

PALLIATIVE CARE FOR THE CHILDREN OF VORONEZH REGION

Yu.Yu. Razuvaeva, *Postgraduate, Assistant*
V.S. Ledneva, *Doctor of Sciences (in Medicine), Associate Professor*
Burdenko Voronezh State Medical University
(Russia, Voronezh)

DOI:10.24412/2500-1000-2022-7-3-41-44

Abstract. *Palliative care for children is a medical service that develops separately from adult palliative care. The purpose of this study is to analyze the medico-social structure of palliative care for children of Voronezh region. Data were collected from 47 medical institutions of Voronezh region. It included the number of children, the area of residence, social status, diagnosis. The method of nutrition and respiration of the child, the need for oxygen therapy, artificial ventilation, psychological and social assistance were also evaluated. It was revealed that the largest number of palliative patients was detected in the Left-Bank district. According to the structure of the detected palliative pathologies, non-oncological diseases prevail in children of the Voronezh region. Also, acquired neurological diseases are most common – cerebral palsy and congenital anomalies of brain development. Oncological diseases in children, according to our data, occupy a small proportion (4%). In the Voronezh Region, depending on the probability of a fatal outcome, irreversible but not progressive conditions with severe disability and the patient's exposure to complications prevail, which requires the organization of a multidisciplinary approach to palliative therapy, the introduction of new diagnostic methods and rehabilitation measures.*

Keywords: *palliative care, children, palliative pathology, Voronezh region, pediatrics, oncology.*

Introduction. At the moment palliative care for children is a unique and independently developing palliative service. Palliative care for children is aimed at improving the quality of life of a child with severe chronic diseases in which the rehabilitation potential is reduced or absent. The International Children's Palliative Care Network (ICPCN) annually registers more than 8 million children worldwide born with genetic diseases and birth defects who will need palliative care in the future [1]. In Russia, 182089 children need primary palliative pediatric care, and 81950 children need specialized care. In the structure of diseases of children in need of palliative care, non-oncological diseases prevail in Russia and account for 93%, these include congenital malformations and genetic diseases - 42%, diseases of the cardiovascular system – 23%, diseases of the neonatal period – 12%, and other diseases account for 16%. Malignant neoplasms in the structure of palliative pediatrics account for 7% [2,3]. In 2009, the European Palliative Care Association identified 4 groups of patients in need of palliative pediatric care:

1. Life-threatening conditions or diseases for which curative treatment is possible, but it may be ineffective.

2. Diseases in which long-term intensive treatment is aimed at prolonging life and allows for normal activity, but premature death is possible.

3. Progressive conditions without curative treatment options, the therapy of which is palliative from the moment of diagnosis.

4. Irreversible, but not progressive conditions with severe disability and the patient's exposure to complications [4].

Palliative care for children of all four groups is based on a multidisciplinary approach, which is aimed at relieving physical symptoms that violate the quality of life of a child and preventing complications of an incurable disease.

The aim of the study: to analyse the structure of palliative care for children of Voronezh region.

Material and methods: Data were collected from 47 medical institutions providing medical care to children: 15 children's polyclinics in Voronezh and Novovoronezh and

32 central district children's hospitals in the period from September 2021 to December 2021. The criteria for inclusion in the study were: the child age from 0 to 18 years, the need for palliative care help. Data were obtained on the number of children in need of inpatient and outpatient palliative care, the area of residence, the social status of the family, the main and concomitant diagnoses. The method of feeding the child (independent, probe or through a gastrostomy), the method of breathing the child (independent, tracheostomy or hardware artificial lung ventilation), the need for additional oxygen therapy, artificial lung ventilation, the need for

psychological and social assistance were also evaluated. All the data obtained were depersonalized, and a register of palliative pathology of children of Voronezh Region was created on their basis. Methods of nonparametric statistics were used to analyze the data obtained.

Results. Information was collected about 356 children of Voronezh region receiving palliative care. Among children with palliative pathology, 35.1% live in the city of Voronezh, and 64.9% in Voronezh region. The distribution of children with palliative pathology by districts is presented in the table.

Table 1. The district structure of palliative care for the children of Voronezh region

District	Number of children	%	District	Number of children	%
Anninsky	4	1,1	Ostrogozhsky	7	2
Bobrovsky	9	2,5	Pavlovsky	13	3,7
Bogucharsky	2	0,6	Paninsky	1	0,3
Borisoglebsky	14	3,9	Petropavlovsky	2	0,6
Buturlinovsky	8	2,2	Povorinsky	3	0,8
Verkhnemamonsky	1	0,3	Podgorensky	6	1,7
Verkhnekhavsky	4	1,1	Ramonsky	10	2,8
Vorobyevsky	5	1,4	Rossoshansky	23	6,5
Gribanovsky	6	1,7	Semiluksky	9	2,5
Kalacheevsky	6	1,7	Talovsky	4	1,1
Kamensky	3	0,8	Ternovsky	3	0,8
Kantemirovsky	9	2,5	Khokholsky	9	2,5
Kashirsky	5	1,4	Ertilsky	11	3
Liskinsky	16	4,5	Railway	24	6,7
Nizhnedevitsky	2	0,6	Comintern	24	6,7
Novovoronezh	3	0,8	Levoberezhny	36	10,1
Novousmanskyy	18	5	Leninsky	8	2,2
Novohopersky	12	3,4	Central	7	2
Olkhovatsky	3	0,8	Soviet	26	7,3

The average age of children receiving palliative care is 10 [7;11], girls - 41%, and boys - 59%. According to the structure of palliative states, non-oncological diseases prevail in Voronezh region and account for 96% of all pathologies. Of these, acquired neurological diseases prevail and account for 69.9%, congenital malformations and genetic diseases - 24.1%, other diseases - 2%. Palliative oncological pathology accounts for 4% among children of Voronezh region.

A detailed analysis of acquired neurological pathology revealed that epilepsy as an independent disease occurs in 2% of children receiving palliative care, spinal muscular atrophy - in 4.8%. The leading positions are

occupied by cerebral palsy and brain damage due to injuries, strokes, meningoencephalitis - 93.2%. At the same time, 106 children suffer from combined comorbid pathology: cerebral palsy and epilepsy.

In the structure of pathologies of congenital malformations and hereditary diseases of Voronezh region, the leading place is occupied by brain malformations (microcephaly, hemiatrophy, hydrocephalus, cysts, encephalomalacia) and account for 45.3%, Duchenne myodystrophy and other unspecified myodystrophy - 22%. Metabolic diseases account for 8.1% and are distributed as follows: adrenoleukodystrophy - 4.6%, leucinosis - 2.3%, neuronal ceroid lipofuscinosis - 1.2%.

There are 5.8% of chromosomal abnormalities which include Down syndrome – 2.3%, and Wolf-Hirshhorn syndrome, Patau syndrome, Edwards syndrome by 1.1%, respectively. Children who have hereditary diseases and receive palliative care in the Voronezh Region account for 7%: cystic fibrosis accounts for 3.5%, Rett syndrome – 2.3% and Foam-Shoiker syndrome - 1.1%. Hereditary ataxias account for 2.3% and are divided into Louis-Bar syndrome and Friedreich ataxia by 1.1%, respectively. Other malformations in children account for 8.1%: 2.3% for isolated congenital heart defects, spinal cord abnormalities (Spina bifida), malformations of the facial skeleton and 1.1% for malformations of the anterior abdominal wall (gastroschisis).

When analyzing the structure of neoplasms of children receiving palliative care, tuberous sclerosis prevails and amounts to 28.6%. Neuroblastoma, medulloblastoma and acute lymphoblastic leukemia account for 14.3%, respectively. Neurofibromatosis, glioblastoma, ovarian tumor and rhabdomyosarcoma account for 7.1%, respectively.

According to the groups of patients in need of palliative pediatric care identified by the European Association of Palliative Care in Voronezh region:

- life-threatening conditions or diseases for which curative treatment is possible, but it may be ineffective account for 5.9%, these include patients with neoplasms, severe malformations, chronic heart failure, chronic kidney disease;

- diseases in which long-term intensive treatment is aimed at prolonging life and allows for normal activity, but premature death is possible – 10.7% and include cystic fibrosis, neurodegenerative diseases, spinal muscular atrophy, myodystrophy;

- progressive conditions without curative treatment options, the therapy of which is palliative from the moment of diagnosis – 2%, these include mucopolysaccharidoses and metabolic diseases;

- irreversible, but not progressive conditions with severe disability and the patient's

susceptibility to complications are the most numerous group and account for 81.4% (cerebral palsy, genetic disorders, congenital and acquired brain/spinal cord injuries, epilepsy).

When analyzing the data obtained, it was revealed that all children need outpatient palliative care, and 71.3% of children additionally need inpatient palliative care. At the moment, 7% of children are fed with a probe, 4 children (1.1%) have a gastrostomy and nutrition occurs through it, all other patients (91.9%) feed themselves. When analyzing the method of breathing, it was revealed that 96.1% breathe independently, and 3.6% of children have a tracheostomy tube installed. Additionally, 2.2% of children need oxygen therapy, and 1.7% of patients need artificial ventilation at home. At the same time, 2% of all palliative patients are fed by the probe method and at the same time they have a tracheostomy installed.

Conclusion. Based on the data obtained, it was revealed that directly in the districts of the city of Voronezh, the largest number of palliative patients was detected in the Left-Bank district. Perhaps the fact that 35 manufacturing enterprises operate on the territory of the Levoberezhny district plays a role. According to the structure of the detected palliative pathologies, non-oncological diseases prevail in the children of Voronezh region, which is compared with statistical data for Russia. Also, acquired neurological diseases are most common – cerebral palsy and congenital malformations, in particular brain malformations. Oncological diseases in children, according to our data, occupy a small share (4%), whereas according to WHO, about 34% of the adult population worldwide with oncological diseases need palliative care [5]. In Voronezh region irreversible but not progressive conditions with severe disability and the patient's exposure to complications prevail, which requires the organization of a multidisciplinary approach to palliative therapy, the introduction of new diagnostic methods and rehabilitation measures.

References

1. The International Children's Palliative Care Network. Palliative Care for Children Living with Non-Communicable Diseases – An ICPCN Position Paper. 2013.

2. Savva, N.N. Palliative care for children in Russia: need, condition, development concept. – M.: Charitable Foundation for the Development of Palliative Care Children's Palliative Care, 2015. – P. 22-23.
3. Savva, N.N. ABC of palliative care for children. – M.: Prospect, 2020. – P. 44-92.
4. ACT. A Guide to the Development of Children's Palliative Care Services. ACT (Association for Children's Palliative Care). Bristol, 2009.
5. Connor S., Bermedo M.C.S. WHO. Global Atlas of a palliative care at the end of life. - World Health Organization/ Worldwide Hospice Palliative Care Alliance. – Geneva, CH/London, U.K.; 2014. 111 p.

ПАЛЛИАТИВНАЯ ПОМОЩЬ ДЛЯ ДЕТЕЙ ВОРОНЕЖСКОЙ ОБЛАСТИ

Ю.Ю. Разуваева, аспирант, ассистент

В.С. Леднёва, д-р мед. наук, доцент

Воронежский государственный медицинский университет им. Н.Н. Бурденко
(Россия, г. Воронеж)

***Аннотация.** Паллиативная помощь детям представляет собой отдельно развивающуюся службу паллиативной помощи. Цель данного исследования – проведение структурного анализа паллиативной помощи пациентам-детям Воронежской области. Были собраны данные 47 медицинских учреждений Воронежской области. Получены сведения о количестве детей, районе проживания, социальном статусе, диагнозе. Также оценивался способ осуществления питания и дыхания ребенка, необходимость в кислородотерапии, искусственной вентиляции легких, психологической и социальной помощи. Выявлено, что наибольшее число паллиативных пациентов находится в Левобережном районе. По структуре выявляемых паллиативных патологий у детей Воронежской области преобладают неонкологические заболевания. Также наиболее часто встречаются приобретенные неврологические заболевания – детский церебральный паралич и врожденные аномалии развития головного мозга. Онкологические заболевания у детей занимают малую долю (4%). В Воронежской области в зависимости от вероятности летального исхода преобладают необратимые, но не прогрессирующие состояния с тяжелой инвалидностью и подверженностью пациента осложнениям, что требует организации мультидисциплинарного подхода к паллиативной терапии, внедрению новых методов диагностики и реабилитационных мероприятий.*

***Ключевые слова:** паллиативная помощь, дети, паллиативная патология, Воронежская область, педиатрия, онкология.*