

## ESSAY

# Clinical protocols in paediatric palliative care – a need in clinical practice

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### Abstract

**Introduction:** Paediatric palliative care is defined by the WHO as the active total care of the body, mind and spirit of a child with serious illness or limited life expectancy, which also involves providing support to the child's family. The aim of paediatric palliative care is to improve the child's quality of life and young adult patients and their families when faced with serious chronic illness.

**Material and method:** In Romania, palliative care needs assessment projects have been carried out at local or national level. As a result of the assessments carried out in the country, it was considered necessary to standardize palliative care services for children and to develop protocols for paediatric palliative care, which would support the professionals involved in these services, as well as to raise awareness of the authorities about the specific care needed by children. Working groups were set up and an international literature review was carried out. Experts from paediatric palliative care services in the country (with more than two decades of experience in clinical practice in this field) established the model protocols, the format and distributed the topics among the members of the working group. The working group developed ten protocols on key aspects of palliative care in children, including initial assessment of the child, treatment of pain and other symptoms, terminal condition, nutritional support, oral cavity care, communication with the sick child and parent, and bereavement support.

**Outcomes:** 10 Protocols in paediatric palliative care designed as algorithms with practical explanations to facilitate their applicability in clinical practice.

**Conclusions:** Numerous studies confirm that symptom management in children and young people in advanced and terminal stages of various specific pathologies is still inadequate. In addition to clinical problems, the psycho-emotional, social and spiritual support needs of the affected child and his/her family often remain unaddressed. The use of protocols developed in the clinical practice of specialists working with children and young people faced with an adverse diagnosis will improve the quality of life for them and their families and create a unified approach to uncontrolled symptoms.

### Rezumat

**Introducere:** Îngrijirea paliativă pediatrică este definită de O.M.S. ca fiind îngrijirea totală activă a corpului, minții și spiritului copilului cu boli grave sau speranță de viață limitată, îngrijire care implică și acordarea de sprijin familiei copilului. Scopul îngrijirii paliative pediatrică este de a îmbunătăți calitatea vieții pacienților copii și tineri și a familiilor acestora, atunci când se confruntă cu boli cronice grave.

**Material și metoda:** În România au fost derulate proiecte de evaluare a nevoii de îngrijiri paliative la nivel local sau național. Ca urmare a evaluărilor făcute în țară s-a considerat necesară standardizarea serviciilor de îngrijiri paliative acordate copiilor și elaborarea unor protocoale pentru îngrijirile paliative pediatrică, care să vină în sprijinul profesioniștilor implicați în aceste servicii, precum și pentru conștientizarea autorităților asupra specificului îngrijirii de care au nevoie copiii. Astfel au fost create grupuri de lucru și a fost realizată o revizie de literatură internațională. Experții din serviciile de îngrijire paliativă pediatrică din țară (experiență de peste două decenii în practica clinică a acestui domeniu) au stabilit modelul de protocoale, formatul și au fost distribuite temele între membrii grupului de lucru. Grupul de lucru a elaborat zece protocoale privind aspectele esențiale ale paliaticei la copii, între care evaluarea inițială a copilului, tratamentul durerii și al altor simptome, starea terminală, suportul nutrițional, îngrijirea cavității bucale, comunicarea cu copilul bolnav și cu părintele, suportul în perioada de doliu.

**Rezultate:** 10 Protocoalele în îngrijirea paliativă pediatrică concepute sub forma unor algoritmi cuprinzând explicații practice pentru ușurarea aplicabilității lor în practica clinică.

**Concluzii:** Numeroase studii confirmă faptul că managementul simptomelor la copiii și tinerii aflați în stadii avansate și terminale ale diverselor patologii specifice este încă inadecvat. Pe lângă problemele clinice, rămân adesea nerezolvate nevoile de suport

psiho-emoțional, social și spiritual ale copilului afectat și ale familiei acestuia. Utilizarea protocoalelor realizate în practica clinică a specialiștilor care lucrează cu copiii și tinerii aflați în fața unui diagnostic nefast va duce la creșterea calității vieții lor cât și a familiilor acestora și va crea un mod unitar de abordare a simptomelor necontrolate.

## Introduction

Palliative care is a relatively new field in the context of health systems, both in terms of service development and in terms of training of staff in interdisciplinary teams in this specialty.

While palliative care services dedicated to adult patients with progressive chronic diseases have gained ground in recent decades and are beginning to be integrated into the mainstream of health services, paediatric palliative care is only recently recognised and palliative care services for children are still underdeveloped. In many countries the specific care needs of children, including the basic needs of pain and symptom control, remain unmet and support for families is poor.

Paediatric palliative care is defined by the World Health Organization as the active total care of the body, mind and spirit of a child with serious illness or limited life expectancy, which also involves providing support to the child's family. The aim of paediatric palliative care is to improve the child's quality of life and young adult patients and their families, when faced with serious chronic illnesses with limited life expectancy, or which make it unlikely that the child will survive to adulthood.

The 2014 World Health Assembly resolution WHA67.19 on palliative care stresses that palliative care is a component of lifelong care and that ensuring children's access to care is an "ethical responsibility of health systems".

Numerous studies confirm (1) that symptom management in children and young people in advanced and terminal stages of various specific pathologies is still inadequate. In addition to clinical problems, the psycho-emotional, social, and spiritual

support needs of the affected child and his/her family often remain unaddressed.

The 2019 EAPC Atlas of Palliative Care in Europe (2) highlights the need for the development of palliative care services for children, education programmes for professionals in the field, improved access to pain and symptom control medication, and the development of specific protocols for paediatric palliative care services. The Atlas describes the existence of palliative care services dedicated to children with limited life expectancy in three care settings in the 51 countries reported: freestanding hospice units, palliative care wards in hospitals and palliative care home programmes.

One of the most recent assessments of the development of paediatric palliative care globally (3), published in 2020, places Romania among the category 3a countries with isolated palliative care services dedicated to children (Table 1). The study concludes that only 21 of the 113 countries analysed provide access to paediatric palliative care services at a reasonable level and therefore less than 10% of the world's population under 20 (35% of the global population) have access to timely palliative care services. More than 778 million children (30.7%), or about one third of the world's children, live in the 55 countries (including Romania) where dedicated palliative care services are isolated and rare.

**Table 1 - Development of pediatric palliative care at global level**

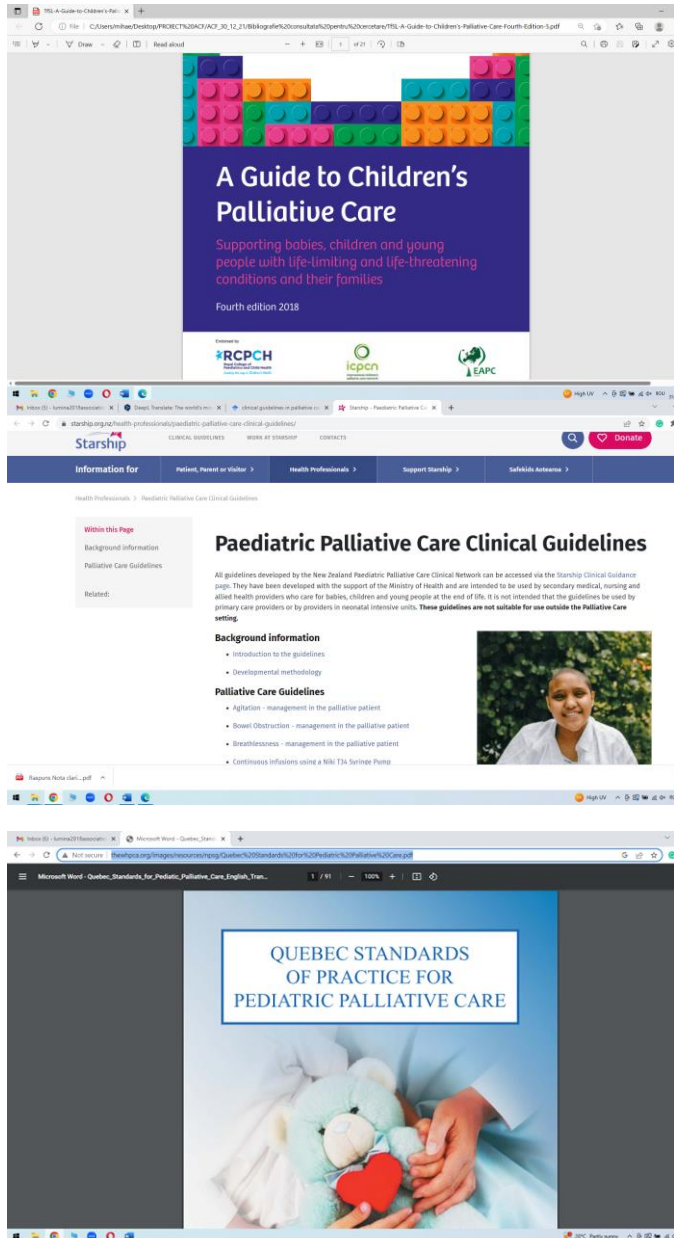
|    | Classification category   | Number of countries (n=198) (%)           | Child population (million children under 20) (% of overall) |
|----|---|---|---|
| 1  | No paediatric palliative care activities  | 21 countries (10.6%)                      | 92M (3.6%)  |
| 2  | Paediatric palliative care activities being organised   | 16 countries (8.1%)                       | 610M (24.1%)  |
| 3a | Isolated paediatric palliative care services  | 50 countries (25.3%)<br>Including Romania | 763M (30.1%)  |
| 3b | Generalised paediatric palliative care services   | 5 countries (2.5%)                        | 16M (0.6%)  |
| 4a | Preliminary state of integration of paediatric palliative care services into the overall health services. | 14 countries (7.1%)                       | 190M (7.5%)   |
| 4b | Advanced stage of integration of paediatric palliative care services into overall health services.        | 7 (3.5%)                                  | 42M (1.7%)  |
|    | Countries with inconclusive data  | 29 (14.6%)                                | 646M (25.5%)  |
|    | Countries without reporting   | 56 (28.3%)                                | 173M (6.8%)   |

In Romania, the first paediatric palliative care services were initiated by non-governmental charitable organisations in the 1990s, in Brasov, Bacau and Oradea. Subsequently, palliative care departments were also set up in several public hospitals (Timișoara, Bucharest, Iași). Over the years, projects to assess the need for palliative care have been carried out at local or national level. In 2018 both adult and paediatric palliative care

in Romania gained ground, with the adoption by the Ministry of Health of regulations (4) on the provision of palliative care services, specifying the environments for the provision of services, the adult and paediatric beneficiaries, the professional training of staff in inter-disciplinary teams.

Material and method: In order to develop and draft these guidelines/protocols in palliative care, a group of experts with

more than two decades of experience in the clinical practice of this field and the holistic approach to children diagnosed with life-limiting/life-threatening illnesses in Romania was created. The expert group met in a hybrid format (online and face-to-face) and conducted a literature review in the field of palliative care for children. Clinical guidelines from New Zealand (5), UK (6) and Canada (7) were consulted.



The material relating to the use of clinical protocols in the practice of palliative care for children has been collected from the international literature and the experience of other

**Example: guidelines for the treatment of pain in children in palliative care.**

countries. Methods of information transfer, narrative analysis of scientific sources published in the international literature in the field of palliative care for children, covering the given topic, were used, using the authors' personal subscriptions to various international libraries such as PubMed, Google Scholar, etc.

After agreeing on the template for editing protocols and clinical guidelines, topics were chosen with the essential aspects of palliation in children, the most frequently encountered in the clinical practice of the experts involved. Each expert worked on one or more themes individually, then a group consensus was reached to finalise the protocols and guidelines.

**Results:** Diagnostic and treatment guidelines/protocols aim to achieve evidence-based best practice guidelines/protocols and involve a regular review of the scientific literature to determine the most effective, nationally acceptable, and cost-effective practice. They are scientifically formulated tools that aim to standardise the medical act, to assist paediatric palliative care practitioners in making optimal decisions regarding the holistic approach to the child and their family in specific clinical situations. In this way, risks are reduced, and the economic value of care is increased. The guidelines have a guideline value and can alert clinicians to medical practices that are not supported by evidence and are unnecessary or may have a negative impact on health outcomes. They also reduce variability in the quality of care and, not least, can inform other healthcare organisations about professional standards.

The 10 Protocols/Guidelines in Paediatric Palliative Care have been designed as algorithms with practical explanations to facilitate their applicability in clinical practice and which will ensure the identification and approval of current activities in the field of palliative care for children and their families. The key issues contained in the 10 guidelines/protocols developed relate to: initial assessment of the child, treatment of pain, constipation, dyspnoea, approach in the terminal condition, nutritional support, care of the oral cavity, communication with the sick child and parent and bereavement support.

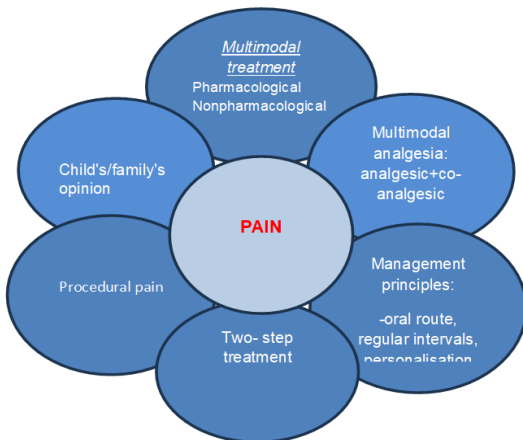
**A GUIDE TO THE TREATMENT OF PAIN IN CHILDREN IN PALLIATIVE CARE**

| General assessment              |   | Screening for the presence of pain (Annex 1) |   | Pain assessment  |  |
|---------------------------------|---|--|---|--|--|
| See protocol Initial Assessment | Children Communicating verbally<br><b>autoevaluation</b><br>(Annex 2) | Painless                                     |   | The diagnosis of pain should include:  |  |
|                                 | Non Verbal children -<br><b>Observational scales</b><br>(Annex 1)     | No   | Yes   |  |  |
|                                 |   |  | <ul style="list-style-type: none"> <li>• Fracture</li> <li>• Intracranial hypertension</li> <li>• Spinal Cord compression</li> <li>• Visceral obstruction/perforation</li> <li>• Localized infection</li> <li>• Intestinal obstruction</li> <li>• Severe uncontrolled pain</li> </ul> | <ul style="list-style-type: none"> <li>• Etiology (Annex 3)                             <ul style="list-style-type: none"> <li>Cancer</li> <li>Other diseases</li> <li>Medical procedure</li> </ul> </li> <li>• Mechanism                             <ul style="list-style-type: none"> <li>Nociceptive</li> <li>Neuropath</li> <li>Mixed</li> </ul> </li> <li>• Location</li> <li>• Intensity -self assessment scales (Annex 2)</li> <li>• Pain characteristics, duration, aggravating/ameliorating factors</li> <li>• Impact on daily activity</li> </ul> |  |

**ANNEX 4. TREATMENT OF PAIN IN CHILDREN IN PALLIATIVE CARE**

- The aims of pain treatment:
1. To ensure good pain control at rest, during activities and during sleep
  2. Minimal side effects of treatment.

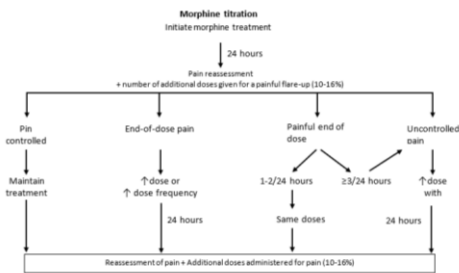
**PRINCIPLES OF PAIN TREATMENT IN CHILDREN**



1. The WHO 2012 guidelines recommend the treatment of pain in children in 2 steps:  
Step 1- Paracetamol/Ibuprofen  
Step 2- major opioid in low dose (oral morphine equivalent <1mg/kg/24 hours as needed) for moderate pain and in usual dose (oral morphine equivalent ≥1mg/kg/24 hours regularly+ supplement as needed) for severe pain; this guideline was withdrawn in 2019 and is currently under review.
2. The term "chronic pain" tends to be replaced by the term "persistent pain" (pain that persists longer than the pain after an acute injury, without the definition specifying a duration of time).

**ANNEX 5. OPIOID TITRATION**

1. The purpose of titration, to determine the dose that achieves the best pain control with the fewest adverse effects.
2. Requires frequent reassessment of pain and dose adjustment
3. There are no maximum doses because there are no ceiling effects (including for newborns). The dose is limited only by intolerable adverse effects.



**Conclusions**

Thus, we can conclude that the development and use of clinical protocols/guidelines in children's palliative care enhances the quality of services provided and has a key influence on increasing the satisfaction and quality of life of patients and their families.

The most important next step is their implementation in the practice of paediatric palliative care specialists and their further development by the Ministry of Health, taking into account the priorities of the system.

In order to provide professionals in palliative care for children with these useful practice tools and to achieve the proposed objectives, it is necessary in the implementation process to take into account all aspects that will influence the final outcome of their application, namely:

- Providing each child palliative care specialist with a copy of these clinical guidelines/protocols.
- Training of child palliative care staff in the use of these tools.
- Monitoring the use of the protocols by systematically assessing the degree of compliance with the requirements of the clinical protocols/guidelines.

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