live the best life.

DISCUSSION

There is no single approach to understanding the components of the implementation of children's right to access palliative care. The problematic issues are the application of both legal and ethical norms [6, 7], as well as the definition of a list of principles for the implementation of children's right to access palliative care. It should be noted that in 2002, the WHO first defined the definition of «palliative care for children». WHO experts understand this term as active, comprehensive care for the child's body, psyche and soul, as well as support for his family members [3]. However, there is still no unified scientific approach to the content of the legal construct "children's right to palliative care". In particular, other forms of palliative care are also distinguished in the legal literature, namely: "supportive care", "end-of-life care", "terminal care", "respite care" [2, 18, 20], however, some researchers point out the inappropriateness of distinguishing the above forms of palliative care.

The grounds for recognizing a child as a subject of legal relations for the provision of palliative medical care remain problematic. According to Article 3 of the special legislative act in the field of healthcare, the term "patient" is an individual who has sought medical assistance and/or who is provided with such assistance [10]. Regarding the subject of our research, it is necessary to take into account the legal status of minors and their right to receive palliative care. In particular, a minor is considered a child before reaching the age of fourteen, a minor is a child aged fourteen to eighteen (Part 2, Article 6) [21]. Based on the content of Article 284 of the Civil Code of Ukraine, a minor child has the right to be provided with medical care (Part 1), however, he or she cannot exercise this right independently [22]. In addition, we note that Article 43 of the special legislative act in the field of healthcare establishes that the use of methods of diagnosis, prevention and treatment of a minor child requires the consent of his legal representative [10]. That is, unlike a minor child, a minor child already has the right to independently exercise the right to palliative medical care. And he can exercise this right in two ways: to consent to medical care (Part 3); or to choose a doctor and methods of treatment in accordance with his recommendations (Part 2, Article 284) [22].

The child's rights to palliative care are ensured not only by the duties of medical workers, but also by the duties of their parents and legal representatives [23]. And violations of children's rights in this area are usually associated with improper representation of their interests by parents and legal representatives, and deficiencies in the provision of medical services [5, 23]. In particular, in the legal literature, some scholars express considerations regarding both lowering and increasing the age of a child for consenting to medical care. However, the provisions of the Convention on the Rights of the Child enshrine the obligation of States Parties to ensure that a child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child. This requirement of the Convention provides children with the opportunity to express their views freely and to have them taken into account in accordance with their age and level of maturity [12]. In our opinion, it is advisable to give a child the right to consent to the provision of palliative medical care from the age of 16. From this age, a child can make informed decisions when seeking medical attention and choose methods of treatment and medical care.

CONCLUSIONS

Accessibility of pre-palliative medical care for children is an important aspect of ensuring the implementation of one of the fundamental, inalienable human rights to life and health as the highest social values. This is recognized in United Nations conventions and protected by many international organizations. The representation and implementation of the right of children to effective access to palliative medical care is an important feature of a modern social, legal state and is a priority task of state policy in the field of health care of any democratic state. Given their age characteristics and limited capabilities, children are significantly limited in their ability to independently exercise their patient rights to palliative care. Therefore, children-patients who need palliative care should have additional guarantees of their rights protection. These rights of children can be classified as universal and special.

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CONFLICT OF INTEREST

The Authors declare no conflict of interest

CORRESPONDING AUTHOR

Oleksandr M. Shevchuk
Yaroslav Mudryi National Law University,
77 Hryhorii Skovoroda St., 61024 Kharkiv, Ukraine
e-mail: oleksandr-shevchuk@ukr.net

ORCID AND CONTRIBUTIONSHIP

Oleksandr M. Shevchuk: 0000-0003-4864-7316 B D
Anatolii M. Shevchuk: 0000-0001-9646-6312 A E
Olena O. Holovash: 0000-0003-0995-6570 C D
Oleksandr O. Mykhailenko: 0009-0007-2699-7901 F
Arina O. Ivanytsia: 0000-0002-4115-9638 C

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