

# Standards for Pediatric Palliative Care

**Dr. Huda Abu-Saad Huijer RN, PhD, FEANS**

Professor of Nursing Science

Director Hariri School of Nursing

American University of Beirut

huda.huijer@aub.edu.lb

## Abstract

Continuous efforts have been made worldwide to improve pediatric palliative care. In Lebanon, palliative care was initially introduced in 1995 through a national cancer control workshop supported by the Ministry of Health and the World Health Organization. Despite all efforts, pediatric palliative care remains a challenging area, because of a lack of resources and inadequate education and training of healthcare professionals. In addition, the absence of standards to support patients, parents, nurses and doctors in making decisions concerning the end of life makes the transition from curative to palliative care more difficult.

This review gives a summary of the basic concepts of Pediatric Palliative Care (PPC) and describes the core standards of care including pain and symptom management, ethics, and legal rights of children and their families.

## ملخص

بذلت جهود متواصلة في جميع أنحاء العالم لتحسين الرعاية الملطفة. في لبنان، عُرض مبدأ الرعاية الملطفة سنة ١٩٩٥ للمرة الأولى من خلال ورشة عمل وطنية لمكافحة السرطان بدعم من وزارة الصحة العامة والمنظمة العالمية للصحة. على الرغم من جميع الجهود، تشكّل العناية الملطفة لدى الأطفال تحدي كبير بسبب نقص الموارد وعدم الكفاءة في التعليم والتدريب لدى المتخصصين في العناية الملطفة. بالإضافة، عدم وجود معايير لدعم المرضى، الأهل، الممرضين، والأطباء في اتخاذ القرارات المتعلقة بنهاية الحياة، يجعل الانتقال من المرحلة العلاجية إلى الرعاية الملطفة أكثر صعوبة. تعرض هذه المقالة لمقدمي الرعاية الصحية ملخص عن مفهوم ومبادئ العناية الملطفة الإهتمام بالأطفال، تصف المبادئ الأساسية للعناية الملطفة، الألم والإهتمام بالعوارض، بالإضافة إلى الأخلاق وحقوق الأطفال وعائلاتهم.

## Introduction

In March 2006, a group of healthcare professionals from Canada, Europe, Lebanon, and the USA met in Italy and discussed the existing situation of pediatric palliative care (PPC) in the different countries. The group was called the International Meeting for Palliative Care in Children, Trento (IMPACT). The outcome of the three-days meeting was a document defining PPC and identifying the standards of care for children with life-limiting conditions.

The following article is based on this document in which IMPACT recommends the implementation of these standards (EAPC taskforce, 2007).

## Definition of Pediatric Palliative Care

The World Health Organization (WHO) defines palliative

care (PC) for children as (WHO, 1998):

- The active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective PC requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes.

This broad definition stipulates that PC should be

initiated at the earliest time possible in the disease trajectory; the patient, the family and healthcare providers are all included in the care process which takes into account the physical, emotional, and spiritual aspects of care; and it includes the need to counsel and support those who are bereaved going a step further beyond the period of care to the patient.

### Children Requiring Palliative Care

Childhood diseases requiring PC may be different from those of adults. Most are rare, familial, and categorized as either life-limiting or life-threatening. "Life-limiting illness is defined as a condition where premature death is usual, for example Duchenne muscular dystrophy; life-threatening illness is one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood, for example children receiving cancer treatment" (EAPC taskforce, 2007).

Four different categories of childhood disease have been identified and developed by the Association for Children with Life-threatening or terminal conditions and the Royal College of Pediatrics and Child Health (ACT, Royal College of Pediatrics and Child Health, 1997, 2003):

- *Category one:* life-threatening conditions for which curative treatment may be feasible but can fail, where access to PC services may be necessary together with attempts at curative treatment. Example of this category: cancer, irreversible organ failure of heart, kidneys, liver.
- *Category two:* diseases which are life-threatening at an early age, where appropriate treatment may prolong life and provide an adequate quality of life. Examples of this category: cystic fibrosis, HIV/AIDS.
- *Category three:* progressive conditions without curative treatment options, where treatment is exclusively palliative and may extend over many years. Examples of this category: Muscular dystrophy, Batten disease, mucopolysaccharidoses.
- *Category four:* non-progressive irreversible conditions, usually neurological disorders with complex healthcare needs leading to many complications and premature death. Examples of this category: severe cerebral palsy, multiple disabilities following brain or spinal cord injuries.

Effective PC requires the involvement of a broadly skilled multidisciplinary team that is committed to working together towards the achievement of best practice. PC services need to be structured to accommodate three levels of specialization (Department of Health and Children, 2001):

*Level 1-* the Palliative Care approach: PC principles should be appropriately applied by all health care professionals.

*Level 2-* General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full-time in palliative care,

have had some additional training and experience in palliative care.

*Level 3-Specialist Palliative Care:* Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

### Core Standards

IMPACT recommends the following core standards to be followed:

#### *Provision of care*

PPC should be initiated at diagnosis of a life-threatening or limiting condition and should be given together with active treatment, enhancing quality of life for the child and the family. The child and the family should decide on the place of care (home, hospital, or hospice) and they should have the opportunity to transfer smoothly between locations without compromising the care.

#### *Unit of care*

The unit of care is the child and the family. The child and family should be involved in identifying needs and in decision-making, and they should be provided with as much information as desired as well as clinical and educational resources that are appropriate to age, cognitive and educational level, and cultural background.

#### *The care team*

The team should include as minimum a physician, nurse, social worker, child therapist or psychologist, and spiritual advisor. They should have the adequate expertise in PC to address the psychological, emotional, spiritual, and social needs of the child and family. The care team should provide individualized care to the child and family in addition to continuity of care at home, and in the hospital; care should be available 24 hours a day, 365 days a year.

#### *Care coordinator/key worker*

One person from the care team must be identified as the patient's and family's care coordinator. The care coordinator should ensure continuity of care, provide the support system needed by the patient and the family, and ensure access to social services and resources.

#### *Symptom management*

Symptoms should be adequately and regularly assessed so that children can receive the appropriate pharmacological, psychological, and physical treatment for their pain and other symptoms 24 hours a day. Psychological, social, and spiritual symptoms should be addressed as well as the physical symptoms.

#### *Respite care*

Respite care is the provision of care, for the ill child by alternate care providers, rather than the parents, when a child is "medically stable", enabling time off from the tiring care these children require. Parents of children with life threatening conditions need time and energy to attend to their own basic physical and emotional needs and to be available to care for other members of their family. Respite care for the family and the child is

essential whether for few hours or for few days.

#### *Bereavement*

Bereavement support, an essential aspect of PC should be initiated at diagnosis of a life-threatening or life-limiting illness and should continue through death and beyond. It should be available for the family, the siblings, the carers, and all those affected by the child's disease and death.

#### *Age-appropriate care*

Cognitive development and age form the basis for a child's understanding of the concept of illness, separation and death. Parents should be present and involved in all phases of the child's care. The care team should provide the care that best meets the needs of the child depending on their age and cognitive development.

#### *Education and training*

All healthcare professionals working with children in need for PPC should receive adequate training and education. It should be part of the national curriculum for pediatric healthcare professionals in addition to postgraduate training and continuing education in this field.

#### *Funding for palliative care services*

PC services should be available to all children requiring it regardless of the financial status. There should be enough funding available from the government and other sectors to provide multidisciplinary and holistic care to children in hospitals, at home, and in the community, in addition to availability of funding to support the teaching and training of healthcare professionals.

### **Pain and Symptom Management in Pediatric Palliative Care**

- The use of a multidisciplinary team to recognize and assess the psychological, social, spiritual, and physical symptoms is essential. Information on symptoms must be gathered from different sources: the child, the parents, healthcare workers, and others such as teachers.

- "Treating the underlying cause of a symptom may be equally as appropriate as providing symptom control" (EAPC taskforce, p.5, 2007). Medication administration should be provided using the least painful and invasive route; side-effects of medications should be anticipated and treated. Similarly, unnecessary painful procedures should be avoided otherwise procedural pain should be anticipated and treated.

- The WHO analgesic ladder approach should be used; adequate doses of analgesics should be administered at regular intervals in addition to doses given on an "as needed" basis to treat breakthrough pain.

- Healthcare professionals, the family, and the child should understand that opioid therapy does not lead to addiction in children with life-threatening or life-limiting conditions but may lead to physical tolerance; therefore when the dose is to be reduced, it should be reduced slowly to avoid symptoms of physical withdrawal; the

appropriate opioid dose is the dose that reduces pain effectively.

- Non-pharmacological therapies are a fundamental part of pain management, however they are considered an adjunct to and not a substitute to pharmacological therapies.

### **Ethics and Legal Rights of Children in Pediatric Palliative Care**

1. Equality: All children shall access palliative care equally irrespective of the family's financial status.

2. Best interest of the child: Children's best interests are the primary consideration in decision-making; it is every child's right to have adequate pain control and symptom management 24 hours a day, and to be treated with dignity and respect and provided privacy; adolescents and young adults' needs shall be planned for.

3. Communication and decision-making: Communication shall be honest and open; the child, the parents, and the siblings shall be included in all decision-making according to their age and understanding. Parents in particular shall be considered as the primary carers and shall be treated as partners in all care and decisions involving their child.

4. Care management: Care shall be provided at home whenever possible; if care is delivered at a hospital, it shall be provided by a multidisciplinary pediatric palliative care team well trained and skilled to attend to the physical, emotional, developmental, and social needs of the child and the family. A care coordinator/key person shall be available for every child and family.

5. Respite care: Every family shall have access to respite care.

6. Family support: Sibling care is an essential part in PPC; bereavement support shall be provided to the whole family as long as needed; family shall have access to spiritual, religious, social, and financial support.

7. Education: Every child shall be supported to attend school, have access to education, and be involved in play and childhood activities.

### **Conclusion**

This document provided core standards for pediatric palliative care that are essential and need to be implemented. A skilled multidisciplinary team following a comprehensive palliative care approach is required to meet the needs of children with life-threatening or life-limiting conditions.

Note: The author served as chair of the Task Force on Pediatric Palliative care of the European Association for Palliative Care which was instrumental in developing these guidelines.

## References

1. Standards for pediatric palliative care in Europe. (2007). A document prepared by the Steering Committee of the EAPC task force on palliative care for children and adolescents.  
*European Journal of Palliative Care*, 14: 2-7.
2. World Health Organization. (1998). Cancer pain relief and palliative care in children. Geneva: World Health Organization.
3. Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Royal College of Pediatrics and Child Health (RCPCH), (1997) A Guide to the Development of Children's Palliative Care Services. Bristol: ACT and London: RCPCH, UK. Retrieved December 12, 2007 from Guide to the Development of Children's Palliative Care Services, A3
4. Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and the Royal College of Pediatrics and Child Health (RCPCH), (2003) A Guide to the Development of Children's Palliative Care Services. (2nd Edition), Bristol: ACT and London: RCPCH, UK. Retrieved December 12, 2007 from [http://www.act.org.uk/component?option=com\\_docman/task,cat\\_view/gid,15/Itemid,26](http://www.act.org.uk/component?option=com_docman/task,cat_view/gid,15/Itemid,26)
5. Department of Health and Children (2001). Report of the National Advisory Committee on Palliative Care. Dublin: Stationery Office. Retrieved January 11, 2008 from <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>