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## The first experience of mobile pediatric palliative team in Ukraine

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**Key words:** Palliative Care, Children, Home Visits.

The aim of the study was to identify needs among young children with life-limiting diseases under 4 years old and their parents living in rural area of Kharkiv region Ukraine during home visiting.

**Materials and methods.** After the creation of the first mobile pediatric palliative team, we reviewed the visits of 31 families at home to define their clinical, and psychological, and social needs. The first mobile pediatric palliative care team has been created for 2015. 31 families who have young children with life-threatening diseases were visited to determine their clinical, and psychological, and social needs.

**Results.** All children (31) had severe pathology of the central nervous system: congenital birth defects (29%); cerebral palsy (35.4%); genetic disorders (12.9%). Parental and children's needs were divided into three categories. Medical needs: orthopedic (93.5%), vaccination (93.5%), food (80.6%), posture (61.3%), salivation (32.2%), anticonvulsant therapy (16%). Psychological problems: communication with siblings (100%); socialization of children (90.3%); sensory activity (83.8%), parental relationships (74.2%). Social issues: the need for support/social worker or volunteers (58.1%), poverty (58.1%), communication with local rehabilitation centers (54.8%), the need for medical equipment (41.9%).

Along with high medical, social and psychological needs of children with incurable diseases, both they and their families feel the lack of pediatric palliative care, and at present they have no access to it. The authors suggest that pediatric palliative care in Ukraine requires its development, application and inclusion in the general health care at all levels of the health system. The establishment of a national concept of modern educational programs, protocols and standards, dissemination of public information communities is also very necessary due to author's point of view.

**Conclusions.** Mobile team that performs home visits may be one of the best ways to start creation of the pediatric palliative care services.

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### Перший досвід виїзних педіатричних паліативних бригад в Україні

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**Мета роботи** – визначити потреби серед дітей молодшого віку з невиліковними захворюваннями у віці до 4 років та їхніх батьків, які проживають у сільській місцевості Харківської області, за допомогою домашніх візитів.

**Матеріали та методи.** Протягом 2015 року створені перші мобільні команди дитячої паліативної допомоги. Здійснили візити до 31 родини, які виховують дітей раннього віку з невиліковними захворюваннями, для визначення їхніх клінічних, психологічних, соціальних потреб.

**Результати.** Діти (31) мали тяжку патологію центральної нервової системи: вроджені вади розвитку (29%), церебральний параліч (35,4%), генетичні розлади (12,9%). Батьківські та дитячі потреби поділили на три категорії. Медичні потреби: ортопедичні (93,5%), вакцинація (93,5%), харчування (80,6%), поза (61,3%), слинотеча (32,2%), протисудомна терапія (16%). Психологічні проблеми: комунікації з братами та сестрами (100%), соціалізація дітей (90,3%), сенсорна активність (83,8%), батьківські стосунки (74,2%). Соціальні питання: необхідність підтримки/соціального працівника або волонтерів (58,1%), бідність (58,1%), зв'язок із місцевими реабілітаційними центрами (54,8%), потреба в медичному обладнанні (41,9%). Незважаючи на високі медичні, соціальні та психологічні потреби, дітям із невиліковними захворюваннями бракує інфраструктури педіатричної паліативної допомоги, натепер у них відсутній доступ до неї.

Автори припускають, що розвиток дитячої паліативної допомоги в Україні вимагає розробки, впровадження та включення її до загальної медичної допомоги на всіх рівнях системи охорони здоров'я, а також створення національної концепції, сучасних освітніх програм, протоколів і стандартів, поширення інформації серед населення громад.

**Висновки.** Виїзна паліативна бригада може бути одним з оптимальних способів початку створення служби педіатричної паліативної допомоги в умовах низьких доходів і ресурсів країни.

**Ключові слова:** паліативна допомога, діти, виїзна бригада.

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### Первый опыт выездных педиатрических паллиативных бригад в Украине

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**Цель работы** – определить потребности среди детей младшего возраста с неизлечимыми заболеваниями в возрасте до 4 лет и их родителей, проживающих в сельской местности Харьковской области Украины, с помощью домашних визитов.

**Материалы и методы.** В течение 2015 года созданы первые мобильные бригады педиатрической паллиативной помощи. Совершили визиты в 31 семью, имеющую детей раннего возраста с неизлечимыми заболеваниями, для определения их клинических, психологических и социальных потребностей.

**Результаты.** Все дети (31) имели тяжёлую патологию центральной нервной системы: врождённые пороки развития (29%); церебральный паралич (35,4%); генетические расстройства (12,9%). Родительские и детские потребности разделили на три категории. Медицинские нужды: ортопедические (93,5%), вакцинация (93,5%), питание (80,6%), поза (61,3%), слюнотечение (32,2%), противосудорожная терапия (16%). Психологические проблемы: коммуникации с братьями и сёстрами (100%), социализация детей (90,3%),



сенсорная активность (83,8%), родительские отношения (74,2%). Социальные вопросы: необходимость поддержки/социального работника или волонтеров (58,1%), бедность (58,1%), связь с местными реабилитационными центрами (54,8%), потребность в медицинском оборудовании (41,9%). Наряду с высокими медицинскими, социальными и психологическими потребностями детей с неизлечимыми болезнями, им и их семьям не хватает педиатрической паллиативной помощи, и на данный момент у них отсутствует доступ к ней.

Авторы предполагают, что развитие детской паллиативной помощи в Украине требует разработки, внедрения и включения её в структуру общей медицинской помощи на всех уровнях системы здравоохранения, а также создания национальной концепции, современных образовательных программ, протоколов и стандартов, распространения информации среди населения.

**Выводы.** Выездная паллиативная бригада может быть одним из оптимальных способов начала создания службы педиатрической паллиативной помощи в условиях низких доходов и ресурсов страны.

**Ключевые слова:** паллиативная помощь, дети, выездная бригада.

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One of the barriers to pediatric palliative care use is that pediatric clinicians generally have lack of understanding and experience [1]. Ukraine is a country with a population of 45 million, that does not have national Pediatric Palliative Care (PPC) policy. Today Ukraine is lacking specialists in pediatric palliative care. There are no hospices for children and specialized departments. There is a lack of literature sources regarding global trends in the development of pediatric palliative care. Unfortunately awareness of the possibility of receiving palliative care for children is low, and the number of online resources of information on pediatric palliative care is extremely limited [2]. Kharkiv region is the largest in area and population of Ukraine (2.95 million people), but there is no access to PPC for children with life-limiting and life-threatening diseases [2].

**Aim.** To identify needs among young children with life-limiting diseases under 4 years old and their parents living in rural area of Kharkiv region, Ukraine, during home visiting.

#### Materials and methods

The target of first experience was 31 families – residents of rural area who have young children with severe disorders of the central nervous system. The mobile pediatric palliative team has been formatted at the Kharkiv Regional Specialized Baby Home №1 (KhRSBH) – an institution that provides medical and social care in young children from rural area (from 2 months to 4 years) without parental care and children who are brought up in families and have the pathology: organic lesion central nervous system and the musculoskeletal system; mental and behavioral disorders; congenital anomalies, deformations and chromosomal abnormalities. These 31 families have been included by a method of random selection. The list of states caused by disorders of the central nervous system and determining the need for the patient to obtain palliative care using 26 codes ICD-X in the classroom (G00–G99) – “Diseases of the nervous system” and 82 codes in the classroom (Q00–Q99) – “Congenital malformations, deformations and chromosomal abnormalities” was used [3,4].

The program of first mobile pediatric palliative team consists from three stages: First stage was “Preparatory Phase”. Communication with families to identify needs in maintaining and obtaining informed consent and, development of schedule visits. Create questionnaires. Second stage was “Providing advice”. Formation of teams depends on prior requests of the families, and organization of visits. The chronometry of visit for each patient was conducted. Visiting every family performed twice with an interval of 1–2 months to supplement the needs analysis and control of the final results of the first exit. Third stage

“Conclusion”. Analysis of the questionnaires and family’s needs.

All findings while visiting family recorded in a special e-database (Exele for Windows) through which used methods of descriptive statistics (Statistica 7.0).

#### Results

First stage. Our team, which consisted of five persons, a coordinator, pediatrician, nurse, psychologist, and physical therapist, identified the needs of families of children with life-limiting diseases. First of all, for the coordinator of the project questionnaire by telephone family members to identify the needs was set up and desires of visiting families at home. All families who have been invited and visiting them at home gave a positive response. In order to facilitate the evaluation of children’s health at survey pediatrician separate document was created “Primary examination visiting doctor service”, an important component of which is the inclusion of the scale to measure the intensity of pain for infants and children with nonverbal communication “FLACC” 1997 [5].

With the purpose of determining a problems in families raising young children with disorders of the central nervous system was created questionnaires for the pediatrician, psychologist, physical therapist. After entering data, and joint discussion among mobile palliative team of the family’s problems, a general conclusion was conducted.

Second stage. Results of the 2nd phase of the project, namely, providing advice to children and their families, was visiting family according with the schedule. Each family received two visits. Visiting teams have also made referrals to qualified public health institutions, nongovernment public organizations, which have been useful in the case. But this is purely the function of district health workers. Considering the basic principles and philosophy of palliative care are examples of stories of our children and their families that lack of communication, support and sometimes basic care, sometimes – public awareness, and sensitivity, and humanity.

The third stage – the analysis of the problems of the 31st families who have children with special needs, through careful study of documents created specifically for visits revealed the basic needs related to medical, psychological and social assistance component.

General characteristics of the cohort are presented in *Table 1*. The number (n) and percentage (%).

It should be noted that no child is receiving oxygen therapy and ventilation at home or had a gastrostomy/tracheostomy.

There were medical problems during in-depth two-time pediatric visits (*Table 2*).



Table 1

**Total demographic and clinical characteristics (n=31)**

Baseline Characteristic	Abs., (%)
Age, mo	
0–12	2 (6.5)
13–24	4 (12.9)
25–36	21 (67.7)
>36	4 (12.9)
Male sex	16 (51.6)
Mother's education less than college degree	5 (16.1)
Mother housewives	15 (48.3)
Married/partnered (single/divorced)	24 (77.4) 7 (22.5)
Low income	26 (83.8)
Parental smoking	5 (16.1)
Pathology of CNS	
Congenital malformation	9 (29.0)
Cerebral palsy	11 (35.4)
Hydrocephaly	3 (9.6)
Microcephaly	4 (12.9)
Genetics metabolic disorders	4 (12.9)
Paralytic syndrome (class of Gross Motor Function Classification System IV–V) [6]	18 (58.0)
Seizures	7 (22.5)
GIT symptoms	
Hypersalivation	20 (64.5)
Regurgitation	2 (6.4)
swallowing difficulties	4 (12.9)
Constipation	7 (22.5)
Orthopedics problem	29 (93.5)
Optic nerve atrophy	2 (6.4)
Mild pain by "FLACC" scale, 1997 [5]	2 (6.4)

The data suggests about more attention needs from the general practitioners to these children and teaching them the basics of palliative care. The policy of young children with life-limiting diseases in Ukraine It is an important component of health care systems.

The result was the outline of psychological and social problems (Table 3, 4).

Despite that only 38% of families needed of psychological support, psychologists identified a large proportion of psychological problems in children and siblings.

Because all children were with special needs, their social needs had been studied.

Half of the families were the need for social services, as it was reported to social services. Unfortunately, the family had not been visited by employees from social services. Therefore, the principle of a holistic approach to support such families is not respected.

During the home visits palliative teams not only find out the needs of children and families. They carried out interviews with parents at their request, performed "family support" function, sometimes they taught parents. Chronometry visits ranged about two hours: 1 hour 2 families in need, from 1 hour to 2 hours – 28 families, more than 2 hours – 1 family.

**Discussion**

The list needs a fairly large and complex. But he defines that our societies still imperfectly care of those with special needs who have never recover. We understand that parents who have

Table 2

**Identified health problems visiting mobile pediatric palliative teams (n=31).**

**The number (n) and percentage (%) (Tables 2, 3, 4)**

Needs	Abs., (%)
Correction of anticonvulsant therapy	5 (16.1)
Correction of child's posture	19 (61.3)
Orthopedic treatment	29 (93.5)
Special equipment	24 (77.4)
Adapting the conditions for the position of "standing" (parent's education)	12 (38.7)
Operation of hip joints	1 (3.2)
Correction of vision	5 (16.1)
Treatment of hypersalivation	10 (32.2)
Monitoring of physical development	31 (100)
Genetic counseling	12 (38.7)
Correction of feeding and nutrition	25 (80.6)
Hygienic care	8 (25.8)
Improve of motor activity	26 (83.8)
Advising on the vaccination of children	29 (93.5)

Table 3

**Revealed psychological problems psychologist visiting palliative teams (n=31)**

Needs	Abs., (%)
Psychological support for parents (parental requests)	12 (38.7)
Parents Psychological support the results of the findings of psychologist	17 (54.8)
The issue of communication and socialization of children	28 (90.3)
Psychological correction intrafamily relationships	23 (74.2)
The concern of parents unborn child	20 (64.5)
Psychological problems in sibling	7 (100)
Organization of developmental space	21 (67.7)
Stimulation of sensory activity	26 (83.8)
Correction and selection of game material	28 (90.3)

Table 4

**Revealed social problems palliative team visiting crew (n=31)**

Needs	Abs., (%)
The need for special equipment	13 (41.9)
Deficiency of money to buy medicines for the child, pay utilities, care items, diapers and others	18 (58.1)
The problem of placement of the child for kindergarten	2 (6.4)
Common ignorance about finding local rehabilitation centers	17 (54.8)
Question benefits	2 (6.4)
Lack of awareness on preferential programs in the region	12 (38.7)
Support volunteers	4 (12.9)
The need for communication with social services	18 (58.1)



children with life-limiting diseases need for support. So the first step to improving the quality of life in low-income country Ukraine may be mobile pediatric palliative service. Our neighbors Moldova and Belarus organized mobile pediatric palliative team and children's hospices [7,8].

Moreover, teamwork is considered the foundation of philosophical and palliative care approach to provide PPC is multidisciplinary approach [9]. The content of multidisciplinary teams should be included specialists from different clinical disciplines [10]. There is convincing evidence that teamwork in palliative care gives children more benefits, while reducing total cost of providing care by reducing the time that patients spent like in hospitals emergency, effective treatment for pain and other serious symptoms [9,10].

Thus, the main goal of a home visiting – to build and maintain the most appropriate system to support child and family in the medical, social, psychological and spiritual sense of existence and continue the service [11].

Authors speculate that the state of pediatric palliative care in the country should include following points:

1. The development and implementation at national level of policies aimed at inclusion of palliative healthcare in the continuous process of providing medical services to patients with life-limiting and life-threatening diseases at all levels of the health system by establishing a national concept, with special emphasis on primary care services care and the organization of palliative care at the community level [12].

2. Content creation pediatric palliative care and its inclusion in the curriculum of secondary and higher medical education training [13].

3. Create a modern regulatory framework for the implementation of palliative care to children in terms of reforming the healthcare industry [12].

4. Create interdepartmental group to promote research in the field of pediatric palliative care, including the development of standards, regulatory documents and models for this type of service [14].

5. Development of communication standards and ethical aspects of pediatric palliative care [15].

6. Providing pain control and pain management [16].

7. Ensuring adequate access to children who need palliative care [17].

8. Ensuring that all components of pediatric palliative care (medical, psychological, spiritual, and social) for children and their families by trained specialists [12,13].

9. Information and education on palliative medical care, achieving universal coverage of children needing palliative care, taking measures to improve the quality and safety of palliative care based on the needs of local communities [18].

### Conclusions

In spite of high medical, social and psychological needs for children with life-limiting conditions there is currently no PPC infrastructure, no access to PPC for children with life-limiting conditions in Ukraine beyond a model project. Home visit mobile team approach could be the better way to begin building of PPC service in condition of low income and resources of the country.

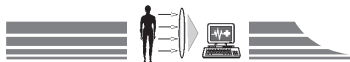
**Prospects for further research.** Pain assessment scales and medical or integrative correction of pain in young children with incurable diseases should be applied.

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**Conflicts of Interest:** authors have no conflict of interest to declare.

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