Continuous professional education of clinicians and raising patients’/families’ awareness improves pediatric palliative care services quality

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BACKGROUND: PALLIATIVE CARE SERVICES IN UKRAINE

EAPC recommendations:
- 1 home care MDT per 100,000 inhabitants
- 1 inpatient service/10 palliative care beds per 200,000 inhabitants

Ukraine (45 mln. population) demand: **450 outpatient, 225 inpatient services/ 4500 beds**
Kyiv (3 mln population) demand: 30 outpatient, **15 inpatient services, 300 beds**

Actual ratio of services per population – **about 3%**

*As access to palliative care should be available 24\7 for all patients and families, palliative care hotlines perfectly supplement existing facilities*

EAHPC White Paper on Palliative Care Education (2013); Radbruch and Payne (2009); IRF (2018)
ALL-Ukrainian Pediatric Palliative Care Hotline

Operational since September 2015 toll-free, free-of-charge, 10-16 on working days:
- Informational and consulting support to terminally ill children/families
- Professional support to palliative care professionals

December 2017:
- 3285 calls, 656 referrals to specialized support
- Full-scale support and management for 29 families
CONTINUOUS EDUCATION: PROJECT RATIONALE

EU/UK statistics on palliative care hotlines calls:
- 37-70% of calls remain uncovered due to lack of knowledge of clinicians
- 5-10% of calls are purely informational and do not relieve the burden for additional clinicians’ consultations due to low patients awareness levels

Ukraine reality:
- Low level of health and social care workers’ palliative care skills
- Insufficient system of raising community awareness of palliative care
- Low level of patients/families awareness of palliative care and patients’ entitlements

Continuous education on palliative care of patients/families and health care professionals increases efficiency of service delivery and reduces the burden on the state health care system

Belman et al. (2005); Jiang and Gentry (2012); IRF (2018)
CONTINUOUS EDUCATION : PROJECT MILESTONES

_Timeframe:_ January 2016 – December 2017

_Target group 1:_
- Palliative care professionals (health and social care workers)

_-Continuous professional education (CPD)-events for palliative care professionals:_
- 5 lectures on pain management, nutrition, legal, psychological and spiritual support, legal and social aspects - 273 participants
- 1 seminar on basics of pediatric palliative care, with international professional associations/speakers participation
- Clinical fellowship of 4 Hotline consultants in the Warsaw Children Hospice (Poland)
- Trainings of healthcare professionals by Belorussian Children Hospice specialists (rehabilitation in palliative care)
CONTINUOUS EDUCATION : PROJECT MILESTONES

*Target group 2:*
- Terminally ill patients, their parents and families

*Raising awareness of patients and families:*
- “Tea Party” – regular sweets-and-tea parties organized by CF Crab for parents - psychologist participation with wide range of topics discussion (pain, nutrition, psychological and spiritual issues)
- Programs on raising nutritional awareness as the factor contributing to the symptoms control for the parents
- Legal support prn (legal adviser consultations) since 2016
- Availability of continuous psychological support – loss, grief and bereavement , subsequent pregnancies planning since 2016
CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

**Objective:** to explore impact of the educational project on efficiency and effectiveness of pediatric palliative care

**Methods:**

- Retrospective analysis of 587 medical histories of the patients referred to specialized support by Hotline consultants during September 2015 - December 2017.
- Assessment based on the overall number of calls per year stratified by reason for patients’ requests (multiple reasons accounted as separate requests)
- Quantitative analysis of main reasons of patients' requests with the distribution represented by the 10-points scale chart
- Dynamic comparison of results per each year (2015-2017)
CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

**Results:** distribution of Hotline service users’ (N=587) requests
CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

Discussion

Requests structure before the project start: pain management - 65%, nutrition support - 20%, psychological and legal issues - 15%

2015
- Pain management—9.5 points, nutrition support—8 points, psychological and legal issues—2.2 and 6.1 points respectively

2016
- Pain management and nutrition support—1 point decrease
- Legal issues 0.4 point decrease - direct correlation with launch of legal adviser consultations
- Psychological support demand 1 point increase – inverse correlation with launch of psychologist consultations

2017 (vs. 2016)
- Pain management—further 0.5 point decrease
- Nutrition support—further 1 point decrease
- Legal issues—further 0.3 point decrease
- Psychological support demand—further 1.3 points increase – inverse correlation with increasing demand for psychologist consultations
CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

2017 vs 2015: requests structure, %

<table>
<thead>
<tr>
<th>Request reason</th>
<th>Before start</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
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<tr>
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<tr>
<td>Psychological/legal</td>
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<td>32</td>
<td>36</td>
<td>41</td>
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CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

2017 vs 2015

- Change in requests structure: pain management –34%, nutrition support –25%, psychological and legal issues -41 %

- Significant decrease of pain management (1.5 points) and nutrition (2 points) requests correlated with increasing number of educational events for both parents and health care professionals.

- Decrease in legal support (0.7 points) requests correlated with increasing parents' understanding of their entitlements due to continuous legal assistance.

- Significant increase in psychological support requests ( 2.3 points) correlated with parents' ability to identify own psychological problems due to continuous psychological consultations ( psychologist proceeded with CPD as well!)
Conclusions:

• Ongoing educational project of CPD of clinicians and raising patients'/families' awareness increases efficiency and effectiveness of pediatric palliative care services.

• Extrapolation of results to all regions of Ukraine may be considered valid as Hotline provides national level support.
FOLLOW-UP

Implications for practice: potential for future research

Evaluation of impact on pediatric palliative care quality of large-scale educational programs

• Clinical research with parents/families’ involvement and education
  – *Symptoms management and quality of life in pediatric oncology (malignant bowel obstruction)* – conducted by the authors in frame of MSc for Supportive and Palliative Care studies, Sheffield Hallam University, UK

• Education of multidisciplinary pediatric palliative care team („hospice-at-home“)- together with Hotline consultants CPD
  - MDT launched in August 2018 on clinical base of Kyiv Children Diagnostic Centre based on Warsaw Children Hospice Standards
IN MEMORIAM

• This follow-up is dedicated to Martin Nunn, MCIPR, MISTD, the passionate advocate of palliative care, our sponsor and patron, who contributed a great deal to what we are today
THANKS FOR YOUR ATTENTION!

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