

PALLIATIVE CARE FOR INFANTS, CHILDREN AND YOUNG PEOPLE THE FACTS



Fondazione
Maruzza
Lefebvre
D'Ovidio
Onlus



EAPC

PALLIATIVE CARE FOR INFANTS, CHILDREN AND YOUNG PEOPLE

THE FACTS

A document for healthcare professionals and Policy Makers

Prepared by
the EAPC Taskforce for Palliative Care in Children

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the Fondazione Maruzza Lefebvre D'Ovidio Onlus

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*Dedicated to the memory of
Vittorio Ventafridda, pioneer of palliative care.
A friend and mentor who inspired
and supported this publication.*

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Contents

Foreword		7
Chapter I	Vision and aims	9
Chapter II	How big is the problem	13
Chapter III	Why Palliative Care for children?	17
Chapter IV	Needs of children with incurable conditions and their families	23
Chapter V	The current situation of Paediatric Palliative Care	27
Chapter VI	The goals of Paediatric Palliative Care	33
Chapter VII	The solutions: care models of PPC	37
Chapter VIII	The costs of Paediatric Palliative Care	43
Chapter IX	Challenges and recommendations for the future	47

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Foreword

Access to palliative care is widely acknowledged as a right for adults and elderly persons suffering from incurable conditions or living with serious chronic illness. In the paediatric age the recognition and diffusion of dedicated palliative care is still at an early stage and the services currently available for children with incurable conditions and their families are fragmented and inconsistent.

The causes behind this situation are multiple and complex: compared to adult patients, the numbers of children eligible for palliative care are much fewer; there is a gap in organizational and managerial policy; a shortage of competent medical staff; emotional and cultural issues related to the care of dying children that condition social acceptance and understanding.

Regardless of their age, these children suffer all the clinical, psychological, ethical and spiritual aspects of incurable illness and death. However, it must be stressed that children are not 'small adults', and should not be treated so; they have specific developmental, psychological, social and clinical needs that must be addressed.

It is for this reason that the European Association for Palliative Care (EAPC) and the Fondazione Maruzza Lefebvre D'Ovidio Onlus decided to work together in an attempt to bridge cultural and organizational gaps by providing policy makers and stakeholders with a general overview of palliative care service provision in Europe, identifying barriers and shortcomings and, at the same time, describing potential solutions for the development of effective, child-specific palliative care programs.

It is our goal that each country develops their own integrated network of family-centred palliative care services based on an interdisciplinary approach which is sensitive to the child's and family's wishes regarding treatment and choice of care setting throughout the course of illness. Only then, we will be able to affirm that we have achieved our primary objective: the recognition of children with incurable illness as individuals, their right to dignity and the best quality of life and care possible.

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Chapter I

Vision and aims

"I don't want to die but I'm afraid of living!"

(Edoardo - 7 years, neuroblastoma)



In recent years the developed world has seen an increase in the prevalence of incurable disease and disability. Medical and technological advances have reduced infant and child mortality rates and, at the same time, have improved the survival rates of children with severe and potentially lethal pathologies, who need complex palliative care.

There is an increase in the numbers of children eligible for paediatric palliative care (PPC).

For many years palliative care was not offered to paediatric patients and even today in Europe, despite the development of PPC programs in several countries, only a minority of children with incurable illness benefit from palliative care services. Many of these children will die in inadequate conditions; without relief from distressing symptoms, usually in a hospital setting and rarely with care support in their own home where many would prefer to spend as much time as possible and eventually die.

Paediatric palliative care (PPC) is an emergent problem in our society that currently has inadequate solutions.

The reasons for these shortcomings in the provision of paediatric palliative care can be attributed to organizational, cultural and economical barriers. The situation is further complicated by the unique aspect of childhood illness and small patient numbers which, together with the multiplicity and broad geographical distribution of cases, determine the organization of palliative care services very different to those provided for adults.

Palliative care for children is unique and specific; it requires skills, organization and resources which are different from those for adults.

Children with life-limiting and life-threatening illnesses deserve a thorough cultural and organizational reappraisal of how we care for them when treatment is not aimed at recovery but at offering the best quality of life possible.

A more efficient use of the resources currently allocated for the care of these patients could be achieved by creating specific paediatric palliative care services and integrated networks that would guarantee a more appropriate management of the illness (at home, in the hospital, in the hospice) whilst safeguarding the dignity and quality of life of young patients and their families. This would result in a reduced demand on acute medical services and, consequently, on healthcare resources (see chapter VIII).

Paediatric palliative care is possible and could be cost effective.

The purpose of this booklet is to examine the state-of-the-art and the need for paediatric palliative care. It documents the importance of child-specific palliative care, sets out the evidence for policy development, describes the needs of children and their families. It also provides arguments for integrating palliative care across health services, summarizes evidence for effective care solutions and formulates recommendations for health care policy-makers. The work of healthcare planners and medical professionals can be facilitated by having access to such a document.

Policy implications

Paediatric palliative care must become an integral part of health care systems in all countries.

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Chapter II

How big is the problem

"My baby has a rare illness, I feel very alone, I don't know what it is and how I will cope..."
(Laura, Angelo's mother - 1 year, Farber syndrome)



In most European countries comprehensive epidemiological data is not widely available, it is collected in different ways (varying criteria) or not at all.

Information relative to numbers, diagnosis, age range and location of children with life-limiting or life-threatening conditions is fundamental to the organization of PPC.

The existing data regards mainly two statistics: **mortality** from life-threatening or life-limiting illness and **prevalence** of life-threatening or life-limiting cases.

Mortality data: research carried out by the Association for Children With Life-Threatening or Terminal conditions and Their Families and the Royal College of Paediatrics and Children Health, in the UK(1) has established the annual death rate from incurable illness at 1 out of 10,000 for children aged between 1 to 19 years. There are variations of mortality figures from different countries. In Italy, UK and Ireland the mortality from life-limiting and terminal illness is 1.0, 1.2 and 3.6 in 10,000 per year respectively (2,3,4).

The pathologies include a broad spectrum of disorders such as neuromuscular diseases, cardiac abnormalities, renal failure, chromosomal anomalies, blood disorders and malignancies (see figure 1).

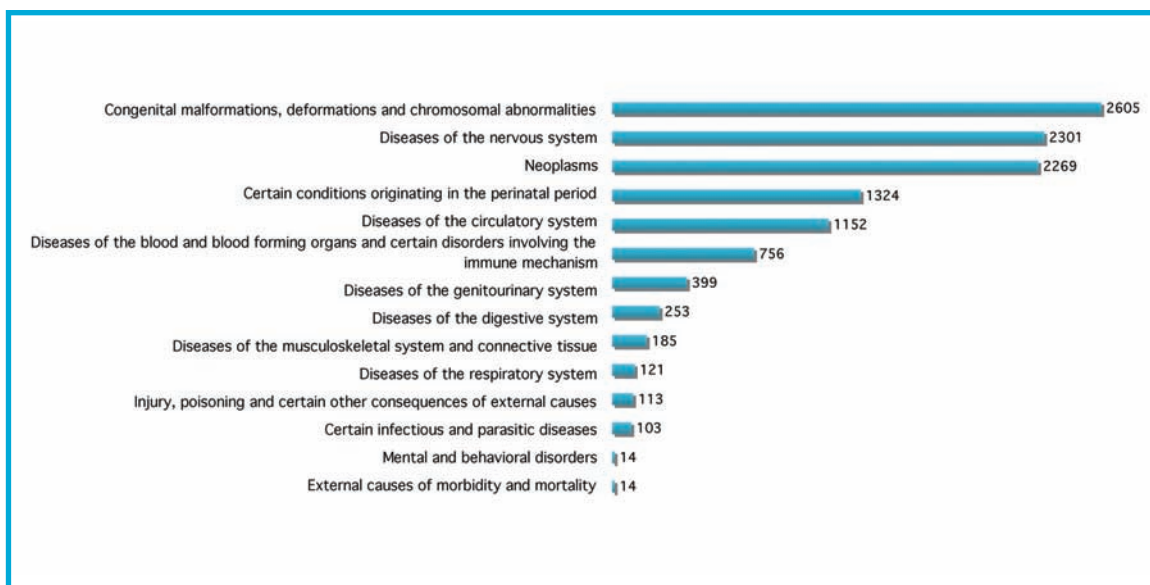


Figure 1. Deaths from causes likely to require palliative care for ages 0-19, England 2001-05, excluding neonatal deaths, source: Department of Health, UK, modified.

There are differences in the mortality rates reported in infancy, childhood and adolescence. In all studies the majority of childhood deaths occur within the first year of life; most of these are caused by congenital and chromosomal abnormalities and deformations. The deaths occurring after the first year of life are more likely caused by diseases of the nervous or circulatory system or cancer.

- **At least 1 child out of 10,000 dies each year from life- threatening or life-limiting illness.**
- **Many die in the first year of life.**
- **The conditions are multiple and often rare.**

Prevalence data: the estimated prevalence rate for children and young people likely to require palliative care services is 10-16 per 10,000 population age 0-19 (15 per 10,000 if neonatal deaths are excluded)(1,5,6). The differences in figures are attributed to the different age ranges and differing eligibility criteria adopted for the studies and not different pathologies.

In all studies about 30% have cancer; the remaining 70% includes a combination of pathologies, predominantly neurodegenerative, metabolic and genetic.

At least 10 out of 10.000 children aged 0-19 years suffer from life-limiting or life-threatening conditions. Less than a third has cancer.

The Facts

In a population of 250,000 people with about 50,000 children, in one year :

- 8 children are likely to die from life-limiting conditions (3 from cancer, 5 from other conditions);
- 60 to 80 would be suffering from a life- limiting condition;
- 30 to 40 of them would need specialized palliative care.

Policy implications

In order to meet the needs of the increasing number of children eligible for palliative care, each country should collect precise, comprehensive epidemiological data regarding the prevalence of conditions requiring paediatric palliative care.

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Chapter III

Why Palliative Care for children?

"Palliative care is for old people who are dying...

I don't want to have anything to do with it!"

(Maria, Giacomo's mother – 3 years, muscular dystrophy)



The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children (1) and their families is as follows:

- it is the active total care of the child's body, mind and spirit, and also involves giving support to the family;
- it begins when a life-threatening illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease;
- health providers must evaluate and alleviate the child's physical, psychological, and social distress;
- effective palliative care 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 centres and even in children's homes.

Paediatric palliative care is:
“The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when a life-threatening illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease”.

It is important to draw a distinction between 'palliative' and 'terminal' care. 'Terminal care' refers to the care of the patient and family limited to the period when curative treatment has been suspended and death is imminent (weeks, days, hours). This misperception seriously impacts eligibility criteria, specific needs and the way in

which services are offered, particularly in the paediatric sector. It should be stressed that not every child with a life-threatening condition needs continuous palliative care throughout the course of the illness.

Conditions eligible for paediatric palliative care.

Childhood conditions requiring palliative care differ from those of adults, they are multiple and wide-ranging, the duration of care is variable and difficult to predict, the diseases are frequently hereditary (they can affect several members of the same family) and rare; they are either life-limiting or life-threatening.

Life-limiting illness is defined as a condition where premature death is usual, but not necessarily imminent.

Life-threatening illness is one where there is a high probability of premature death but there is also a chance of long-term survival to adulthood.

Four different groups of childhood conditions have been identified (2):

Group 1 - Life-threatening conditions for which curative treatment may be feasible, but can fail (for example, cancer, organ failure of heart, liver or kidney, infections).

Group 2 - Conditions requiring long periods of intensive treatment aimed at prolonging life, but where premature death is still possible (for example, cystic fibrosis, HIV/AIDS, cardiovascular anomalies, extreme prematurity).

Group 3 - Progressive conditions without curative options, where treatment is palliative after diagnosis (for example, neuromuscular or neurodegenerative disorders, progressive metabolic disorders, chromosomal abnormalities, advanced metastatic cancer on first presentation).

Group 4 - Irreversible, non-progressive conditions with severe disability causing extreme vulnerability to health complications (for example, severe cerebral palsy, genetic disorders, congenital malformations, prematurity, brain or spinal cord injury).

Very ill newborn infants at the end of their life should also be considered as candidates for palliative or comfort care.

Aspects that distinguish palliative care for children.

The distinctiveness and complexity of palliative care for children comes from (3):

1. Small numbers: compared to adults, the number of paediatric cases requiring palliative care are much fewer; this aspect, together with the broad geographical distribution, can pose problems at an organizational, training and costs level

2. A broad range of conditions (neurological, metabolic, chromosomal, cardiologic, respiratory and infective diseases, cancer, complications of prematurity, trauma) and the unpredictable duration of illness: many pathologies are rare and familial, some remain undiagnosed.

3. Limited availability of drugs specifically for children: most drug treatments available are developed, formulated and licensed for use in adults; medicines are often in large, unpleasantly flavoured tablets and rarely available in liquid suspension form (especially prolonged release opioid pain treatments) that are easily administrable to young children. Many drugs do not provide explicit labelling for use in children regarding indications, age, doses and side-effects. As a result, in the absence of suitable alternatives, many drugs used in paediatric palliative care are commonly prescribed 'off-label'.

4. Developmental factors: children are in continuous physical, emotional and cognitive development; this affects every aspect of their care, from the dosage of medication, to communication methods, education and support.

5. The role of the family: the parents legally represent their offspring in all clinical, therapeutic, ethical and social decisions and are heavily involved as care-givers and decision-makers.

6. A relatively new branch of medicine: the need to extend palliative care to the paediatric age is a consequence of technological advances permitting the prolonged survival of an increased number of children with complex pathologies that until recently would have led to rapid deterioration and death. This has given rise to cultural limitations and a lack of expertise in the specific care of these children.

7. Emotional involvement: when a child is dying, it can be extremely difficult for the family members and caregivers to accept the failure of treatment, the irreversibility of the illness and death.

8. Grief and bereavement: following the death of a child it is more likely to be severe, prolonged and often complicated.

9. Legal and ethical issues: the legal referents are the child's parents or guardian. The child's legal rights, wishes and participation in choice-making are often not respected. There can be conflict between ethics, professional conduct and legislation, particularly where children are concerned.

10. Social impact: it is difficult for the child and the family to maintain their role in society during the course of the illness (school, work, income).

The pathologies eligible for PPC are multiple and wide-ranging, the duration of care is variable and difficult to predict. Palliative Care DOES NOT exclude curative treatment.

Features of PPC that affect organizational choices:

- Smaller, more varied patient population
- Different range of conditions
- Limited availability of child-specific drug treatments
- Developmental factors
- Parents are heavily involved as care-givers and decision makers
- Lack of trained medical staff
- Great emotional involvement
- Difficulties in managing grief and bereavement
- Major difficulties in defining moral and juridical issues
- Social impact

All these aspects determine the need to organize dedicated palliative care services specifically for children for care both at home and in a hospice setting.

Children with life-limiting and life-threatening conditions require specific and dedicated PPC services. Individual needs affect the type and amount of care required which, in turn, condition organizational choices and specific healthcare models.

Policy implications

- 1. Policy-makers need to consider palliative care for children as different from that of adults and develop services accordingly.**
- 2. Age, development and personal resources must be considered in the planning and organization of care programs for children.**
- 3. Policy-makers should introduce appropriate legislation for the regulation of palliative care for infants, children and adolescents.**

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Chapter IV

Needs of children with incurable conditions and their families

"I must live!"

(Andrea – 15 years, Wilm's tumor)



Children with life-limiting and life-threatening conditions and their families have diverse and multiple needs (clinical, psychological, social, spiritual) (1).

The needs of Children

Physical needs:

- symptom control: the timely pharmacological and integrative non-pharmacological management of pain and other symptoms by appropriately skilled professionals (consequently resulting in a reduction in the number of unnecessary hospital admissions) (2,3);
- the attainment of their full potential of growth and development: these aspects must be considered and included when considering any form of treatment;
- advanced care planning is essential (4).

Psychological needs:

- open and clear communication appropriate to the developmental stage of the child is necessary (3,5);
- continual emotional support to help the child cope with emotive issues; understanding, acceptance, anger, self confidence, trust and love;
- access to resources and tools that promote the development of the child's personality, self-awareness (and that of others), the enhancement of individual characteristics and talents and, where possible, the continuation of daily routines, incentives, targets and future projects.

Social needs:

- recreational opportunities, tools, techniques and activities appropriate for individual needs;
- schooling for as long and often as possible, even at home with individual tuition;
- social activities offering appropriate opportunities for interaction with peer groups, possibly through voluntary groups and organizations.

Spiritual needs:

- access to appropriate spiritual care and support respecting the family's cultural and religious background.

All these individual needs are in continuous evolution, both in prevalence and intensity, directly linked to the child's psycho-physical-emotional development, the phase of the illness and its effect on growth and maturity.

Children have complex palliative care needs determined by age, the course of the illness, the family unit and the cultural environment which require combined healthcare and community solutions.

The needs of the families

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 care and affection, regardless of genetic relationships. Family members may include biological, marital, adoptive, and custodial families (6).

The parents of children with life-threatening illnesses, in addition to being parents, become healthcare providers. To avoid institutionalizing their children they take on important responsibilities which include administering treatments for which they receive little or no training and no payment. They are expected to take decisions in the child's best interest at a time when they are highly stressed and grieving the loss of their child's health (6,7).

Siblings often live the illness with feelings of guilt and loneliness, paying the price of social isolation which often goes hand in hand with a terminal condition. Members of the extended family (grandparents, uncles, aunts and friends) play an important role sharing responsibilities and providing emotional support (8).

Families facing the death of a child need support on many levels:

- *a thorough knowledge of their child's condition and how best to care for him/her;*
- *financial help: changes in lifestyle can affect employment status and the financial security of the family of children who have life-threatening conditions;*
- *appropriate emotional and bereavement support must be provided to reduce long-term morbidity within the whole family, including grandparents. Professional support for siblings is vital (9,10);*
- *religious and spiritual needs have to be met.*

**The needs of families are multiple and complex,
the support of an experienced interdisciplinary team is essential.**

Policy implications

Palliative care is family-centred; families and siblings have complex needs which need to be assessed and managed properly. All these needs cannot be addressed by a single individual but necessitate the intervention of an experienced interdisciplinary team.

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Chapter V

The current situation of Paediatric Palliative Care

"I feel terrible... who will help me?"

I don't want to live like a larva!"

(Elisa –13 years, muscular dystrophy)



For many years palliative care was not offered to paediatric patients and even today because of inadequacies in service provision and planning, difficulties in defining eligibility criteria, a shortage of skilled medical staff and a lack of public awareness, only a small percentage of children with incurable illness can benefit from palliative care.

A substantial proportion of children with terminal conditions die in hospital and/or in acute care facilities, mainly in intensive care units (1). This has a serious impact on the quality of life and death of children and the quality of life of the families which can lead to an improper use of healthcare resources.

Too many children with incurable conditions die in hospital, often in intensive care facilities.

Table 1. Location of death for children (0-19 excluding neonates) in Ireland and England. (Source: Department of Health and Children, the Irish Hospice Foundation; Department of Health, UK)

Place of death	Ireland (2001)	England (2001-05)
Home	124 (22%)	1,811 (19.2%)
Hospital	281 (50%)	6,985 (74.2%)
Hospice		393 (4.2%)
Other	161 (28%)*	223 (2.45%)**

* Local authority institutions, private homes

** Psychiatric hospitals, nursing homes, residential homes, private home not the usual residence of the deceased

Recent studies suggest that in regions where family-centred paediatric palliative care networks, supported by dedicated children’s hospices, are operative, the number of hospital admissions and the incidence of death in hospital for children and adolescents are considerably lower. This phenomenon not only reduces the demand on acute wards and ICU’s but implicates an improved quality of life for the patient and family (2).

Integrated home-care and PPC programs improve the quality of life of the child and family making the best use of available resources.

Dying children suffer from many, often distressing, symptoms. The most common symptoms reported are pain, lack of energy, fatigue, dyspnea, nausea, lack of appetite, drowsiness, cough, and other psychological symptoms like sadness, nervousness, worrying and irritability (3,4,5). The majority of these children usually experience a great deal of suffering from at least one symptom and 89% present significant general suffering (5) (fig 2).

Too many children suffer unnecessary pain and distress due to poor symptom management.

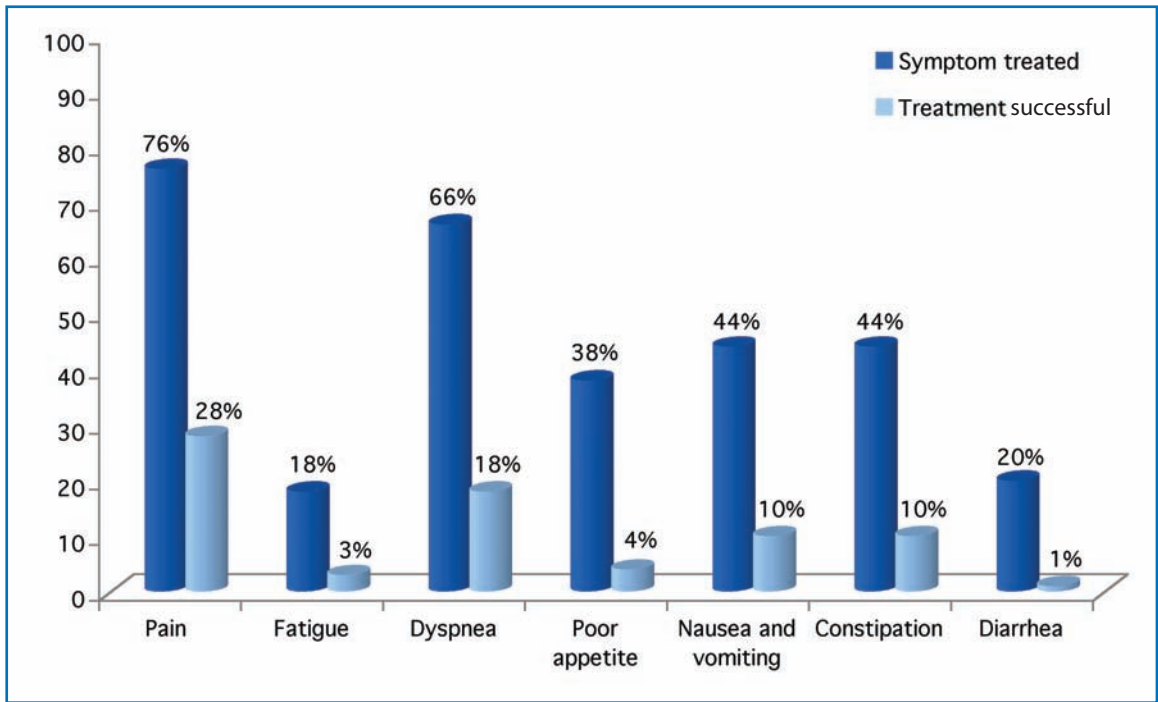
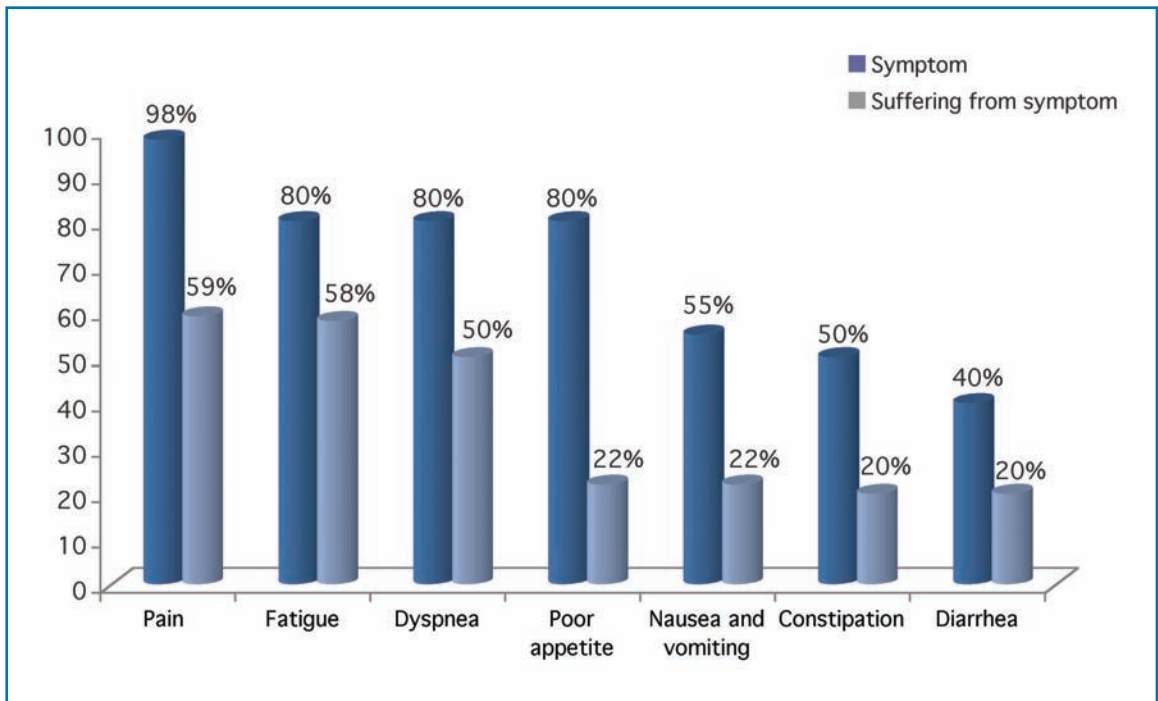


Figure 2. Symptoms and suffering in the last month of life (Source; Wolfe et al. 2000).

Although recent studies indicate that pain and symptoms are effectively controlled in children with cancer receiving palliative care (6), symptom management remains a healthcare challenge; many children receive inadequate treatment or no treatment at all (fig. 2).

Symptom assessment, prevention and management are the basis for enhanced quality of life and are fundamental to all paediatric palliative care programs.

The clinical and global management of the child and family is often characterized by abandonment and isolation because the necessary specialized services are not available (7). As a result, the family takes on the entire burden of the child's care with the inevitable clinical, social and financial consequences. Alternatively, the child is hospitalized even when the clinical conditions do not require hospitalization.

Too many families are left on their own to cope. Continuous support for the family, independent of the care setting, is essential to effective paediatric palliative care programs.

A lack of knowledge and skills are frequent barriers to the daily practice of PPC. The lack of training is particularly evident in: pain and symptom management, the referral of patients to palliative care services and in communication with dying children and their families. This is attributable to the absence of formal education and training in palliative care.

There is a significant lack of knowledge and training.

Policy implications

It is urgently necessary to program and organize paediatric palliative care services that adequately address the needs of children and families. It is also necessary to provide adequate education and training for those providing palliative care services.

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Chapter VI

The goals of Paediatric Palliative Care

"You are my friend... I am your job!"

(John, Sofia's father - 16 years, brain tumour)



The organization of PPC must include:

1. Access to specialized services by skilled carers. A PPC program must be capable of meeting the specific needs of the child and family throughout the course of the illness and bereavement, independently of the child's age, pathology, place of residence and care setting. Services must offer continuity of care, available around the clock (24/7), either at home, in hospital, hospice or in other institutions in the community such as group homes or orphanages (1).

Paediatric palliative care programs must guarantee around the clock support (24/7).

2. Holistic and family-centred care. Palliative care for children is focused on enhancing the quality of life for the child and support for the family: it is a holistic approach and needs to be family-directed (1).

Paediatric palliative care programs must be family-centred.

3. *Symptom assessment and management.* Unnecessary suffering must be avoided through the availability of effective drug treatments combined with practical, cognitive, behavioural, physical, integrative and supportive therapies.

The assessment and management of distressing symptoms are fundamental in maintaining and improving a child's quality of life.

4. *Communication and information.* Open and clear communication between health care providers, the child and the family should be a primary goal of PPC. Together they should establish common care objectives, discuss treatment options, share choices and decisions. Honest and comprehensible information concerning the child's condition, possible outcome, treatment and available services should be provided. Where young or cognitively impaired children are concerned, the parents should determine, with the guidance of professionals, how, when and what information to share with the child. Adolescents and young adults should be directly informed and involved in decision-making if they wish so. Empathic and supportive communication is critical when addressing end-of-life issues (2).

Effective communication with the child and family is essential to the success of palliative care programs.

5. *An interdisciplinary approach.* Since a single professional figure cannot guarantee all the necessary support for the child and family, palliative care is best provided using an integrated interdisciplinary approach. This requires coordination between the child, family, teachers, school staff and healthcare professionals including nurses, primary care physicians, social workers, chaplains, bereavement counsellors and consultants (3).

Paediatric palliative care must be provided by an interdisciplinary team.

6. Respite care. 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 can be provided in the home by a trained professional, family member, volunteer, or paid sitter. Out-of-home respite can be provided by hospital units, residential facilities (paediatric hospices), licensed foster-parent respite care or medical day-care programs (1).

Respite care for the family and the patient is essential.

7. Caregiver support. Health care professionals must be supported to prevent 'burnout' (4). The caregivers' physical, psychological and spiritual well-being should be integral to the provision of paediatric palliative care (6); institutions should work to identify and minimize occupational risks and stresses.

Professional and emotional demands on the palliative care team are high: the solutions are prevention, monitoring and support.

8. Education and training of health care professionals. An improvement in the knowledge and attitudes of nurses and physicians towards palliative care after educational interventions has been reported in several studies (5,6,7).

Adequate education and training is crucial to all PPC programs.

9. Public awareness. Recent studies have shown that the public awareness and knowledge of palliative care is scarce. Public education is one area in palliative care that has not received adequate attention. The general public needs to receive information and education regarding the services provided, treatment modalities and the effective treatment of pain and other symptoms. These issues pose challenges for palliative care that should be taken seriously (8).

The general public must be better informed of the importance of paediatric palliative care programs.

10. Monitoring and indicators. The identification of quality and process indicators for monitoring the applicability, efficacy and efficiency must be an integral part of any PPC program.

Ongoing evaluation and monitoring to gauge patient/family satisfaction with care provision, symptom management and quality of life are essential to effective, evidence-based paediatric palliative care programs.

Policy implications

PPC programs must be planned and implemented respecting fundamental criteria of efficacy, efficiency, safety and sustainability. Services must be continually assessed and revised according to predefined standards.

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Chapter VII

The solutions: care models of PPC

"I'd rather die, than go back to the hospital!"

(Carlo – 8 years, C2 transverse myelitis)



The interdisciplinary care team (including physicians, nurses, psychologists, physiotherapists, occupational therapists and social workers) is fundamental to any paediatric palliative care solution. The team aims to provide around-the-clock, holistic, family-centred care throughout the illness, death and bereavement. The organization should be centred on home-care with immediate access to a paediatric hospice and appropriate respite care available when necessary (1). The family physician or paediatrician should maintain a central role as a reference figure for the child and family.

There are three levels of intervention for PPC:

1. Primary level of paediatric palliative care or palliative approach: aimed at children with relatively frequent and less severe conditions, where the principals of paediatric palliative care are practiced by all healthcare workers.

2. Second or intermediate level of paediatric palliative care: aimed at more complex cases requiring the intervention of hospital and community primary care staff who are not exclusively involved in paediatric palliative care services but who have specific skills determined by recognized standards.

3. Third or specialized level of paediatric palliative care: aimed at very complex conditions that necessitate continuous care of professionals working exclusively in the paediatric palliative care sector; members of a specialized interdisciplinary care team.

For the organization of specialized paediatric palliative care services, two potential care settings must be considered: in the home and in residential settings.

Home-care

Family-centred home-care is the goal of paediatric palliative care, it is what most families want and has a positive impact on the child's quality of life (2).

The advantages of being cared for at home are numerous. Home-care greatly diminishes feelings of fear, isolation and helplessness. It allows the child to participate in family activities and offers important opportunities for communication and socialization. It also allows extended family members to share care responsibilities. Nonetheless, it must be considered that for some children or families, home-care may not be the best option.

Home-care requires the involvement of a multidisciplinary team to support the family: there must be 24 hour access to paediatric palliative care expertise, to appropriate respite and immediate hospital care if needed. A designated 'key worker' to coordinate the child's care with the family, community carers, local hospital and specialist centres is essential (2,3).

Home-care can greatly improve the quality of life of the young patients and their families.

The two main healthcare models involved in home care are:

1. Hospital-based care: where a team based at a paediatric tertiary centre continues to care for the child discharged from hospital. The team is often comprised of clinical nurse specialists, a consultant, a registrar, a psychologist, clinical ethicist and administrators. They work closely with other teams in the hospital, including the chronic pain service, disease specific teams, the intensive care unit (NICU/PICU) (most children die during the first year of life), other hospitals, hospices, G.P.s, local community health services and schools (4). Because of the relatively low patient numbers, the implementation of this type of solution is not viable,

in organizational and economic terms, outside of highly populated urban areas.

2. Community-based care: where a community-team cares for the patient and the family. This solution permits the child to lead a regular family and social life; it offers the possibility of broad geographical coverage and the provision of multidisciplinary services. However, this solution can suffer from discontinuity of hospital treatment, insufficient resources and inadequate skills; all too often, the bulk of the child's care is delegated to the family unit. The success of this care model depends on communication and interaction between hospitals and community services, training in paediatric palliative care for local primary care staff, skills training for the family preparing them to assist the community-based services and the availability of medical supplies and equipment. Community teams should be able to call on the experience of a specialist paediatric palliative care team when needed.

It has been shown that care provided to children by community services can be far more cost effective than allowing children to spend inappropriate time in hospitals (i.e. delayed discharge) or attending hospital outpatients (i.e. for routine testing) (5).

The goal of PPC, independently of the model chosen, is to favour child/family-centred home-care.

Residential solution

Home-care is not always feasible; for particularly complex cases, exhaustion, emotional stress or logistic and organizational reasons, temporary residential solutions are necessary. Residential solutions for children with life-limiting or life-threatening disease can be provided primarily in three care-settings; hospice/nursing homes, in hospital acute wards/intensive care units and, more recently, in inpatient paediatric palliative care units.

1. The hospice and/or dedicated nursing home: these have the advantage of focusing expertise in the management of rare, complex cases in an environment suited to the child's and family's needs. Covering wide geographical areas, it has the necessary patient numbers to develop expertise and the dedicated resources to be economically viable. It has the disadvantage of separating the child from its home environment (4).

2. Hospital acute wards: for its nature, mission and organization this is not the ideal setting for palliative care in children. It has been shown that children who die in hospital

with complex chronic conditions are more likely to have experienced longer periods of mechanical ventilation and hospitalization before death (6).

3. Inpatient paediatric palliative care units: these "hospices within a hospital" offer specialized palliative care from diagnosis, through the interim periods of advancing disease, up to and including the final stages of the illness.

Dedicated paediatric hospices provide a better solution than hospitals for children receiving palliative care. It is inappropriate that children be cared for in hospices for adults and elderly persons.

Proposed healthcare model

As all of the single organizational models mentioned above have limitations, the majority of current paediatric palliative care programs adopt a combination of the solutions described. They are modules within a single network, where various public healthcare bodies work with other agencies to provide continuous, flexible care throughout the course of the illness. Families can access the various care-settings within the network according to the child's and family's needs. Diverse care solutions may be favoured temporarily depending on the child's condition and specific situation at any one time. A specialized paediatric palliative care team acts as a reference for all the caregivers in the network; this model of healthcare provides a raised level of expertise and enhanced support for the family.

Various international studies recognize that dedicated paediatric palliative care networks, covering large areas and encompassing both home-care and residential solutions (paediatric hospices), offer the most effective, efficient and sustainable healthcare model for children with incurable illnesses and their families.

Home care service networks supported by specialized teams together with temporary residential alternatives offer the most effective, efficient and viable palliative care solution for children and their families.

Policy implications

PPC programs must be sufficiently flexible to allow the child and the family access to the different care options at different phases of the illness.

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Chapter VIII

The costs of Paediatric Palliative Care

*"I understand that my son is a 'cost' on society, but believe me
...I would do anything for it not to be so..."*

(Marco's father - 7 years, mucopolysaccharidosis)



At the present time, in most European countries, only a small percentage of children with incurable illness die at home, even if this is what most children and their parents would prefer. A large percentage die in hospital, often in intensive care facilities. Furthermore, due to the lack of advanced care planning, their illness may be characterized by periods of frequent and prolonged hospitalizations, again in intensive care units or in paediatric palliative care units. Consequently, the cost of caring for these patients is relatively high, particularly during the terminal phase of their lives (1).

The current provision of paediatric palliative care is disjointed and inconsistent, not only between countries but also from region to region in the same country, depending on the local authority's healthcare policy regarding palliative and home-care services. It is, therefore, difficult to estimate the real costs of palliative care organization compared to the conventional care of these patients in hospitals.

It is often claimed that an increase in home and hospice care, resulting in a reduction in highly technological interventions in a hospital setting, can produce significant savings in spending for the care of children with incurable illness. However, very few studies evaluating the impact of a palliative care programs for children on health care costs have been published, the evidence to support this claim is not strong and derived almost exclusively from studies in adult. In view of the differences in care provision, it is hazardous to project the results of the studies performed in adults to the paediatric population.

The few randomized studies in terminally ill adults are either too small or with methodological flaws and do not indicate significant cost savings. The non- randomized studies in hospices for adults show a wide range of savings in costs, from none to 68%. Data collected in adults suggest that savings during the last month of life can be between 25 and 40% of health care costs; these savings decrease to 10-17% over the last 6 months and to 0-10% over the last 12 months of life.

In adults it has been estimated that medical care at the end of life consumes 10 to 20% of the total health care budget and 27% of the Medicare budget in the USA (2).

Some estimates incorporated into healthcare policy development programs indicate possible savings amounting to 40-70% of total healthcare spending for the care of children with incurable conditions, through the organization and provision of PPC services. These savings are achieved by reducing the number of hospital admissions and the length of hospitalization, particularly in intensive care units. However, these estimates do not take into account the set-up or running costs of PPC programs (3).

A study focusing on the financial impact of providing palliative care in an inpatient hospital setting showed that children receiving care coordinated by a palliative care program underwent fewer radiology procedures and received better support from the pharmacologic services. This reflected a greater attention to the patient's comfort and to the treatment of pain (5). It was also assessed that the average daily costs of home-care for children with cancer are significantly lower than those for hospitalized patients undergoing the same procedures (€ 154 and € 515 per day respectively) (5). The overall savings involved are uncertain and probably less than most people anticipated; nevertheless, studies do suggest that hospice and home-care should be encouraged as they do not seem to be more expensive than traditional hospital care yet they provide a much enhanced quality of life for patients and their families (6).

The positive impact of palliative care on the quality of life of the child and family can reduce the overall costs to society.

Therefore, every country, or even every region, should collect exhaustive data regarding the costs of care for children with incurable conditions eligible for palliative care before starting a paediatric palliative care program and closely monitor spending once the program is implemented. The evaluation should include the costs of all hospital, hospice and home-care medical staff and care-givers involved in the programs, symptom management and the real economic and social costs for the child and family. The costs of support for the family after the child's death should also be considered, as bereaved parents with unresolved grief can represent a high cost for society (i.e. being on sick-leave)(7). Evaluation of the quality of life, though difficult, should also be considered. Research in this area is also strongly recommended.

There is a lack of studies evaluating the costs of paediatric palliative care.

Policy implications

Comparative cost evaluation and effective resource allocation should be conducted during the planning and implementation of PPC programs

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Chapter IX

Challenges and recommendations for the future

All those involved in the implementation of successful paediatric palliative care programs face a number of challenges.



Policy-makers

1. A considerable amount of evidence shows that infants, children, and adolescents with incurable conditions unnecessarily suffer from underassessment and under-treatment of their needs due to a lack of appropriate child-specific palliative care services.
2. The needs of these children and their families are individual and complex; they require continuous, integrated palliative care and treatment which is child-specific, flexible and family-centred.
3. Existing paediatric palliative care provision is aimed predominantly at children with cancer; other life-limiting and life-threatening conditions are often excluded.
4. Access to PPC pertains to the right to health and care as expressed in many national and international documents.
5. A number of studies have shown compelling evidence that daily costs for patients in palliative care are no higher when compared to care in a hospital setting.

6. Commercial drug companies are not required to develop, produce and test existing drug formulations for use in the paediatric age. Many effective drug treatments are unavailable, difficult to administer or are prescribed 'off label' to children affected by incurable illness.

Health Professionals

1. There is a misperception among healthcare professionals, legislators, administrators and the general public that palliative care is only beneficial when all curative efforts have been exhausted and death is imminent.
2. Few practitioners have extensive experience in dealing and communicating with children with incurable conditions and their families.
3. A lack of appropriate legislation may hinder patient/family-centred decision-making.
4. Eligibility criteria based on prognosis, which is often difficult to predict in children with complex pathologies different to cancer, seriously delay referral and exclude many children from the benefits of paediatric palliative and hospice care.
5. The child's cognitive, emotional and social development condition every aspect of care and communication, this can pose decisional challenges for families and professionals in establishing what is best for the child.
6. The expertise of professionals working in PPC must be adequately recognized.

Researchers

1. In developed countries, resources are usually allocated for medical research in acute care interventions; studies concerned with paediatric palliative care and treatment are virtually inexistent.
2. The allocation of resources for research in paediatric palliative care must be advocated.
3. Standards and indicators for the efficiency and quality of paediatric palliative care provision must be developed.
4. Research in PPC must be specific and cannot be extrapolated from the results of research in adults.
5. Research should build on evidence that already exists, be innovative, bridge gaps in knowledge and establish 'best practices'.

The public

1. Modern, developed societies do not expect children to die.
2. Families often believe that doctors can cure everything.
3. Palliative care is erroneously linked to the end of curative treatment; to accept referral to the palliative care team is often perceived as 'giving up' on the child. This conviction excludes many children from receiving the benefits and enhanced quality of life that palliative care can offer.

4. Death, no longer considered a natural process to be experienced in and shared by the community, has become a 'medical event' delegated to the medical profession in a hospital setting that is frequently ill-suited to address the special needs of dying children and adolescents.

General Recommendations

1. Palliative care must be developed and made available to children with life-threatening conditions with the goal of improving symptom management and quality of life.
2. A multidisciplinary family-centred approach to paediatric palliative care should be initiated at the diagnosis of life-threatening conditions.
3. Changes in the regulation and reimbursement policies of palliative care and hospice services should be implemented to improve the accessibility of palliative care for children.
4. All healthcare providers should be well-trained and competent in providing paediatric palliative care.
5. Resources to support paediatric palliative care research should be made available.

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The Fondazione Maruzza Lefebvre D'Ovidio Onlus

The Fondazione Maruzza Lefebvre D'Ovidio Onlus is an independent, family run charity, established by Antonio and Eugenia Lefebvre D'Ovidio following the death of Maruzza, their eldest daughter, to cancer in 1989. The Foundation's aim is to promote excellence and equity in the provision of palliative care and support for persons affected by life-threatening or life-limiting conditions and their families, regardless of age, cultural, social and economic background.

EAPC Taskforce: Palliative Care in Children

The EAPC Taskforce: Palliative Care in Children was established in the Autumn of 2006 following an initiative, promoted by the Fondazione Maruzza Lefebvre D'Ovidio Onlus, the Livia Benini Foundation and the No Pain for Children Association, bringing together a group of international paediatric palliative care experts to discuss the situation of paediatric palliative care provision and the development of integrated family-centred services in Europe. The aim of the Taskforce is to build on work already accomplished and to devise concrete proposals for the reform and improvement of palliative care services for infants, children and adolescents with life-limiting or life-threatening illnesses and their families.

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NOTE

www.maruzza.org
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