

## PAIN RELIEF AND PALLIATIVE CARE IN LEBANON PEDIATRIC PALLIATIVE CARE

### State of the Art

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**ABSTRACT : Advances in medicine have significantly reduced child mortality worldwide ; however those caring for children with life-threatening medical conditions are usually committed to employing curative and life-prolonging treatments until death is at hand. This type of intensive care and attention can expose children and their families to unnecessary suffering, particularly if inadequate attention is paid to the children's physical and emotional distress.**

**This review presents healthcare providers with the basic concepts of pediatric palliative care (PPC) available to assist them in the care of the child with life-threatening medical conditions. It defines PPC and the principles guiding it ; it reviews the reasons behind PPC emphasizing developmental and epidemiological aspects of childhood death ; it discusses the needs of children with life-threatening conditions and the needs of their families ; and it examines PPC services available, and the obstacles and challenges faced in providing PPC.**

#### INTRODUCTION

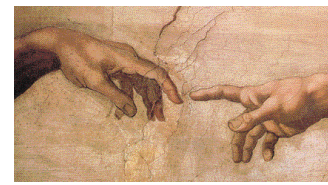
Children are not supposed to die, but they do. The death of a child is clearly out of the natural rhythm of life, and it is a deep loss for the family as well as for those involved in the care of the child. Janusz Korczak [1], a pediatrician during the early 20<sup>th</sup> century, was a pioneer to advocate children's rights and many of today's palliative care (PC) principles. He advocated the children's right to die prematurely and the need to secure them a human and comfortable death, free of pain and suffering, if they can not be restored to life.

Current advances in medicine have significantly reduced child mortality worldwide ; however those caring for children with life-threatening conditions are usually committed to using curative and life-prolonging options until death is at hand. This intensive care can

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expose children who are fragile and delicate and their families to unnecessary suffering, particularly if inadequate attention is paid to the potential burdens and to the children's physical and emotional distress. A more comprehensive approach to care is needed regardless of the decisions made about curative or life-prolonging treatments. PC is appropriate for any patient at any stage of a life-threatening illness, from diagnosis to end of life and bereavement, regardless of age.

The goal of this review is to provide healthcare providers with the basic concepts of pediatric palliative care (PPC) and to assist them in the care of the child with life-threatening medical conditions. This article will define PPC and the principles guiding it ; it will review the reasons behind PPC mainly the developmental aspects and the epidemiological facts ; it will discuss the needs of children with life-threatening conditions and those of their families ; and it will examine PPC services, and the obstacles and challenges faced in providing PPC.

#### WHAT IS PEDIATRIC PALLIATIVE CARE ?

##### Definition

The World Health Organization (WHO) defines PC for children as [2] :

- 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 emphasizes the prompt management of symptoms ; it includes the patients, family, and healthcare providers in the caring process ; it takes into consideration the physical, emotional, and spiritual aspects of care ; and it goes beyond the period of care to include counseling and support of the bereaved.

##### Principles

The following are universal principles that guide PPC [3-4] : 1) PC programs should be available to children who have life-threatening diseases, not just those in whom death is imminent ; 2) care should be available to

children whether at home or in the hospital ; 3) life-prolonging treatment and PC are not mutually exclusive ; 4) interdisciplinary PC teams should be available for the child 24 hours a day ; 5) the unit of care is the child and family ; 6) respite care should be available ; and 7) bereavement care should be available for families of children who die.

#### WHY PALLIATIVE CARE FOR CHILDREN ?

##### Developmental aspects

Children are not little adults. Physicians, nurses, parents, and others working with children with life-threatening conditions should take into consideration the developmental aspects and differences among infants, children, and adolescents that may impact prognosis, treatment, communication, and decision-making processes.

Cognitive development and age are basic for children's understanding of illness and death (Table I). The child should be told about illness and death in a language that is developmentally appropriate especially that the concept of death varies with age. For infants, death is perceived as separation and abandonment, for this reason the child's separation from the parents should be minimized during hospitalization period. For toddlers, death and illness are perceived as punishment for bad thought or actions ; healthcare providers should assure children that they are not being punished, and should provide clear and honest explanations of the illness and treatments. In the middle and late childhood years, there is gradual understanding of the concepts of death and illness. Healthcare providers should allow children to be involved in the decision-making process, provide opportunity for them to interact with the medical staff, and encourage them to share feelings and ask questions. Children should be treated with dignity and respect, and provided with clear, honest, and direct communication, and encouraged to associate with friends. In the adolescent period, death is seen as irreversible, universal, and

inevitable ; healthcare providers should provide adolescents with privacy, and find ways to recognize and support their unique identity. Adolescents are usually concerned about their independence and feel loss of control. In this stage, issues of sexuality should be recognized and addressed [5-6].

##### Epidemiology of Childhood Death

Currently, comprehensive data from developed and developing countries related to childhood death, number of children with life-limiting conditions, and children in need of PC services is still not available. According to the literature from Europe and the United States (US), conditions requiring palliative care are on the increase. Korones [4] reported that in the US, the number of deaths in children 5 years or younger dropped from 30% to 1.4% between the years 1900 and 1999. However, 50,000 children still die every year with 10,000 children dying from complex chronic conditions like neuromuscular diseases, cardiac abnormalities, renal failure, metabolic abnormalities, chromosomal anomalies, blood disorders, and malignancies. More than 500,000 children suffer from life-threatening conditions ; they are the primary potential beneficiaries of PC services.

In England, 42,400 childhood deaths occurred in 2001-2005 from causes that most likely required PC services ; in addition there have been on average 2,109 neonatal deaths per year from conditions likely to need PC [7]. Childhood mortality rate from life-limiting conditions is reported to be 1.2 in 10,000 in the United Kingdom and 3.6 in 10,000 in the Republic of Ireland [8].

In Lebanon, WHO reported a neonatal mortality rate in 2004 of 19‰ live births and infant mortality rate in 2005 of 27‰ live births. In 2002, 64.9% of deaths among children less than five years were due to neonatal diseases, 11% to injuries, and 22% to other causes [9].

In 2005, more than 70% of all cancer deaths occurred in low and middle income countries. In Lebanon, cancer

<p><b>TABLE I</b></p> <p>OVERVIEW OF CHILDREN'S CONCEPTS OF DEATH*</p> <p>*From American Academy of Pediatrics (2000) Committee on Psychosocial Aspects of Child and Family Health.</p>	AGE (years)	Concept of death
	0 to 2	➤ ➤ ➤
2 to 6	➤ ➤ ➤	Death is reversible and temporary Death is personified and often seen as punishment Magical thinking that wishes can come true
6 to 11	➤ ➤ ➤	Gradual awareness of irreversibility and finality Specific death of self or loved one difficult to understand Concrete reasoning with ability to see cause-and-effect relationships
> 11	➤ ➤ ➤	Death is irreversible, universal and inevitable All people and self must die, although latter is far off Abstract and philosophical reasoning

killed approximately 2,600 people in 2005, 1500 of those were under the age of 70 [10]. The National Cancer Registry in Lebanon reported 58 new cancer cases among children in 2002 ; this number increased in 2003 to 237 [11-12]. No recent reports are available from the Ministry of Public Health ; however, the American University of Beirut Medical Center (AUBMC) reported 121 new pediatric cancer cases in 2005 and 116 in 2006 [13-14]. The number of children living with cancer and other life-limiting illnesses in Lebanon is increasing due to early detection and enhanced treatment methods. These children are most likely to benefit from PC services.

#### WHICH CHILDREN NEED PALLIATIVE CARE ?

PPC may be needed for a wide range of diseases that are different from adults ; many of these childhood diseases are rare and familial and may be life-limiting or life-threatening. *“Life-limiting illness is defined as a condition where premature death is usual, e.g. Duchene 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 e.g. children receiving cancer treatment”* [8]. The diagnosis usually influences and guides the type of care that the child and family might need. Four different categories of childhood diseases have been identified and developed by the Association for Children with Life-Threatening Terminal Conditions and their Families and the Royal College of Pediatrics and Child Health [15] :

- 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. Examples 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.

The need for PC differs between children ; it may be needed from infancy and for many years for some children, while others may not need it until they are older and only for a short time. The transition between aggressive curative treatments and PC may be confusing and unclear ; both approaches may be needed in combination, each becoming more dominant at different times [16].

#### NEEDS OF CHILDREN WITH LIFE-THREATENING CONDITIONS

##### Holistic care

Children and adolescents are physically, emotionally, cognitively, and spiritually in continuous development. Their needs and understanding of illness and death are different depending on their development stage ; they communicate differently, they cope differently, and they express their emotions and feelings differently [17]. For such reasons, a holistic care approach is needed for children with life-threatening conditions and since no one person can provide all the necessary care and support for the child, an integrated interdisciplinary approach is the best method to coordinate and manage care. The provision of PC for children involves coordination between the child, family, teachers, school staff, and healthcare professionals including nurses, primary care physicians, social workers, chaplains, bereavement counselors, and consultants [5].

##### Symptom assessment and management

Children with life-limiting conditions suffer from many distressing symptoms. Drake, Frost and Collins [18] reported that dying children at the last week of life had a mean number of 11.1 symptoms and that six symptoms occurred in 50% or more of the children. Other studies found the most common symptoms to be pain, lack of energy, fatigue, and dyspnea ; other symptoms include nausea, lack of appetite, drowsiness, cough, and other psychological symptoms like sadness, nervousness, worrying, and irritability [19-20]. Wolfe and colleagues [20] reported that 89% of the children experienced a great deal of suffering from at least one symptom, and 51% suffered from three or more symptoms.

Pain is a major symptom in pediatric palliative care, both in children with cancer and those with non-malignant life-limiting or life-threatening conditions [20-21]. In Lebanon, Daher and colleagues [22] reported that cancer patients suffer needlessly and do not get enough pain relief. Pain is the symptom the most studied especially in cancer patients and it is the most common and most feared by patients and families ; it remains however inadequately controlled [23].

Fatigue is another common symptom in children with life-limiting conditions especially cancer, and is the least successfully treated. Fatigue was prevalent in almost 100% of children, as conveyed by parents [20], and in more than 75% in a study assessing symptoms of dying children [18].

As long as symptoms are not assessed and measured adequately, children will continue to suffer needlessly. Measurement of symptoms is considered as one aspect to evaluate the overall quality of life and quality of PC. Several validated tools are available in the literature to measure the prevalence of symptoms in the pediatric population. The most commonly used comprehensive tool is the Memorial Symptom Assessment Scale (MSAS) that

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**TABLE II**  
GUIDELINES TO ASSIST SIBLINGS OF DYING CHILDREN\*

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- Siblings should be included in discussions of care from the time of diagnosis, through death of the child, and beyond.
  - "Protecting" siblings by excluding them may cause long-term harm.
  - Siblings should be included in discussions about end-of-life care.
  - Siblings should be included in funeral planning.
  - Certain resources should be made available to support siblings through their grief and bereavement.
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\*Spinetta et al. Guidelines for assistance to siblings of children with cancer : Report of the SIOP working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology* 1999 ; 33 (4) : 395–8.

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measures the frequency, severity, and distress level of 30 symptoms [24] ; another tool is the Global Distress Index which combines the ten most prevalent and distressing physical and psychological symptoms. Other tools available are more symptom-specific like the pain tools (Visual Analogue Scale, Numeric Rating Scale, the Faces Scale).

Management of symptoms should follow an aggressive approach to improve symptom control and decrease symptom burden. IMPaCCT [8] provided the following core standards for symptom management :

- Every child should have access to professional pharmacological, psychological and physical management of pain and other symptoms, 24 hours a day, 365 days a year.
- Every child must have their symptoms assessed so that they can receive an appropriate treatment to achieve an acceptable level of comfort.
- Psychological, social and spiritual symptoms must be addressed, as well as physical ones.
- Symptom management must be accomplished through means acceptable to the patient, family and professionals.

#### NEEDS OF FAMILIES

##### **Family centered care**

The unit of care is the family, defined as the persons who provide physical, psychological, spiritual and social comfort to the child, and who are close in knowledge, care and affection, regardless of genetic relationships [17]. Since most children with life-limiting conditions cannot make their own decisions, they rely on family members mainly parents and siblings who become their main advocates.

The needs of the family must be addressed since the family is the major support for the sick child. Families have emotional, religious/spiritual, educational, and financial needs, as well as needs related to their personal, household, and well-child care. Providing families with knowledge and guidance concerning the disease process, complications, treatment, side-effects, and prognosis gives them assurance. Psychologists can provide support in dealing with daily stresses and in strengthening family relationships. Families need to evaluate their financial

situation since a life-limiting illness may lead to increased medical bills and cause changes in lifestyle and employment status ; family caregivers should be encouraged to accept help from other family members and friends [6].

##### **Siblings**

Siblings of chronically ill and dying children are often at risk of feeling isolated and becoming forgotten because parents shift their full attention and care to the sick child. Research indicates that having a sibling with a life-threatening illness during childhood contributes to an increased risk of adverse psychological outcomes, including low self-esteem, somatization, school problems, interpersonal aggression with peers and delinquency, feelings of isolation, anxiety, depression and anger [3-4]. A study done on children's perceptions of their siblings' death at home or hospital reported that those who were involved in the home care perceived themselves prepared for the death of their sibling, received consistent information and support from their parents, were involved in most activities concerning the dying child, were present for the death, and viewed their own involvement as the most important aspect of the experience. Siblings who received care at the hospital reported being inadequately prepared for the death, isolated from the dying child and parents, unable to use their parents for support and information, and useless in terms of their own involvement [25].

The International Society of Pediatric Oncology established guidelines to assist siblings of dying children [26] (Table II).

##### **Communication and information giving**

In PC, communication is considered an essential and critical element when addressing end-of-life issues with the child and family. It should be clear, honest, and consistent even when communicating bad news [4].

The child and family have the right to be informed about the condition/illness, available treatment options, clinical trials, and their potential benefits, risks and burdens. The child and family also have the right to share in decision-making depending on the child's developmental stage and the family's cultural beliefs. Parents who become the child's advocate, determine how, when, and what information is shared with the child, taking into

account the uniqueness of the child, family and situation characteristics, such as temperament, cognitive abilities, developmental level, cultural beliefs and values [3].

It should not be assumed that parents and children prefer not to talk about death and end-of-life issues. An important recent study found that bereaved parents who discussed death with their children did not regret having done so ; on the other hand, parents who did not discuss death with their child did regret not having done so [27].

#### PALLIATIVE CARE SERVICES

PC services should be accessible to children and families in a setting that is desired and appropriate to their needs. It may be a tertiary center/hospital, an inpatient hospice, home, or any other setting.

Research indicates that home is generally considered the preferred site of living until death, however in practice, support for family and caregivers at home is not always available. Home care requires involvement of a multidisciplinary team and clear, honest and detailed information and communication about managing the child's care. There must be a 24-hour access to expertise in PPC and also access to appropriate respite, immediate access to hospital, if needed and a key worker to coordinate the care between family, carers in the community, local hospital and specialist centers [28].

A study conducted by Dangel [29] on the status of PC services in Europe reported that a significant number of countries considered PC services to be underdeveloped, insufficient, poor, or absent. Inpatient hospice for children was rare or absent in all 17 countries studied except in the UK ; PC services were reported to be provided in pediatric hospitals in nine countries.

Similarly in Lebanon, PC services for children need to be developed as reported by the majority of pediatric nurses (98%) and physicians (100%) in a survey on the knowledge, attitudes, and practices of nurses and physicians in PC. Only 25% of Lebanese pediatric nurses and 33% of Lebanese pediatricians considered that PC is provided by a specialized PC unit at the hospital where they work.

Respite care for family members and the child is essential ; it is defined as *"the provision of care, for the ill child by alternate care providers, rather than the parents, when a child is 'medically stable' (i.e., in his usual state of health), enabling time off from the exhausting care these children require"* [3]. Parents of children with life-limiting conditions need time and energy to look after their own basic physical and emotional needs and to be available to care for the other members of their family. They need some time off to restore their energy in order to continue caring for their sick child.

#### OBSTACLES TO PEDIATRIC PALLIATIVE CARE

Providing PC to the pediatric population is very challenging ; societies in general do not expect children to

die and believe that medicine can cure all diseases. In addition poor communication and feelings of guilt force parent and caregivers to choose all life-prolonging therapies to avoid being accused of not caring enough for their child ; determining the best interest of the child is usually very difficult for families and healthcare professionals [3].

Dangel [29] reported that in Europe several obstacles to develop PC programs exist : lack of funds and reimbursement, lack of awareness, lack of cooperation between hospice programs and pediatricians, physicians' attitudes, lack of staff, lack of governmental support and policies, and lack of education.

#### Education

Lack of education and awareness regarding PC services exists among the public and among healthcare professionals ; very few physicians and nurses are highly experienced in the care of dying children and their families. There is a misperception among the public, administrators, and healthcare professionals that PC is offered only when all other curative efforts have been extensively used [3].

A study conducted in the Netherlands among general practitioners described the lack of knowledge and skills in PC as barriers to daily practice [30]. Similarly, Raudonis, Kyba, and Kinsey [31] found nurses working in long-term care to lack knowledge on principles of PC and on pain and symptom management.

Recently, a survey conducted in Scotland on public awareness of palliative care found the majority of respondents to have some knowledge of palliative care, with 32% reporting no knowledge and only 3% to have high levels of knowledge of PC [32].

Improvements in the knowledge and attitudes of nurses and physicians have been reported in several studies after receiving training in PC [33-34]. Healthcare professionals have consistently reported the need for further education and training in palliative care. Similarly in Lebanon, almost all pediatric nurses and physicians in a survey conducted recently have reported the need to develop educational program in PC.

The European Association for Palliative Care (EAPC) recommended that all professionals and volunteers working in PPC should receive comprehensive training and support ; in addition PC training must be a core part of the curriculum that should be developed by each country [8].

#### Research

Another challenge and at times an obstacle facing the provision of adequate PC is conducting research in this area. Research in PPC that will eventually provide the evidence-base leading to improvements in care and education is still lacking. Adequate funding for research must be available to ensure the delivery of best practices. The vulnerability of this population (children and parents) and the ensuing burdens should be taken into consideration when designing such studies [35].

## CONCLUSION AND RECOMMENDATIONS

The aims and principles of PPC emphasize the involvement of the child and family in the decision-making process. The burden of care on the family, however, need not be underestimated. There is evidence suggesting that parents can feel isolated, lonely, depressed, and bewildered by the experience. Adequate support, the availability of a back-up system, and the provision of respite care are important [36].

PPC services need to be developed in Lebanon ; the integration of PPC education in the curricula of nursing and medical schools is a must [36]. Policy makers have a major role to play in introducing regulations that will facilitate care provision in this field. Finally, PPC research is still lacking and is highly warranted.

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