



## Home-based pediatric palliative care model effectiveness in developing countries: a retrospective analysis of Ukraine experience

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### Abstract

**Background.** Pediatric palliative care services in the world are provided through two principal models: institutional and home-based. Integration of those models is also applied.

**Aim:** To assess the effectiveness of home-based pediatric palliative care model in the developing economy setting of Ukraine.

**Design:** Retrospective analysis of Ukrainian nation-wide data from pediatric palliative care providers using different pediatric palliative care models was conducted.

**Data sources:** Original research data for January 2014 – December 2018 based on the Ukrainian National Scientific Medical Library database records available for four service providers (N=4) (one institutional, two home-based, one integrated model), was analyzed. 7 studies (N=7) were evaluated based on the set of outcomes: morbidity and mortality, health care utilization, patients' quality of life, cost-and time- effectiveness and continuity of care.

**Results:** Use of home-based pediatric palliative care model in Ukraine improves health-related and health care utilization outcomes and the patients' quality of life by wider coverage of families' psychological/social demands, including home-based death. Under the developing economy conditions, it is more cost-and time-effective than institutional model. Due to Ukraine geographic specifics, it allows wider population coverage and better health services use. To ensure continuity of care, coordination of services between different care providers and rapid transfer protocols elaboration is essential.

**Conclusion:** Home-based pediatric palliative model is an effective way of the development of national pediatric palliative care infrastructure under lower middle income country conditions.

**Keywords:** pediatric palliative care (PPC), life-limiting conditions (LLC), institutional, home care model, developing economy

## **Background**

Pediatric palliative care services in the world are based on two principal models: institutional and home-based (1,2). The institutional type implies inpatient (hospital ward or hospice) stay of the children with life-limiting conditions (LLC) (1,2,3). The home-based model entails outpatient care provided by mobile unit at patients' home (2).The integration of both approaches is also applied (1,3). Most European countries initially adopted the institutional care model, but compared to the statistics of the 2000s, the majority of them are now creating mobile units (1,4). Reduction of costs and length of hospital stay, improvement in patients' satisfaction rate, and possibility for them to die at home are mentioned among home care benefits (4,5,6,7,8) though focused research exploring advantages and disadvantages of different models, is scarce (1,4,5,6,7,8), especially for developing countries (9)

In Ukraine, a lower middle income country (10) both models have been applied since opening the first children hospice in late 2013 (11,12). Children hospices are created based on specialized orphanage facilities, where most of the patients (89-100%) need palliative care due to multiple LLC (14,15,17). With the demand of 450/225 outpatient/inpatient services respectively as recommended by EAPC (13), actual ratio of services per population hardly exceeds 3% in Ukraine (16). 3 children hospices, 3 palliative care hospital units and 4 mobile units (1 integrated with the hospice) in 4 cities, currently provide palliative care in Ukraine (16). Different pediatric palliative care models are legally defined in Ukraine, but the experience on exploration of their feasibility is limited (18). The aim of the current study is to assess the effectiveness of home-based model in Ukrainian setting of a developing economy.

## Methods

Retrospective analysis of Ukrainian nation-wide data (original research) for January 2014 – December 2018 was done based on the Ukrainian Scientific National Medical Library database records (11,12,14,17,18,15,19). Seven studies (N=7) available for four pediatric palliative care service providers (N=4) using different models (one institutional, two home-based, one integrated type) were identified. The impact of home-based model on the quality of services was assessed based on the set of outcomes as morbidity and mortality, health care utilization, patients' quality of life, economic effectiveness and continuity of care.

## Results

**Morbidity, mortality and health care utilization.** The analysis of LLC structure in the patients demonstrated the prevalence of ACT/RCPCH Groups 3 and 4 (20): irreversible conditions with multiple comorbidities stipulating the complex care needs. In Ukraine pediatric population those mainly include central nervous system and neuromuscular diseases (35-89%), congenital birth defects and genetic disorders (29 -42%) (12,14,15,17). Prevalence of ACT/RCPCH Group 2 conditions requiring long-lasting intensive treatment (20) may also reach above 50% (19).

In Marabyan et al. prospective study of 38 children with LLC cared in hospice (14), 28 patients (74%) had severe complications (71% - seizures, 13% -surgery, 3% -acute pneumonia) related to the progression of the main condition; 4 (10,5%) of the patients died.

Rehabilitation was successful only in 1 (2,6%) case(14). In Penkov et al. retrospective study of 14 children with LLC (17) who received inpatient care during 3 years, 12 children (85%) required hospitalization due to seizures (4 were sedated) and 2 (15%) - periodic cardiorespiratory intensive care; 14(100%) of those children died. In the children who died frequency of hospital admissions (N=88) was 1-15 per year and was not age-dependent ( $r=0,56$ ;  $p>0,05$ ); the length of hospital stay (1-437 days/5-59 days in terminal phase) was not dependent of the number of hospital admissions. In Riga et al. study (15), only 5 (16%) of 31 home-cared patients with severe CNS pathology required anticonvulsant therapy, and were successfully managed without hospitalization. Like in the other countries, the increase in hospitalization frequency and prolonged treatment period in children requiring palliative care is also observed under the inpatient/orphanage conditions (14,17). The authors concluded that institutional model impairs rehabilitation (14), adversely affects the disease trajectory and health care utilization (17), and increases morbidity and mortality (14,17).

Under Ukrainian conditions of low population density (85.82-98.63), home care proves extremely time efficient (12).The total hospice patients' structure in Andriishin et al. (12) study was geographically represented by majority (47-100%) living within the area of proximity (35 km), while mobile unit covers 60-200 km territory (12). Different from the countries where the home-based model under conditions of extreme population density (201-267/km) ensures only limited coverage (1), in Ukraine it may increase the health services use rate (12).

**Quality of life (QoL).** Shchurovska et al.(19), in the report on 26 home-cared patients, including 51% of those of Group 2 (SMA) concluded the patients' engagement into social activities was more easily achieved under home conditions, and home care increased parents-rated QoL. Families' requests analysis by home-based care providers demonstrates that better families' satisfaction rate is easier achieved under home care due to the specifics of their needs, where medical requests represent only 59 - 80%, and psychological and social problems (socialization of children (90.3 %), communication with siblings (100 %) significantly prevail (15,16,19).

The compliance with preferences of parents/children for home as place of death is rated as a major QoL factor (1,4) which contributes to QoL improvement in the final disease phase(7). Ukrainian data reveal the majority of hospice-cared patients died in the hospital conditions (14,17,18), while home care model increased possibilities to die at home (19). Apart from the negative impact on QoL and bereavement stage trajectory, the child death in the hospital was

strongly associated with psychological stress of the hospital staff (19). The outcome of 100% cases of hospital deaths as reported by 2 studies (14,17) exceeds the rate in the European population of children with LLC (74%) (4).

**Time and cost-effectiveness.** The administrative and legal aspects make home-based care more time-effective in Ukraine setting. The average period between the concept development and Ministry of Health approval lasts up to 1 year/3 months, training of the team - up to 6-9/1-3 months, and the period for start-up funds collection - up to 9-12/3-6 months, for institutional and home-based care models respectively(11,12,19).The prevalence of ACT/RCPCCH Groups 2-4 conditions in the structure of patients LLC increases running costs, but home care reduces significant start-up expenditure implied by institutional model (11). The comparative analysis of expenses structure for children hospice of 15 beds and mobile unit for 30 patients demonstrates that start-up costs of home care are several time less compared to the institutional model (up to 190 000 USD whereof the current health expenditure in the country is only 6,13% of GDP, with 2 639.82 GDP per capita)(10,11). The home-based model is associated with reduction of hospital charges and low start-up funding (4,5,8), and two-fold savings in running costs compared to inpatient care, may be observed(11). Thus the model may be feasible for a start phase of creation of pediatric palliative care services infrastructure (15).

**Continuity of care.** Home-based model was associated with worse impact on continuity of care, as it requires seamless coordination of services between different care providers and rapid transfer protocols, currently lacking in Ukraine (3,18). Due to the prevalence of ACT/RCPCCH Groups 2-4 conditions(20), causing the events where immediate hospitalization is essential, the frequency of acute events (cardiorespiratory distress, arrhythmias, hemorrhagic stroke) in children with LLC was high above average (31-54%) and those were better managed under hospice conditions (14,17).

**Limitations and implications for practice.** The study limitations are sample size (data availability for less than 50% operators, small number of studies outlining specific outcomes), specifics of orphanage-based hospice care less focusing on psychological needs (9,14), and the lack of official data on the incidence and prevalence of pediatric LLC in Ukraine (16,18). Despite those limitations, the study provides a multifaceted analysis of effectiveness of home-based model in Ukraine, which may be used for further development of pediatric palliative care infrastructure and addressing the existing gaps in the national policy.

## Conclusions

In the pediatric population with LLC requiring prolonged and complex care, home based pediatric palliative care model improves health-related and health care utilization outcomes. Home-based model is associated with improved QoL due to better coverage of families' psychological/social demands, including home-based death. Cost-and time-effectiveness of mobile units' establishment improves health care resources use in lower middle income country. In the environment of Ukraine, due to the geographic specifics, it allows wider population coverage. To improve the continuity of care, elaboration of the rapid transfer protocols and coordination between different providers is essential. Home-based model may be effective way of establishing national pediatric palliative care infrastructure in the developing country.

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