

## Palliative Care for Children. Problems and Ways to Solve Them

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### Abstract

The article briefly describes the history of the emergence and development of palliative care in Western countries and in the Russian Federation. Shows significant differences between adult and children's palliative care, which requires a different approach to the treatment of these patients. Solved problems in palliative medicine: an acute shortage of trained personnel and hospital beds, the low efficiency of drug treatments, the high cost of treatment of children in need of such assistance. The issues of funding of palliative medicine. The necessity of inclusion in standards of pediatric palliative care of low-level laser therapy. Given problem facing children's palliative care Centre in Moscow and the Department of Pediatric Palliative Medicine.

**Keywords:** *Children's Palliative Care; Low-Level Laser Therapy*

### Introduction

Palliative care has developed with the hospice movement and is now widespread. The first hospice of St. Christopher appeared in the United Kingdom in 1967. It was founded by Cecily Saunders and is rightly considered the founder of the modern hospice movement. Home care for children diagnosed with cancer was set up in Virginia (Edmarc Hospice for Children) 1978 [1]. At Oxford in 1982 opened Helen and Douglas House Children's Hospice and in 1985, a branch in Children's hospitals EST. Mary's Hospital in New York City. In the late 1980s, palliative care units in the United States opened several institutions, such as the Cleveland Clinic and the Wisconsin College of Medicine. there are more than 1,400 of them.

In Russia, the provision of hospice care for children began in 1993 with the organization in Moscow of a pediatric oncologist, Professor E. I. Moiseenko "Hospice at home for children with cancer". Later on this basis, an autonomous non-profit organization "First Hospice for Children with Cancer" was founded, which works in collaboration with the Institute of Pediatric Oncology of the Russian Cancer Center. N. N. Blokhina RAMN. This organization was a pioneer in the development of palliative care for children in Russia.

Since 2003, a non-state medical institution "Children's Hospice" under the direction of proto-Jeremy Alexander Tkachenko has been organized in St. Petersburg. The activity of the hospice as a charitable organization was to provide not only socio-psychological, but also specialized medical care for children at home. In 2010, the first children's hospice hospital in Russia in St. Petersburg opened. Patients of hospice - children with severe malformations and malignancies.

Palliative care for children has been provided since 2006, when, on the orders of the Moscow Department of Health, the Children's Health Center (CPC MPA) has established a department of palliative care for children at home, which has been established provided comprehensive medical-social-psychological assistance. In 2010, also on the orders of the department, a 10-bed inpatient unit was opened, and since 2013, Russia's first 30-bed palliative care center has been opened.

Features of pediatric palliative care. Palliative care is an approach that improves the quality of life of patients faced with pain through prevention and relief, early diagnosis, impeccable assessment and treatment of pain and other physical, psychological and spiritual problems life-threatening disease. Given definition Epalliative care was articulated WHO experts in 2002.

It's not a Children's palliative care deals with a number of aspects of the life of an incurable child - medical, psychological, social, cultural and spiritual. In addition to anesthesia and the culpable of other pathological symptoms, psychosocial and spiritual support of the patient is needed, as well as moral and psychological support to loved ones in the care of him and in the course of loss. A comprehensive approach that combines different aspects of palliative care is a sign of high-quality medical practice, a significant part of which is palliative care. Maintaining the best possible quality of life of the patient is the key to determining the essence of palliative medicine, as it is focused on the treatment of the patient, not the disease that affected him.

The unique features of palliative care for children dictate the need to create institutions for children separate from adults, which should be taken into account when planning a pediatric palliative care service. The incidence of children with malignancies is much lower than in adults, but children suffer from severe abnormalities and malformations at an early age, genetic diseases, a number of chronic progressive diseases, including cystic fibrosis, myodystrophy, etc. Palliative care for children is based on the same principles as that of adult palliative care, but it also has its own specifics. The patterns of causes of child mortality and adult mortality are completely different, making the principles of palliative care for adults inappropriate for palliative care for children. Many childhood diseases are rare, the duration of the disease can vary greatly from a few days to several years. A child can live to an early adult age, which will require palliative care for many years. Children with diseases leading to premature death need multidisciplinary and multidisciplinary services over a long period of time. These services include: psychological support, the possibility of providing further education, support for parents and close relatives of the child, timely pain relief. staff need to take all measures to deal with the psychological stress of the staff and their emotional burnout caused by working with the dying Children.

The Association for the Support of Children with Life-Threatening and Terminal Conditions and Their Families at the Royal College of Paediatrics and Child Health treats diseases leading to premature death (Life-limiting Conditions) as conditions in which there is no reasonable hope of a cure and from which a child/adolescent will die either before the age of 40 or before the death of his parents. The Association proposes the following classification of life-threatening and premature-death conditions in which palliative care is provided to children. The classification does not include all the conditions in which the child is badly needed for palliative care, it is necessary to take into account the differences in the course of the disease, its severity, the complications caused by it and the need to take action, and the nature of their impact on the child and his family.

**Group 1:** Life-threatening diseases in which radical treatment may be feasible but often fail. after successful radical treatment (e.g. malignancies, irreversible/malignant heart, liver and kidney failure).

**Group 2:** Conditions in which premature death is inevitable, but prolonged intensive treatment can increase a child's life expectancy and allow him to remain active (e.g. cystic pulmonary hypoplasia/polycystic lung disease).

**Group 3:** Progressive incurable conditions, usually lasting for many years, when it is possible to carry out only palliative therapy (e.g.: Batten disease/neural waxy lipofuscinosis/Tay-Sachs disease [1] mucopolysaccharidosis; muscular dystrophy).

**Group 4:** Irreversible/incurable but not progressive conditions/diseases that cause severe child disability, predisposition to frequent complications and the possibility of premature death (e.g. severe cerebral palsy; multiple severe disabling consequences of diseases and injuries).

However, this does not mean that all children and young people in these four groups need active palliative care for the duration of the disease. Some of them, such as children in the second group, may have long periods of relatively good condition and, even if they are largely disabled, may be without active palliative care. Others in the same group may need active palliative care at an early stage of the disease. Therefore, the need for palliative care should always be determined individually.

Children with congenital and cancer-related diseases are most often in need of palliative care. Analysis of 515 children receiving palliative care in 6 hospitals in the U.S. and Canada from January to March 2008, showed that 40.8% of children had genetic/congenital diseases, 39.2% of neuromuscular diseases, 19.8% of cancers, respiratory diseases in 12.8% and gastrointestinal diseases in 10.7%. It's not a Children with advanced diseases are typical of shortness of breath, nausea and vomiting, constipation, itching, fatigue, reflux esophagitis, as well as various complaints concerning sleep disturbance, agitation, drowsiness and weakness. Oh 89% of parents reported that in the last month of life children mostly suffer from one of the symptoms and most often it is pain, fatigue or shortness of breath. It's not a To ensure the acceptable quality of the last days of life requires the special attention of staff to timely identify and stop the above symptoms and frequent constipation, nausea, anxiety, etc. For diseases that children receive palliative care, it is difficult to predict their course and prognosis. Parents to the requirements of continued treatment. Only close, open communication of the medical team with parents can prevent their distrust of doctors and contribute to timely psychological support and necessary palliative care A survey of parents of deceased children has identified the main priorities contributing to improving the quality of palliative care. information about the tactics of the therapy, the availability of medical personnel and their emotional support, the preservation of close relations between parents and children and faith.

### Public and international cooperation

International cooperation in palliative medicine unites almost all developed countries of the West. In March 2006, an international meeting was held in Trento, Italy palliative care for children (International Meeting for Palliative Care in Children, Trento) (IMPaCCT), a team of medics from Europe, Canada, Lebanon and the United States met, to discuss the current situation of children's palliative care in Europe. It also addressed how to improve the quality of palliative care for children and the training of palliative care staffs [2-13].

The first pan-European centre dedicated to improving the quality of palliative care was established in Trondheim, Norway, in 2009. The centre is based on the FACULTY of NTNU and at St. Olav University Hospital (Trondheim) and coordinates between groups and individual researchers across Europe, particularly Scotland, England, Italy, Denmark, Germany and Switzerland, along with the United States, Canada and Australia.

In 1995, the Palliative Medicine and Rehabilitation Fund was established in Russia to help the national health care in the creation of a new direction - palliative medicine. It is one of the first non-profit non-governmental organizations in Russia to help develop optimal methods of palliative medicine and the principles of its organization in Russia. The Foundation's priorities include seminars, conferences and congresses on palliative medicine, as well as the publication of thematic literature and the scientific and practical journal Palliative Medicine and Rehabilitation.

In 2006, the Foundation established the All-Russian Social Movement "Medicine for quality of life", which since its inception has held the All-Russian Medical Forum, raising the most pressing problems of Russian health care, one of which is the organization of palliative care. In 2009, in accordance with the Declaration III of the All-Russian Medical Forum, the All-Russian public organization "Union of Medical Workers" was established. The aim of this organization is to consolidate the medical community in addressing the challenges of

modernizing health care, their professional support and assistance in developing and implementing the best organizational and methodological to improve the quality of life of the citizens of the Russian Federation.

In 2009, the Gift Life Foundation for Children with Cancer and Other Severe Diseases actively assisted in the establishment of a palliative care centre for children in Moscow and to promote the development of this Russia.

After the adoption in 2011 of the Federal Law No. 323-Fz "On the Basics of Citizens' Health in the Russian Federation," the prerequisites for the association of specialists engaged in the provision of palliative care incurable patients in Russia. The all-Russian social movement "Medicine for quality of life" and "All-Russian Association of Medical Workers" initiated the creation of the Russian Association of Palliative Medicine, the founders of which were representatives of the medical community from 44 subjects of the Russian Federation.

**Problems:** One of the significant problems in palliative medicine is the lack of beds and trained staff. Only 23% of these hospitals have beds that are designed for palliative care. There is an acute shortage of doctors trained to provide palliative care. Experts note that in order to improve palliative care there is a need to make changes in the system of funding, medical education, as well as in the hospitals themselves.

In the UK in 2005 there were just under 1,700 hospices consisting of 220 inpatient units for adults with 3,156 beds, 33 inpatient units for children with 255 beds, 358 home services, 104 hospice at-home services, 263 day care and 293 hospitals Commands. These services together helped more than 250,000 patients in 2003 and 2004. Nevertheless, the country plans to increase the bed fund for palliative care for children.

In Western countries, much attention is paid to the training of nurses and doctors working in palliative care units. In 1998, The Initiative for Pediatric Palliative Care was launched in the United States. Based IPPC in Newton, Massachusetts and serves palliative care departments and centers in the U.S. and Canada IPPC's main task is to train medical staff in palliative care and centres and to improve the quality of palliative care. Training determines the fact that palliative care for children develops independently and is formed in an independent medical specialty, which requires special training of doctors, nurses and psychologists, social specialists to work with this special group of patients. Some countries have certification courses in palliative medicine, such as the United Kingdom, the United States and Australia, and the medical student training program includes a section of palliative care. Palliative care is a professional activity, in most diseases it is specialized pediatric care. In the UK, for example, to become a specialist in palliative care in pediatrics, a doctor must study 2 years.

Since 1999 at the First Moscow State Medical University. I.M. Sechenova has started training doctors to work in the system of palliative care for adults. Today, in addition to the course of palliative care at the Department of Oncology faculty of postgraduate vocational education of the First Moscow State University. I.M. Sechenova on the basis of RMAPO in a number of subjects of the Russian Federation (Ulyanovsk, Tyumen, St. Petersburg, Ufa, Yaroslavl, Chelyabinsk, Arkhangelsk, Moscow) already operate on a permanent or optional basis 8 courses of palliative medicine q21. The department of pediatric palliative medicine, organized by the Department of Pediatric Palliative Medicine, will be trained by pediatricians Rossi'd like to National The IssIE Dovalym medical and them University EtOm and Meni NI Pie about What the Center for Palliative Care for Children.

Funding is an important problem. In the UK Funding ranges from 100% through the National Health Service and almost 100% funding to charities, but the service is always free for the patient.

Federal Law No. 323-Fz "On the Basics of Protecting the Health of Citizens in the Russian Federation" provides for free palliative care for Russian citizens. Russian charitable foundations provide substantial assistance to Russian children: "Give Life," "Be a Man," "Life" and a number of others.

The costs of palliative care, especially in pediatrics, are quite high. This is because children receive more aggressive treatment at the end of life than sick adults. Funding is clearly lacking. The American Association of Pediatricians notes that children in need of palliative

care receive quality-of-life therapy, but these costs are not adequately reimbursed by Medicaid. Treatment, turn on the new, more expensive antibiotic and Children with cystic fibrosis, long-term artificial ventilation of the lungs children with neuromuscular passions, or surgical interventions, that can alleviate symptoms diseases, as well as the need for other types of expensive care, may lead to the denial of hospitalization of such children [14-22].

**Treatment:** The development of standards for pediatric palliative care is now a global priority. Today, the main focus of specialists in providing palliative care to children is drug therapy. observed in children with advanced disease. Meanwhile, the specialists note that almost all children admitted to palliative care departments received long-term drug therapy prior to admission, which included an average of 9.1 drugs. This explains the low effectiveness of further drug treatment and does not exclude these children develop a drug disease. Children, especially those who received long-term medical treatment, particularly sensitive to xenobiotic load in the form of pharmaceuticals. in order to reduce the cost of palliative care, Western specialists are looking for non-pharmacological approaches in the treatment of pain and other symptoms of various diseases, experts note that the use of pharmacological therapy in conjunction with psychological intervention is more effective compared to mono drug therapy [23]. Non-pharmacological activities including massage, acupuncture, use of heat and cold, game and music therapy are recommended [8,24].

Domestic researchers have long noted the potentiating effect of drugs when incorporating laser therapy into complex treatment, and the earlier drug treatment is supplemented by laser therapy, the faster it is achieved desired result. Laser therapy, which has been recognized in Russia, is practically not used in Western countries. proven in the treatment of many diseases in children, can significantly improve the quality of medical palliative care and reduce the cost of its implementation. As mentioned, American experts note the increasing costs in the treatment of cystic fibrosis. Studies of domestic scientists have shown that the use of laser therapy in this pathology not only improves the quality of the therapy, but also significantly reduces the cost of treatment.

Studies of Western specialists have proved that the appointment of oxygen therapy for shortness of breath in patients receiving palliative care, effective only in cases where the cause of shortness of breath is hypoxemia. Domestic researchers have revealed the fact that laser hemotherapy contributes to an increase in oxygen transfer by hemoglobin by 30%, which in many cases can completely replace the purpose of oxygen. Such examples of the effectiveness of laser therapy in palliative medicine can be cited many, but, unfortunately, despite the high efficiency and safety of laser therapy, it is still relatively rare. But the number of studies on the possible negative effects of laser radiation on the human body have proved the absence of negative side effects, both during laser exposure and in the long term after him. A study of literary sources over a nearly forty-year period revealed no mention of the negative effects of laser radiation on children's bodies.

Unfortunately, in the approved MHealth and Social Development of the Russian Federation (22.09.2008 No. 7180-RH) methodical recommendations on the organization of palliative care for adults, medical care also does not provide in the treatment of palliative patients use of laser therapy. And this despite the fact that over more than 40 years of clinical studies conducted in our country has been proven its high effectiveness in the treatment of many diseases.

Of course, the experience of palliative care in Western countries has a great deal. But that doesn't mean we have to copy it blindly. It is necessary, having taken the best from the accumulated experience of our colleagues from the West, to introduce progressive, highly effective domestic developments into palliative medicine [25-30].

### Conclusion

Taking into account the existing problems, the new Children's Centre for Palliative Care faces important tasks aimed at organizing the training of nursing and medical staff, improving the quality of treatment, development of domestic standards of palliative care, development of methods aimed at combating the syndrome of emotional burnout of service personnel, reducing the cost of palliative care without compromising its quality. In order to improve the quality of treatment at the newly created Department of Palliative Care for Children, laser therapy is planned. The accumulated experience of the Center will be widely introduced into domestic palliative medicine. The heal-

th modernization program for 2011 - 2012 provides for the establishment of palliative care units (centres) in all subjects of the Russian Federation. At present, solving the problems is the most important pressing problem of national health care.

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