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**PALLIATIVE CARE FOR CHILDREN: PROBLEMS AND SOLUTIONS**

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**Abstract**

In the article the problem of palliative care availability and its deprivation, as well as opportunity of distant monitoring of health status of palliative patients, regulation of child palliative care in Russia have been analysed. The social practice of providing palliative care for children in conditions of medical digitalization, characteristics of digital interaction in the system of “doctor-patient”, provision of palliative care for children have been shown. Both children who need palliative care and their parents, families and medical personnel face a great number of difficulties. Essential (social, psychological, medical and managerial) aspects have been regarded and highlighted in the work. The authors have revealed organizational problems and inconsistency of the legislative base concerning palliative care that cause decrease in care providing and availability. The lack of well-qualified specialists in the field of palliative care, their workload, emotional burnout and fear during the work with drugs force people to “leave” their profession. Low awareness of patients and their parents’ rights in mass media exposes insufficient effectiveness of palliative care. Palliative care in Russia requires a systemic coordination among government health care and social development authorities, professional medical community, patient organizations, charitable services activities, as well as resource support. The use of modern digital and information technologies is the key to timely, effective and high quality provision of palliative care to children and their parents, which meets the WHO requirements in a difficult life situation.

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*Keywords:* Children, digital health, end-of-life, online communication, palliative care

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## 1. Introduction

Palliative care is a comprehensive support of an incurable patient and his family that includes physical, emotional, social and spiritual components. Unfortunately, incurable statuses are also inherent in children. An exact number of palliative patients among children who need this kind of care is not stated but it is known that the number of children with disappointing diagnoses is increasing in conditions of developing medicine because its diagnostic capacities are sufficient for determining a diagnosis before lethal outcome. On the legislative level, it is stated that every person has rights to obtain medical care within the framework of state guaranties (Constitution of the Russian Federation, adopted by popular vote 12.12.1993).

There are different situations when even radical treatment is not effective when attacking a disease, and, in this case, there is a need to provide a better quality of life for both a child and his parents and to help in mitigation of new symptoms of a disease (Barling & Davis, 2016). Palliative care is intended to help a child to stay a child up to the end in terms of study, playing games, development, communication with relatives and friends. People constantly need socializing and self-actualization. These traits are inherent in children even more than they do in adults, and there is a need to give such an opportunity before the “end-of-life” that can be provided in different locations: in hospices, palliative departments of hospitals, palliative mobile teams, at home. But not always children have an opportunity to stay with their parents. Both children and their relatives rely on getting qualified medical help in conditions of a complicated social and psychological status.

## 2. Problem Statement

The number of cases when a child needs palliative care is growing. According to the Federal State Statistics Service, there is an annual growth of children with congenital anomalies, malformations, chromosomal defects (web-site of the Federal State Statistics Service). In addition, there is a tendency of a growing number of oncology diseases. In the National plan on children in Russia up to 2020, we can point the increase in the morbidity rate almost in all categories among children from 15 to 17 years old. Disappointing statistics encourages people to develop medical technologies not only in the field of genetics, but also in palliative care for both adults and children. Provision with worthy “end-of-life” is the duty of the country, but sometimes it can be difficult.

## 3. Research Questions

Despite establishing the palliative departments for children in Russia, the problem of palliative care's deprivation has not been solved yet (Podluzhnaya et al., 2018). It is connected with different factors that hinder a fast and effective solution of this problem.

Considering the legal aspect of the “Palliative care” specialization in Russia, there is a collision: there is no qualification “palliative care doctor” both in the list of specializations and in the education majors, and there are no qualification requirements to this specialization. But in 2018 the professional standard of this specialization was accepted. Therefore, “palliative care doctor” exists de jure, but de facto

it is impossible to obtain this qualification (Decree of the Ministry of Education and Science of the Russian Federation of 12.09.2013 g. N 1061). At the same time Federal law 21.11.2011 No. 323 implies that palliative care is rendered by health professionals who have finished their universities majoring in this specific field of study.

The legislative base of palliative care is developing quite slowly in Russia. Only in 2011, palliative care was accepted as a type of medical care. In 2012, the Decree of Healthcare Ministry No. 1343 of 21.12.2012 stated the regulation of providing with palliative care for adults. A new Decree of the Healthcare Ministry, No. 193 of 14.04.2015, pointed children's rights for getting palliative care. The Decree of the Healthcare Ministry, No. 187 of 23.05.2015, is meant to regulate palliative care for adults.

Continuing the discussion about the legislative base, some authors specify the necessity of teaching palliative care in universities and colleges. Accordingly, the survey of therapists and GPs doctors pointed to the insufficiency of knowledge and experience in the "end-of-life" patients. 98% of respondents marked that palliative care questions must be included in the program of doctor's professional study (Vvedenskaya, 2013). By the way, they are not included in neither Russia nor abroad (Stjernswärd et al., 2007). In 1989, the World Health Organization recommended to introduce studying courses of ache treating and palliative care in all educational programs (World Health Organization, 1990). In Great Britain, Canada, Australia students master the discipline "Palliative care" since the 3rd and 4th years of study. In the same countries, there are palliative medicine courses, which palliative service doctors graduate. Let us compare them with Russia, where one can find a few courses of palliative medicine in some medical universities of country (Moscow, Ulyanovsk, Nizhny Novgorod). In all cases, universities' rectors support integration of palliative medicine courses in the education programs of students, but they state that it is too difficult to find some free time in students' schedule to put them in the curricula (Sullivan et al., 2004).

Lack of finance, psychological factors, feeling of suffering, spiritual ache are general characteristics for almost all families with a palliative child (de Clercq et al., 2019; Mitnick et al., 2010; Rosenberg & Wolfe, 2017). All of them need psychological support (Walter et al., 2019a, 2019b). But this type of help is not adopted well, so patients are face-to-face with their problems.

Parents can also get some benefits for their child from the budget of the country, but by the reason of ignorance of laws, the majority of them do not obtain it (Podluzhnaya et al., 2018).

There is a problem of palliative care coverage in media. Generally, society does not have enough information about palliative care service. Accordingly, the survey the majority of people have never heard about aims to render palliative care. Parents whose children need palliative care can get tired both physically and spiritually. Different social services, volunteers must be involved in this process and should be held on the base of orphanages; residential schools for children within the framework of state order help to spread care not only for children, but also for their parents.

In relation to the base disease, the child's family often suffers from social disadaptation, the usual formed lifestyle destructs, stress accumulates, the health status of the family members' breaks, the financial status gets worse, and as the result there is a crisis in the family relationship.

In the research, it is noted that the family institute is changing in these conditions: the quarter of studied families mark the consolidation during the period of a child's disease. And destruction of

families' relationships is mentioned by 8.1 % of the respondents. 10.3 % of families are at a risk zone – it matches the dates of other authors in terms of the percentage: 15–30 % of divorces.

Also, according to this research, relationships among close and distant relatives, friends, colleagues change both in a better or worse way. Sometimes families with an ill child can feel stigmatization from society due to a diagnosis of a child. These families keep distance from others, alienate from society, survive isolated in a difficult period of life. All these factors have a negative influence on the system “parent-parent-child”. The emotional and psychological background disturbs. This destructive behavior and feel of life disrupt intra-family values. Research shows that tough illness shifts priorities to the side of family interests. Despite the fact that the majority of families mobilize and look for maximum of resources for children support, it is necessary to organize an additional resource provision.

In 2012 a working group of the ICPCN committee developed a number of priorities that should be followed in the system of palliative care development. It was noted that "working through local communities and Internet sites" was important and this direction had become the second priority in the recommendations for the development of palliative care after such priorities as: education, dialogue with the government, spread of WHO recommendations.

The Russian Federation tries to move in this direction. The experience of the Khanty-Mansi Autonomous Region is quite interesting and important. The special social service portal was created there. This portal contains information about citizens who need to receive social services, as well as about citizens, entrepreneurs, organizations that are ready to provide any assistance. Within the framework of this project, the portal offers services for the care of seriously ill citizens, assistance in childcare, “social taxes” for people with limited mobility. These services are provided both on paid and free bases.

In the context of the developing digitalization of society, medical institutions, in accordance with the state's program of digitalization of healthcare system, try to use new methods of socialization, including remote ones. In Chelyabinsk, the support of children who need palliative care is carried out, including online services, for example, "Skype".

In contemporary conditions, the digitalization has a great positive influence on development of medicine including palliative care service. Foreign authors mark positive aspects of social nets and modules. Messengers can soften loneliness. Patients may overcome such barriers as physical restriction, distance and logistic problems via internet-technologies (Guo et al., 2016).

#### **4. Purpose of the Study**

The purpose of the study is to analyze the spectrum of problems in the field of palliative care provision and to develop possible ways of its improvement.

#### **5. Research Methods**

The basement of this exploration is the analysis of legislative documents, national and foreign publications concerning the problems of palliative care (PubMed, E-library).

## 6. Findings

Insufficient development of palliative care institutes forces regional governments to develop its own legal acts to improve its provision. In July 2016, the government of Perm Region accepted a new document – Register of children who need palliative care. With this Register, one can get useful information: the nosological structure of diseases of these patients, the number of children who need respiratory therapy and enteral feeding support. Using this Register the government of Perm can react perfectly as compared to regions without the Register (Kochetkova, 2020).

During provision with palliative care, there are some problems with specialists' timing. Lack of palliative medicine doctors and some extra-staff (psychologists, massage therapists, social workers) leads to a raised workload on a medical team (Baker et al., 2006; Walter et al., 2019a, 2019b). Besides this fact, a high burnout forces doctors to “leave” their specialization (Vishnyakov et al., 2014). In addition, doctors of palliative medicine experience a great stress during the work with drugs. Nowadays the rights of medical personnel are not well protected, doctors are afraid of criminal prosecution. Moreover, there is a limitation in medicines and their forms, in particular for children: pastille, sweets, dragee, suppositories. Also, there is a lack of care for parents' courses of palliative children. Sporadic courses of care for parents were developed in Russia, particularly in Perm region in 2015 (Podluzhnaya et al., 2018). One more strategic problem is psychological and social maladjustment of siblings. These are feeling of unnecessary and rejection that accompany the promotion of deviant behavior. During full psychological and educational training both parents, their ill child and siblings, it is possible to get teambuilding of the family, meaningful emotional involvement of each member of the family, adequate communication. All this factors expose the necessity of setting up both psychological and social work and medical and social work in this group of population. And the activity of social services should contribute to positive background of parents' communication with psychologists which is quite strange for citizens of Russia in contrast to citizens of the USA or Europeans.

The analysis reveals the set of problems. Firstly, there are organizational problems and inconsistency of the legislative base concerning palliative care that cause decrease in its providing and availability.

Secondly, the human factor has an important role. The lack of well-qualified specialists in the field of palliative care, their workload, emotional burnout and fear during the work with drugs forces people to “leave” their profession.

Thirdly, low awareness in mass media of patients and their parents' rights exposes insufficient effectiveness of palliative care.

## 7. Conclusion

It is necessary to state that palliative care in Russia requires a significant systemic coordination of government health care and social development authorities, professional medical community, patient organizations, charitable services activities as well as resource support (human, financial, material). The use of modern digital and information technologies is the key to timely, effective and high quality

provision of palliative care for children and their parents, which meet the WHO requirements in a difficult life situation.

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