

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

**Tetyana Vilchynska, Clinic of Children's Palliative Care
Kateryna Burlak, CF Crab, Kyiv, Ukraine**

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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



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



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

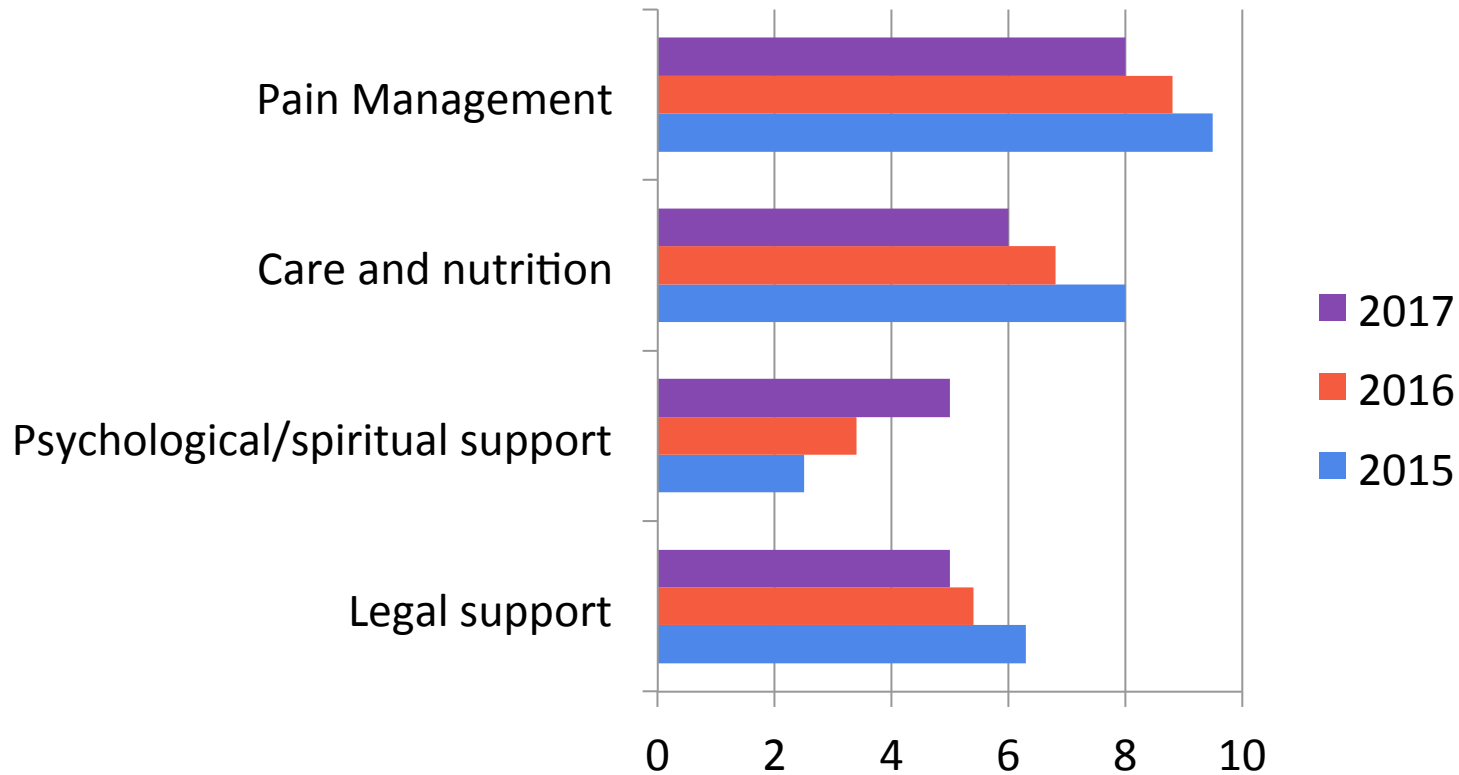
Methods:

- 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 6,1points 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, %

Request reason	Before start	2015	2016	2017
Pain	65	37	35	34
Nutrition	20	31	29	25
Psychological/ legal	15	32	36	41

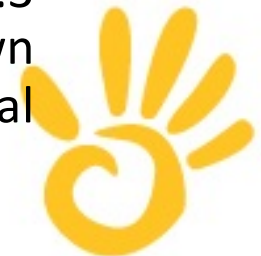


CONTINUOUS EDUCATION: IMPACT ON SERVICES

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!)



CONTINUOUS EDUCATION: IMPACT ON SERVICES QUALITY RESEARCH

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!

Tetyana Vilchynska, Head of Clinic of Children's Palliative Care
+380 50 331 31 29, tatyana.vilchinskaya@gmail.com

Kateryna Burlak, Head of All-Ukrainian Pediatric Palliative Care Hotline
+ 380 67 872 66 29, palliativeline@gmail.com

