

# Palliative Care in Children

Huda Abu-Saad Huijer  
American University of Beirut,  
Lebanon

## 1. Introduction

In recent years the incidence of incurable disease and disability has been on the increase in developed and developing countries which in turn is increasing the need for pediatric palliative care all over the world (Gwyther & Cohen, 2009; Rogers et al., 2011). Medical and technological advances have certainly reduced infant and child mortality rates and, at the same time, have improved the survival rate of children with severe and potentially lethal pathologies, not always, however, offering the hope of a cure. This has produced an increase in the overall number of gravely ill children who continue to suffer from life-threatening problems.

For many years palliative care was not offered to pediatric patients and, even today, only a small percentage of children with incurable illness can actually 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 in their own home (Feudtner et al., 2011; Gwyther & Cohen, 2009).

Multiple cultural, organizational, educational and economical reasons have given rise to and have influenced the persistence in these shortcomings in patient care.

The purpose of this chapter is to examine the state of the art and need for palliative care in children. It sets out evidence for policy development, documents the importance of palliative care for children, describes the needs of children and their families, provides arguments for integrating palliative care across health services, summarizes evidence for effective care solutions, and formulates recommendations for health care policy.

## 2. Why palliative care for children?

The World Health Organization (WHO, 1998) defines Palliative care for children as:

*“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 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 centers and even in children's homes”.*

Childhood diseases requiring palliative care differ from those of adults; they are usually rare and familial and are either life-limiting or life threatening.

**Life-limiting illness** is defined as a condition where premature death is usual, for example 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, for example children receiving cancer treatment.

It is important to draw a distinction between 'palliative' and 'terminal' care. 'Terminal care' refers to the care of the patient and family during the period when death is imminent (weeks, days, hours). Palliative Care is not terminal care but includes end-of-life care (EAPC Taskforce, 2007). This misunderstanding seriously conditions eligibility criteria, specific needs and the way services are offered, particularly in the pediatric sector.

## 2.1 Spectrum of illness

Four different categories of childhood diseases have been identified (Aldrich, 1995):

|                |  |
|----------------|--|
| <b>Group 1</b> | Life-threatening conditions for which curative treatment may be feasible, but can fail (for example, cancer, organ failure of heart, liver or kidney, infections)  |
| <b>Group 2</b> | 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)   |
| <b>Group 3</b> | 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) |
| <b>Group 4</b> | 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)                        |

It is difficult to predict the duration of palliative care in children: in some cases (congenital disease), it may be limited to the first years of life; in others (neurological, cardiac and autoimmune pathologies) it can be long-term; while in others, it is concentrated in a brief period before death. In all these situations, there is no distinction between curative practices aimed at prolonging and enhancing the quality of life and treatment that is purely 'palliative'. Both approaches coexist, each prevailing depending on the phase of the disease and the circumstances (Fig. 1).

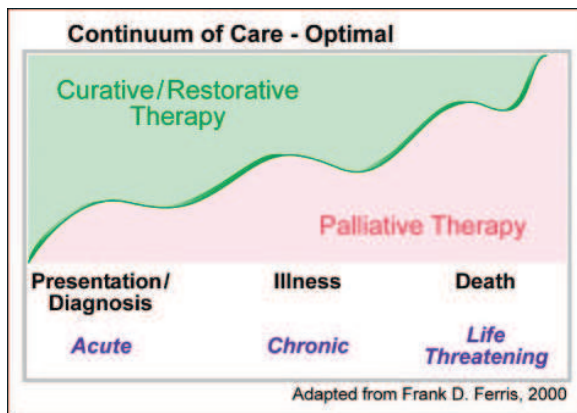


Fig. 1. New Model of Palliative Care (Korones, 2007)

Cognitive development and age along with child's experiences form the basis for a child's understanding of the concepts of illness and death which tend to change over time and vary between one child and another. Palliative care is as a result different in children in the following areas (Korones, 2007):

- Different spectrum and duration of illness
- Smaller, more varied patient population
- Specificity and complexity of services required.
- Parents are generally more involved as care-givers and decision-makers
- Developmental factors influence the child's understanding of illness and death, as well as their ability to communicate and participate in decision-making
- Sibling and extended family needs
- Grief in parents is more likely to be severe, prolonged and complicated

### 3. Epidemiological evidence

According to van de Wetering and Schouten-van Meeteren (2011), in developed countries the survival rate of children with cancer exceeds 75%. Children can tolerate more intense and combination therapies that have improved survival rates. 25% of children in developed countries will enter the palliative phase and ultimately die from their disease, while this rate exceeds 70% in developing countries.

Comprehensive epidemiological data is not available or is imprecise in many countries. In order to provide effective palliative care solutions, information relative to numbers, diagnostic category, age range and location of children with life-limiting or life-threatening conditions is essential. The available data regards mainly two statistics: mortality from life-threatening or life-limiting illness and the prevalence of life-threatening or life-limiting cases.

The published literature in the UK indicates that the prevalence of some conditions requiring palliative care is increasing, probably because of improvements in the survival

rate of low birth weight babies and increased life expectancy (Department of Health, UK, 2007). It is estimated that approximately 20,100 children and young people in the UK aged 0-19 years are likely to require access to palliative care services annually (18,000 if neonatal deaths are excluded). The estimated prevalence rate for children and young people likely to require palliative care services is 16 per 10,000 population age 0-19 (15 per 10,000 if neonatal deaths are excluded).

In England, there were 42,400 deaths of children and young people from causes likely to have required palliative care in the period 2001-2005 (Fig. 2). The proportion of deaths likely to require palliative care is highest among children less than 1 year and lowest among older children (15-19 years) and young adults (20-24 years). There have been on average 2,109 neonatal deaths per year from causes likely to require palliative care in the period 2001-2005 (Department of Health, UK, 2007).

Three-quarters of non-neonatal deaths likely to require palliative care among children and young people aged 0-19 occurred in hospitals. The proportion of deaths in hospitals is lower for young adults aged 20-39 (61%) than it is for young children under one year (88%) or 1 - 4 years (74%). Almost all (98%) of neonatal deaths occurred in hospitals. In the years 2002-2005, the average proportion of deaths requiring palliative care at age 0-19 (excluding neonates) that occurred at home ranged from 14.5% to 25% in London (Department of Health, UK, 2007).

There are variations in mortality figures among countries. In the UK and Ireland the mortality from life-limiting and terminal illness is 1.2 in 10,000 in the UK (Department of Health, UK, 2007) and 3.6 in 10,000 in the Republic of Ireland (Department of Health and Children, the Irish Hospice Foundation, 2005).

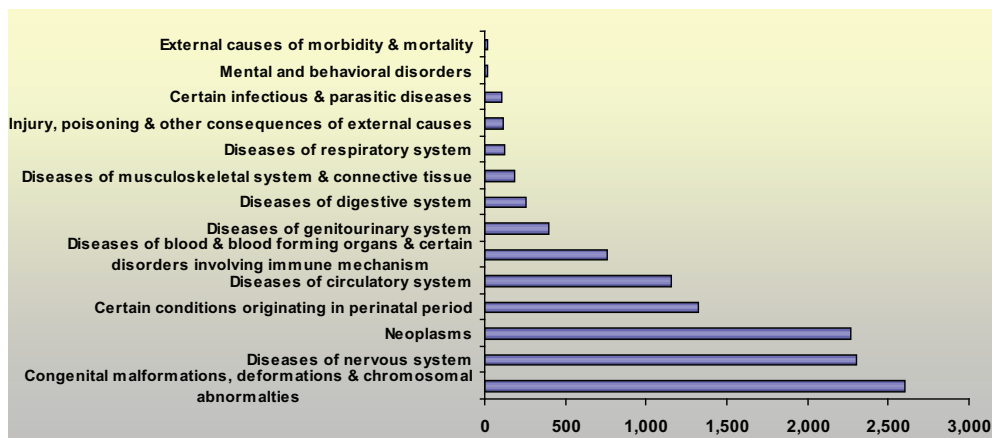


Fig. 2. Data from causes likely to require palliative care for ages 0-19, England 2001-05, excluding neonatal deaths (Department of Health, UK, 2007)

As for causes of death, in the UK 83% of the palliative care deaths in the neonatal period are from "conditions originating in the neonatal period". This group of conditions also accounts for 34% of the deaths in the 28 day to 1 year group. After the age of 1 year the most common causes of palliative care related death are congenital malformations, deformations and chromosomal abnormalities, neoplasm, and diseases of the nervous system. During the year

2001-6, 68% of palliative care related deaths in the 1-19 year age group took place in a hospital setting, 8% occurred in hospices and 22% occurred at home (NHS, 2011).

In the United States, in 1900, children 5 years of age or younger accounted for 30% of all deaths; in 1999, that number dropped to 1.4%. Despite this change, more than 50,000 children die every year, and more than 500,000 children suffer from life-threatening conditions in the US (Korones, 2007).

According to the American Academy of Pediatrics, 50% of pediatric deaths in the USA are one year of age or younger; most of these infants die from complications of prematurity, perinatal complications, or congenital abnormalities. The death of older children (1 to 19 years) is from accidents, homicide, or suicide. However, a minority of infants and children (approximately 10,000 a year) die from complex chronic conditions that encompass a broad spectrum of disorders such as neuromuscular disease, cardiac abnormalities, renal failure, metabolic abnormalities, chromosomal anomalies, blood disorders, and malignancies. Children who have complex chronic conditions are the primary potential beneficiaries of palliative care services (Korones, 2007).

#### **4. Needs of children**

Pediatric palliative care is based on the same principles as adult palliative care but also recognizes the unique needs of the children, the adolescents, and the families faced with a child's illness and death (Liben & Goldman, 1998; Pritchard et al., 2011).

**Physical needs:** Pain and other symptoms are common and should be managed in a timely and skilled manner. This requires that healthcare providers be knowledgeable with pharmacologic and non-pharmacologic treatments for pain, dyspnea, nausea, and vomiting and other symptoms (Himelstein et al., 2004; Wolfe et al., 2000). Planning ahead can reduce pain and other symptoms; providing the child with the adequate pain killers and using distraction or other forms of non-pharmacologic therapies before an invasive procedure can assist in reducing the stress and anxiety associated with the procedures (Mercadante, 2004).

**Psychological needs:** The developmental stage of children affects their emotional and spiritual needs. The use of non-verbal and expressive communication methods such as drawing pictures, writing stories, and playing music can help children express their anger, fears, hopes and dreams (Himelstein et al., 2004). Honest and open communication with the terminally ill child is very important; children need to have hope and need to trust the healthcare provider (Abu-Saad Huijjer, 2001; Hilden & Chrastek, 2000). Additionally, children need to feel safe in the environment they are in, and hence presence of a familiar person like a family member or a close friend, is of great assistance (Hynson & Sawyer, 2001).

**Social needs:** Children undergo a process of physical, emotional, cognitive and spiritual development. Religious and cultural beliefs, patterns of coping, disease experience, previous experience with loss and death, sadness, and other emotions associated with grief, all influence a child's understanding of death (Canadian Hospice Palliative Care Association, 2006). Additionally, children are members of many communities, including families, neighborhoods and schools. School is an integral part of their lives, and it is essential they

have ongoing opportunities to pursue their education. Their continuing role in these communities should be incorporated into their dying journey.

**Spiritual needs:** Spiritual support should be available if and when requested taking into consideration the religious and cultural background of the family.

Special attention is given to the needs of adolescents and young adults who require palliative care (Pritchard et al., 2011). The emotional and social needs of this population are complex and vary significantly, depending on the level of maturity of the patients and the extent to which they have made the transition from complete dependence on parents and family to independence. Newly gained independence can be lost with severe illness and the patients again find themselves dependent on their parents for physical, financial, and emotional needs. In addition, peer involvement and support are vital in this period of life especially because adolescents feel isolated from their social surroundings and friends while on treatment and whenever they are being hospitalized. Social support is often provided by other adolescents and young adults of a similar age group being treated for cancer and receiving palliative care (Pritchard et al., 2011).

## **5. Needs of family**

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. Family members may include biological, marital, adoptive, and custodial families (Canadian Hospice Palliative Care Association, 2006).

Parents of children with life threatening illnesses become healthcare provider, mental health counselor, spiritual counselor, home health aide, in addition to being parent, spouse and employee. They perform roles for which they receive little or no training and no payment, in order to avoid institutionalizing their child. They bear heavy responsibilities which may include making decisions in the best interest of the child at a time when they are highly stressed and grieving the loss of their child's health (Goldman, 1998; Hinds et al., 2005; Hynson et al., 2003; National Hospice and Palliative Care Organization, 2001).

The needs of the family can be categorized as follows (Texas Children's Cancer Center, 2000):

**Educational needs:** preparation and education that is specific to the unique needs and concerns of family members in various aspects of care provides a sense of competence and ease during a frightening transition.

**Emotional needs:** anticipatory grief and guilt can be addressed by social workers, support groups, and counselors. Relationships between couples and among families might weaken due to the increased stress and tension; encouraging individual family members to seek support outside the family circle can ease this burden.

**Religious and spiritual needs:** resources such as chaplain, other spiritual leaders, or social worker may be of help to the child and family who seek spiritual comfort. They can offer support by learning to be comfortable with death, listening to the family, and performing small acts of kindness.

Financial needs: changes in lifestyle can affect employment status and the financial security of the family. An examination of the economic resources available to the family, coupled with early planning, can help families manage finances.

In a study following up the needs of families of children who died from cancer (Monterosso, Kristjanson, & Phillips, 2009), parents reported the need for clear and honest information about their child's condition and prognosis throughout the trajectory of illness. Parents also requested access to, and advice from, multidisciplinary health professionals when caring for their child at home. Parents verbalized their preference to care for their child at home wherever possible and reported being well supported by immediate and extended family and friends.

## 6. Needs of siblings

Siblings of chronically ill, dying children are at risk of becoming forgotten. They feel isolated because the priorities of the parents shift to the care of the sick child, and their own needs are not considered as priority. They are at high risk for school problems, problems with parent-child relationships, and other psychological and social problems following their siblings' deaths.

Siblings have unique needs during and after a child's death (Lauer et al., 1985). Grief for a child is a process that might take time to resolve; it can last weeks to months. Grief can be manifested differently in children: shock and numbness, anger, guilt, disobedience, temporary regression, and believing deceased is still alive. One should be aware of this range of manifestations in order to intervene and help the grieving sibling accordingly (Table 1) (American Academy of Pediatrics, 2000; Texas Children's Cancer Center, 2000).

Siblings of children who die at home cope better with the loss than children whose siblings die in the hospital. At home, they are more likely to know what is going on, to take part in the care, and to be present at the time of death. In the months and years following the death, they are more comfortable with what happened and have better relationships with parents and friends (American Academy of Pediatrics, 2000; Texas Children's Cancer Center, 2000; Lauer et al., 1985).

|  |
|--|
| <ul style="list-style-type: none"> <li>Siblings should be included in discussions of care from the time of diagnosis, through death of the child, and beyond.</li> </ul> |
| <ul style="list-style-type: none"> <li>"Protecting" siblings by excluding them may cause long-term harm.</li> </ul>  |
| <ul style="list-style-type: none"> <li>Siblings should be included in discussions about end-of- life care.</li> </ul>  |
| <ul style="list-style-type: none"> <li>Siblings should be included in funeral planning.</li> </ul>   |
| <ul style="list-style-type: none"> <li>Certain resources should be made available to support siblings through their grief and bereavement.</li> </ul>                    |

Table 1. Guidelines for Assistance to Siblings of Children Who Have Cancer (Korones, 2007; Spinetta, 1999)

## 7. Effectiveness of pediatric palliative care

When comparing the availability of palliative care services for children with cancer in economically diverse regions of the world, low income countries were most likely to report self-payment for oncologists, palliative care services, and symptom management medications. Availability of specialized palliative care services, pain management, bereavement care, high-potency opioids and adjuvant drugs was significantly less likely in low income countries. Physicians in low income countries were significantly less likely than others to report high-quality symptom management, emotional support, bereavement support, interdisciplinary care, and parental participation in decisions (Delgado et al., 2010).

### 7.1 Symptom assessment and management

Children dying in the hospital suffer from many symptoms that are often distressing. In the last week of life, symptom prevalence increases and some symptoms like lack of energy, drowsiness, skin changes, irritability, pain, and edema of the extremities occur in 50% or more of children (Saad et al., 2011; Drake, 2003).

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 (Collins et al., 2000; Hongo et al., 2003; Saad et al 2011; Wolfe et al., 2000). Overall, the majority of children (Fig. 3) experience a great deal of suffering from at least one symptom (Saad et al 2011).

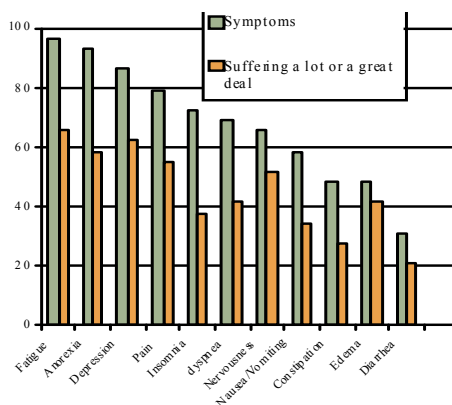


Fig. 3. Symptoms and their burden (Saad, Abu-Saad Huijer, Nouredine, Muwakkit, Saab, & Abboud, 2011)

Although pain is a major symptom in pediatric palliative care (Breau et al., 2003; Wolfe et al., 2000), pain assessment, pain management, and post-intervention reassessment are underreported in the medical charts by both physicians and nurses (Carter et al., 2004). Symptoms can be controlled if clinical guidelines including effective drug treatment combined with practical, cognitive, behavioural, physical and supportive therapies are followed (Canadian Hospice Palliative Care Association, 2006; Charlton, 2005; Korones, 2007; Selove et al., 2006; Texas Cancer Council, 1999).



## 7.2 Communication and information-giving

Informative, effective communication between health care providers, the child, and the family is critical when addressing end-of-life issues. In a study conducted by Saad et al. (2011), lack of communication was seen by parents as a barrier to effective and holistic care. The main concerns raised by the parents were: accessibility to healthcare services & empathy and acceptance of parents' situation and behaviors by the healthcare team. Providing parents with the information they desire in order to participate in informed decision-making should be a primary goal. Compassionate delivery of distressing news to the parents is an important step in facilitating adjustment. Parents can maintain a sense of hope for their child's survival even after being told that their child's death is certain (Hinds et al., 2005).

The child's right to be informed about his or her illness, available treatment options, clinical trials and their potential benefits, risks and burdens depends on the child's stage of development (Canadian Hospice Palliative Care Association, 2006). Parents determine how, when, and what information is shared with the child, with the guidance of professionals, taking into account the child's temperament, cognitive abilities, developmental level, and cultural beliefs and values (Canadian Hospice Palliative Care Association, 2006).

Parents have the right to know about the child's disease condition, available treatment options, and their potential benefits, risks and burdens, and palliative care. They have the right to make decisions about all treatments including the right to withhold treatment, and to determine goals for care (Canadian Hospice Palliative Care Association, 2006). In lower income countries, where poverty, limited resources, cultural norms and the absence of laws safeguarding self-determination are present, parents were seen to participate less in decisions regarding their child's care than in higher income countries (Delgado et al., 2010).

Language and cultural differences create barriers to information-sharing by healthcare providers to parents who are in need of pediatric palliative care. Inadequate information sharing contributes to frustration, anger, and sadness for parents long after their child's death. Therefore, healthcare providers are in a very critical position when providing information to parents from a diverse cultural background and need to be very sensitive to this issue (Davies et al., 2010).

## 8. Pediatric palliative care services

The needs of each family are unique and change over time; therefore a spectrum of services is needed in order to provide flexible care (ACT, Royal College of Pediatrics and Child Health, 2007):

- A locally based palliative care service led by a pediatrician or other appropriate senior professional and including a multidisciplinary network.
- Access to a children's hospice for short term respite, terminal and emergency care and bereavement support.
- Training, information, and psychological support for all carers (health carers, social workers, volunteers, family members).
- Specialists/tertiary hospital services (diagnosis, treatment, clinical management, and specialist palliative care services).
- District hospital services (inpatient and outpatient services for symptom management).

- Short term breaks or respite care services
- Medications, medical equipments, and supplies.
- Bereavement support services.
- Specialist palliative care support services

Providing care to children using community services is more cost effective than allowing children to spend inappropriate time in hospitals. Community services can manage for example children with cystic fibrosis who require intensive courses of antibiotics to be treated at home rather than in the hospital. Similarly, children who need long-term intravenous nutrition or tube feedings can be managed more effectively at home (York Health Economics Consortium/Department of Health Independent Review Team, 2007).

Bereavement services are provided for parents who have lost a child and for children who have lost a sibling (Rolls & Payne, 2003). Despite the growing evidence that families would prefer their children to die at home (Collins, 1998; Hannan & Gibson, 2005; Himmelstein, 2006; Vickers & Carlisle, 2000), for the last decade, most children used to die in hospital. Recently, a new study published in the UK reported that similar proportions of children are dying at home (45%) and in hospital (47%), and the percentage dying in a hospice or care home has increased from 2% to 10% between 1996 and 2006 (Shah et al., 2011).

Deciding on the place of care and place of death for children is difficult and depends on several factors (Hearn & Higginson, 1998):

- Families value time left with children and therefore want their child to remain at home, in part to retain normality, but also because it is what the child often wants.
- Families want to feel safe and secure, having control but also wanting support. This leads some families to choose hospital in the absence of good community support.
- Families do not know what to expect, knowing how long a child will live is important. Having a child living longer than expected is emotionally and physically problematic, and conversely if the child dies sooner the family feels cheated of time spent with child.
- Specialist services are known to differ from conventional care (Department of Health and Children, the Irish Hospice Foundation, 2005). Specialist teams improve satisfaction by managing patient and family needs at home, improving symptom control, reducing hospitalization, and decreasing overall costs.

## 9. Ethical issues

Ethical issues about care for infants and children with life-limiting or life-threatening conditions have mainly focused on decisions (Institute of Medicine of the National Academics, 2003).

Decisions about who decides: Parents have the legal right to make decisions about medical care for the child but this does not mean that parents and physicians should exclude children from decisions about their care. Decisions may be constrained by culture, organizational or governmental policies, and environmental factors.

Decisions about treatment: Stopping versus not starting treatment: most physicians and ethicists consider these two options as the same. It is important for those deciding such interventions to be extremely knowledgeable about all clinical aspects that are in the best interest of the child.

Life-sustaining treatments: examples include cardiopulmonary resuscitation, mechanical ventilation, mechanical provision of nutrients or fluids, blood transfusions, antibiotics, and dialysis. It is now generally accepted by physicians, ethicists, policymakers, and the public that abstaining from life-sustaining treatment is appropriate when death is near.

Decisions about the criteria for decisions: a major goal of palliative care is to enhance the quality of life of the child, and not only to prolong it. When taking decisions in the course of care, parents and physicians should identify and weigh the potential benefits and burdens and their influence on the quality of life. As health care costs have increased in the past decades, disagreements often rise about the provision of services that are not beneficial. Consensus in the clinical field has been that resources should not enter the physicians' judgments about patient care unless supported by available scientific knowledge.

Not all conflicts can be avoided but it depends on the way they are handled can increase or decrease the potential for damage. Developing evidence-based and consensus based guidelines, improving communication skills and sensitivity to cultural differences, and developing organizational policies and procedures are possible strategies to deal with conflicts.

## **10. Pediatric palliative care solutions**

### **10.1 Holistic and family-centered care**

Palliative care for children is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement. Pediatric palliative care is a holistic approach, and as such enhancing the quality of life needs to be family-directed and should serve as the guiding principle in determining the plan of care throughout the illness.

### **10.2 Place of care**

"Children, during the trajectory of illness from diagnosis to end of life care and bereavement support for their families, require care from different services. Acute care may be provided by inpatient hospital services, whilst ongoing support may be provided by community teams. Respite care may be provided by hospices, whilst end of life care may be provided by hospices, hospitals or community teams in the families' own homes" (Hynson & Sawyer, 2001). Palliative care for children has a combined hospital, hospice and community focus for care delivery.

Home is the preferred place for care during the illness trajectory and more specifically during the end-of-life period and it has been verbalized by children and their families (Monterosso, Kristjanson, & Phillips, 2009; van de Wetering, & Schouten-van Meeteren, 2011). In the UK, the number of children provided with palliative care at home and eventually dying at home is increasing gradually (Shah et al., 2011).

### **10.3 Care coordination and management**

Since no one person can provide all necessary support for the child and family, palliative care is best provided using an integrated interdisciplinary approach. The provision of

palliative care for children involves coordination between the child, family, teachers, school staff, and health care professionals including nurses, primary care physicians, social workers, chaplains, bereavement counselors, and consultants (American Academy of Pediatrics, 2000).

The following has been recommended as a core standard concerning the care coordinator on the palliative care team (European Association of Palliative Care (EAPC) Taskforce, 2007): One professional from the palliative care team must be identified as the family's care coordinator or key worker. The care coordinator will help the family to build and maintain an appropriate support system of professionals so the family will be ensured access to social services, practical support (including appropriate aids and home adaptations), spiritual and respite care. The care coordinator will act as the main link, providing continuity, ensuring that the care provided is consistent with the needs of the child and family.

Since chronically ill children are often cared for by a number of healthcare providers and across a variety of settings, including clinics, inpatient units, home and school, the absence of clinical leadership and effective interdisciplinary communication across care settings may cause conflicting therapeutic goals among providers, placing unnecessary burdens on the children and their families (Department of Health and Children, the Irish Hospice Foundation, 2005; National Hospice and Palliative Care Organization, 2001; Wolfe et al., 2000).

#### **10.4 Respite care**

Respite 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, enabling time off from the exhausting 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 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, licensed foster parent respite care or medical daycare programs" (National Hospice and Palliative Care Organization, 2001). Respite for family carers and the child is essential, whether for few hours or a few days; it should be possible to provide respite care in the family home and away from home (European Association of Palliative Care (EAPC) Taskforce, 2007).

#### **10.5 Caregiver support**

Health care professionals must be supported by the palliative care team, their colleagues, and institutions in dealing with the child's dying process and death. Institutional support may include paid funeral leave, routine counseling with a trained peer or psychologist, and regularly scheduled remembrance ceremonies or other interventions such as inviting bereaved families to return and celebrate with staff the deceased child's life (American Academy of Pediatrics, 2000).

The following are some guiding principles and norms of practice for caregivers support (Groot et al., 2005):

Formal and informal caregivers' physical, psychological, and spiritual well-being should be integral to the provision of pediatric palliative care. Ongoing programs should be in place to

address employee issues and improve work life satisfaction. The institution should work to identify and minimize occupational risks and stresses. Formal caregivers should have access to ongoing support, including grief and bereavement support. Formal caregivers should have the opportunity to reflect on their own comfort and ability to enter into difficult conversations with children and families.

### **10.6 Education and training of health care professionals**

Studies evaluating the knowledge and understanding of physicians and nurses regarding palliative care in several countries, whether developed or developing, depicted lack of knowledge and skills in that area and were considered as barriers to daily practice (Abu-Saad Huijjer & Dimassi, 2007; Amery et al., 2010; Groot et al., 2005; Raudonis et al., 2002; Rogers et al., 2011; Walker & MacLeod, 2005). Lack of knowledge was mainly seen in pain and symptom management, referring patients to palliative care services, and talking to dying children and their families (Abu-Saad Huijjer, 2006; Abu-Saad Huijjer & Dimassi, 2007; Feudtner et al., 2007; Groot et al., 2005; Raudonis et al., 2002; Walker & MacLeod, 2005). This lack of knowledge is attributed to the absence of formal education and training in palliative care (Abu-Saad Huijjer & Dimassi, 2007; Barclay et al., 2003; Rogers et al., 2011). Improvement in the knowledge and attitudes of nurses and physicians towards palliative care after educational interventions have been reported in several studies (Cramer et al., 2003; Duong & Zulian, 2006; Ersek et al., 2005; Fischer et al., 2003) and several others stressed the importance of integrating palliative care in undergraduate curricula (Ury et al., 2000). A study conducted recently in Lebanon recommended that pediatric palliative care would be improved with the implementation of structured educational programs for the staff, especially symptom management and communication, improvement of psychological, social and spiritual support for families with a seriously ill child (Saad, Abu-Saad Huijjer, Nouredine, Muwakkit, Saab, & Abboud, 2011).

The following recommendations are made regarding the education and training of health care professionals including nurses (Wolfe et al., 2000): Appropriate faculty expertise, time and resources must be mandated to address pediatric palliative care issues. Pediatric residency and subspecialty fellowship programs must incorporate pediatric specific palliative care information. Continuing education programs and certification is needed to make pediatric palliative care more available and accessible. Training in pediatric palliative care for home care and hospice workers, parents, and volunteers must be provided to enable competent care for children living with life threatening conditions, particularly in the terminal phase. Finally, counselors, psychologists, school teachers and officials need training to effectively accommodate the needs of terminally ill children and their classmates.

### **10.7 Public education**

A survey conducted in Scotland (Scottish Partnership for Palliative Care, 2003) on public awareness of palliative care in general showed the majority of respondents reporting some knowledge of palliative care, with 32% reporting no knowledge and 3% high levels of knowledge. Almost 90% felt palliative care should be offered to all those with terminal illnesses, with cancer ranking top on the list. Twenty percent preferred staying at home as long as possible, 10% had a preference for hospitals and the majority favored hospice care. The majority would like to see issues of death and dying more openly addressed and information about palliative care services more generally available.

Public education is one area in palliative care that has not received adequate attention. The public needs to be educated regarding the services provided, treatment modalities, and that pain and other symptoms can be adequately treated and relieved. These issues create challenges for palliative care that should be taken seriously (Abu-Saad Huijjer, 2001).

## 11. Conclusion

In conclusion, the number of children needing palliative care is small and geographically spread over large areas. The duration of care can be prolonged and is difficult to predict. Children have complex palliative care needs that require the interventions of an expert multi-disciplinary team. Pediatric palliative care services must be an integral part of community health services. Home care improves the quality of life of the child and family provided skilled support and assistance are available. Hospital-based palliative care does not always offer the best solutions for the child and family. Education and training of health care professionals in pediatric palliative care is insufficient.

A considerable body of evidence shows that children, adolescents and young people suffer unnecessarily due to underassessment and undertreatment of their problems and due to lack of palliative care services to meet their needs. Children experience a multitude of unique problems and disabilities and as such require a family-centred approach to treatment and care. The predominant focus of the existing palliative care services in this age group is still on cancer; children with other life-threatening conditions are left out.

There is a misperception among healthcare professionals, legislators, administrators and the general public that palliative care is only of use when all curative efforts have been exhausted and that it is mutually exclusive with life-prolonging care. Very few practitioners are experienced in guiding decision-making or in caring for dying children and their families. Variation in the cognitive, emotional and social development of the child affects communication and decisional capacities. Determining the best interests of a child is as a result difficult for families and professionals.

Societies do not expect children to die. Families often believe medicine can currently or imminently cure all diseases. Death is inherently a social/community event, not a medical event. At the present time, it is placed in the hands of a medical community ill-prepared to meet these unique needs, particularly for children, who frequently die in the hospital. Poor communication, guilt, and societal expectations, often force children to endure therapies that adults, given the choice, reject for themselves. Families willing to forgo life-prolonging therapy are at risk of being accused of not caring about their child.

There is a huge disparity in Western countries in resource allocation for research, favoring "cure oriented" acute care interventions over palliative care. Adequate funding for research in pediatric palliative care must be allocated. Only then will children and families be assured that they are receiving proven therapies. Outcome measures relevant to the child and family must be developed. Research applied to children must be derived from children and their families. Research should build on evidence that already exists, be innovative, and fill existing gaps in knowledge and applied practice (National Hospice and Palliative Care Organization; 2001).

The conduct of research in palliative care or end-of-life care, and the recruitment of participants remain a major challenge (Tomlinson et al., 2007). The potential that the child is

unaware that he/she is dying, and the possibility that parents have not yet come to terms with the inevitability of their child's death are some of the prevailing reasons. The ethical issues around pediatric palliative care and end-of-life research are significant; researchers must consider and address all the challenges in order to eliminate potentially preventable emotional burden on the child and the parents.

## 12. References

- Abu-Saad Huijjer, H. (2001). *Evidence-based palliative care, across the life span*. London: Blackwell Science.
- Abu-Saad Huijjer, H. (2006). Palliative care: Views of patients, home carers, and health professionals. *Supportive Palliative and Cancer Care*, Vol. 3, pp. 97-103.
- Abu-Saad Huijjer, H., & Dimassi, H. (2007). Palliative Care in Lebanon; knowledge, attitudes, and practices of physicians and nurses. *Lebanese Medical Journal*, Vol.55, pp. 121-128.
- ACT, Royal College of Pediatrics and Child Health. Children palliative care services. A guide to the development of children's palliative care services, Second Edition. 2003.
- Aldrich, L.M. (1995). Sudden death: crisis in the school. *Thanatos Magazine*; Fall.
- American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health (2000). The pediatrician and childhood bereavement. *Pediatrics*, Vol.105, No.2, pp. 445-447, ISSN 0031 4005.
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care (2000). Palliative Care for Children. *Pediatrics*, Vol.106, No.2, pp. 351-357.
- Amery, M.J., Rose, C.J., Byarugaba, C., & Agupio, G. (2010). A Study into the Children's Palliative Care Educational Needs of Health Professionals in Uganda. *Journal of Palliative Medicine*; Vol.13, No.2, pp. 147-153.
- Barclay, S., Wyatt, P., Shore, S., Finlay, L., Grande, G., & Todd, C. (2003). Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales. *Palliative Medicine*, Vol.17, pp. 27-39.
- Breau, L.M., Camfield, C.S., McGrath, P.J., & Finley, G.A. (2003). The incidence of pain in children with severe cognitive impairments. *Archives of Pediatrics & Adolescent Medicine*, Vol.157, No.12, pp. 1219-1226.
- Canadian Hospice Palliative Care Association, 2006. Pediatric Hospice Palliative Care, Guiding Principles and Norms of Practice. Retrieved October 10, 2007 from [http://www.chpca.net/marketplace/pediatric\\_norms/Pediatric\\_Norms\\_of\\_PracticeMarch\\_31\\_2006\\_English.pdf](http://www.chpca.net/marketplace/pediatric_norms/Pediatric_Norms_of_PracticeMarch_31_2006_English.pdf)
- Carter, B.S., Howenstein, M., Gilmer, M.J., Throop, P., France, D., & Whitlock, J.A. (2004). Circumstances Surrounding the Deaths of Hospitalized Children: Opportunities for Pediatric Palliative Care. *Pediatrics*. Vol.114, No.3, pp. e361-e366, ISSN 0031 4005.
- Charlton, J.E. (Ed). (2005) *Core Curriculum for Professional Education in Pain* (3rd edition), IASP Task Force on Professional Education, IASP Publications, Seattle.
- Collins, J.J., Byrnes, M.E., Dunkel, I.J., Lapin, J., Nadel, T., Thaler, H.T., Emanuel, E.J., & Weeks, J.C. (2000). The measurement of symptoms in children with cancer. *Journal of Pain and Symptom Management*, Vol.19, No.5, pp. 363-377.
- Collins, J.J., Stevens, M.M. and Cousens, P. (1998) Home care for the dying child, *Australian Family Physician*, Vol.27, No.7, pp. 610-614.

- Cramer, L.D., McCorkle, R., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E.H. (2003). Nurses' attitudes and practice related to hospice care. *Journal of Nursing Scholarship*, Vol.25, pp. 249-255.
- Davies, B., Contro, N., Larson, J., & Widger, K. (2010). Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics*, Vol.125, No.4, pp. e859-e865, ISSN: 1098-4275
- Delgado, E., Barfield R.C., Baker, J.N., Hinds, P.S., Yang, J., Nambayan, A., Quintana, Y., Kane, J.R. (2010). Availability of palliative care services for children with cancer in economically diverse regions of the world. *European Journal of Cancer*, Vol.46, pp. 2260-2266.
- Department of Health (Editor): Palliative Care Statistics for Children and Young Adults. Health and Care Partnerships Analysis. Cochrane, H., Liyanage, S., Nantambi, R. 2007 (a). Retrieved October 22, 2007 from [http://www.dh.gov.uk/prod\\_consum\\_dh/idcplg?IdcService=GET\\_FILE&dID=140063&Rendition=Web](http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=140063&Rendition=Web)
- Department of Health and Children, the Irish Hospice Foundation (Editor): A Palliative Care Needs Assessment for Children (2005). Retrieved October 22, 2007 from [http://www.dohc.ie/publications/needs\\_assessment\\_palliative.html](http://www.dohc.ie/publications/needs_assessment_palliative.html)
- Drake, R., Frost, J., & Collins, J.J. (2003). The symptoms of the dying children. *Journal of Pain and Symptom Management*, Vol.26, No.1, pp. 594-603.
- Duong, P.H., & Zulian, G.B. (2006). Impact of a postgraduate six-month rotation in palliative care on knowledge and attitudes of junior residents. *Palliative Medicine*, Vol.20, pp. 551-556.
- Ersek, M., Grant, M.M., & Kraybill, B.M. (2005). Enhancing end-of-life care in nursing homes: Palliative Care Educational Resource Team (PERT) program. *Journal of Palliative Medicine*, Vol.8, pp. 556-566.
- European Association of Palliative Care (EAPC) Taskforce (2007). IMPaCCT: standards for paediatric palliative care in Europe. *European Journal of Palliative Care*, Vol.14, pp. 2-7.
- Feudtner, C., Kang, T.I., Hexem, K.R., Friedrichsdorf, S.J., Osenga, K., Siden, H., Friebert, S.E., Hays, R.M., Dussel, V., Wolfe, J. (2011). Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study. *Pediatrics*, Vol.127, pp. 1094-1101
- Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rourke, M.T., & Kang, T.I. (2007). Hopeful thinking and level of comfort regarding providing pediatric palliative care: A survey of hospital nurses. *Pediatrics*, Vol.119, No.1, pp. e186-e192, ISSN: 1098-4275.
- Fischer, S.M., Gozansky, W.S., Kutner, J.S., Chomiak, A., & Kramer, A. (2003). Palliative care education: An intervention to improve medical residents' knowledge and attitudes. *Journal of Palliative Medicine*, Vol.6, No.3, pp. 391-399.
- Goldman, A. (1998). ABC of palliative care: Special problems of children. *British Medical Journal*, Vol.316, No.7124, pp. 49-52.
- Groot, M.M., Vernooij-Dassen, M.J.F.J., Crul, B.J.P., & Grol, R.P.T.M. (2005). General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliative Medicine*, Vol.19, pp. 111-118.
- Gwyther, L., & Cohen, J. (2009). Introduction to Palliative Care, In: *Legal Aspects of Palliative Care*, Hospice palliative Care Association of South Africa, pp. 2-6. Retrieved from [http://www.osf.org.za/File\\_Uploads/docs/Legal\\_Aspects\\_of\\_Palliative\\_Care-Entire\\_book.pdf](http://www.osf.org.za/File_Uploads/docs/Legal_Aspects_of_Palliative_Care-Entire_book.pdf)



- Hannan, J., & Gibson, F. (2005). Advanced cancer in children: how parents decide on final place of care for their dying child. *Health and Social Care in the Community*, Vol.13, No.5, pp. 441-450.
- Hearn, J., & Higginson, I. (1998). Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine*, Vol.12, pp. 317-332.
- Hilden, J.M., & Chrastek, J. (2000). Tell the children. *Journal of Clinical Oncology*, Vol.18, No.17, pp. 3193-3195.
- Himmelstein, B.P. (2006) Palliative Care for Infants, Children, Adolescents and their Families, *Journal of Palliative Medicine*, Vol.9, No.6, pp.163-181.
- Himmelstein, B.P., Hilden, J.M., Boldt, A.M., & Weissman, D. (2004). Pediatric palliative care. *New England Journal of Medicine*, Vol.350, No.17, pp. 1752-1762.
- Hinds, P.S., Schum, L., Baker, J.N., & Wolfe, J. (2005). Key factors affecting dying children and their families. *Journal of Palliative Medicine*, Vol.8, S.1, pp. S70-S78.
- Hongo, T., Watanabe, C., Okada, S., Inoue, N., Yajima, S., Fujii, Y., & Ohzeki, T. (2003). Analysis of the circumstances at the end of life in children with cancer: Symptoms, suffering, and acceptance. *Pediatrics International*, Vol.45, No.1, pp. 60-64.
- Hynson, J.L., Gillis, J., Collins, J.J., Irving, H., & Trethewie, S.J. (2003). The dying child: how is care different? *Medical Journal of Australia*, Vol.179, pp. S20-S22.
- Hynson, J.L., & Sawyer, S.M. (2001). Pediatric palliative care: Distinctive needs and emerging issues. *Journal of Pediatrics and Child Health*, Vol.37, pp. 323-325.
- Institute of Medicine of the National Academics (2003). Ethical and legal issues. In *When children die. Improving palliative and end-of-life care for children and their families* (pp.293-327). The National Academy Press: Washington.
- Korones, D.N. (2007). Pediatric palliative care. *Paediatrics Review*, Vol.28, pp. e46-e56, ISSN: 1526-3347.
- Lauer, M.E., Mulhern, R.K., Bohne, J.B., & Camitta, B.M. (1985). Children's perceptions of their sibling's death at home or hospital: the precursors of differential adjustment. *Cancer Nursing*, Vol.8, No.1, pp. 21-27.
- Liben, S., & Goldman, A. (1998). Home care for children with life-threatening illness. *Journal of Palliative Care*, Vol.14, No.3, pp. 33-8.
- Mercadante, S. (2004). Cancer pain management in children. *Palliative Medicine*, Vol.18, pp. 654-662.
- Monterosso, L., Kristjanson, L.J., & Phillips, M.B. (2009). The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine*, Vol.23, pp. 526-536.
- National Hospice and Palliative Care Organization; 2001. *A Call for Change: Recommendations to Improve the Care of Children Living with Life Threatening Conditions*. Alexandria, VA: Retrieved November 26, 2007 from [www.nhpco.org/files/public/ChIPPSCallforChange.pdf](http://www.nhpco.org/files/public/ChIPPSCallforChange.pdf)
- NHS East of England (March 2011). Better care, better lives: Achieving the vision for the palliative care of children & young people in the east of England. Retrieved June 03, 2011 from [http://www.eoe.nhs.uk/page.php?page\\_id=2073](http://www.eoe.nhs.uk/page.php?page_id=2073)
- Pritchard, S., Cuvelier, G., Harlos, M., & Barr, B. (2011). Palliative care in adolescents and young adults with cancer. *Cancer*, Vol.117, No.10 suppl, pp. 2323-8.
- Raudonis, B.M., Kyba, F.C.N., & Kinsey, T.A. (2002). Long-term care nurses' knowledge of end-of-life care. *Geriatric Nursing*, Vol.23, pp. 296-301.
- Rogers, S.K., Gomez, C.F., Carpenter, P., Farley, J., Holson, D., Markowitz, M., Rood, B., Smith, K., & Nigra, P. (2011). Quality of life for children with life-limiting and life-

- threatening illnesses: Description and evaluation of a regional, collaborative model for pediatric palliative care. *American Journal of Hospice and Palliative Medicine*, Vol.28, No.3, pp. 161-170
- Saad, R. Abu-Saad Huijer, H. Nouredine, S. Muwakkit, S. Saab, R. Abboud, MR. (2011). Bereaved Parents' Evaluation of the Quality of a Palliative Care Program in Lebanon. *Pediatric Blood & Cancer*, Vol.28, No.3, pp.161-170 Scottish Partnership for Palliative Care (2003). Public Awareness of Palliative Care. Retrieved November 28, 2007 from <http://www.palliativecarescotland.org.uk/publications/aware.pdf>
- Selove, R., Cochran, D., & Todd Cohen, I. (2006). End-of-life pain management in children and adolescents. In The Hospice Foundation of America, *Pain management at end-of-life: Bridging the gap between knowledge and practice*. Retrieved July 3, 2008 from <http://www.hospicefoundation.org/teleconference/books/lwg2006/selove.pdf>
- Shah, A., Diggins, N., Stiller, C., Murphy, D., Passmore, J., & Murphy, M.F.G. (2011). Place of death and hospital care for children who died of cancer in England, 1999–2006. *European Journal of Cancer*, in press.
- Spinetta, J.J., Jankovic, M., Eden, T., et al. (1999). 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*, Vol. 33, pp. 395–398
- Texas Cancer Council (1999). Pain Management in Children with Cancer. Retrieved on November 10, 2007 from <http://www.childcancerpain.org/>
- Texas Children's Cancer Center, Texas Children's Hospital. (2000). End-of-Life Care for Children. The Texas Cancer Council.
- Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., Wrathall, G., & Sung, L. (2007). Challenges to participation in pediatric palliative care research: a review of the literature. *Palliative Medicine*, Vol.21, pp. 435-440.
- Ury, W.A., Reznich, C.B., & Weber, C.M. (2000). A needs assessment for palliative care curriculum. *Journal of Pain and Symptom Management*, Vol.20, No.6, pp. 408-416.
- van de Wetering, M.D., & Schouten-van Meeteren, N.Y.N. (2011). Supportive care for children with cancer. *Seminars in Oncology*, Vol.38, No.3, pp. 374-379.
- Vickers, J.L. and Carlisle, C. (2000) Choices and control: parental experiences in pediatric terminal home care, *Journal of Pediatric Oncology Nursing*, Vol.17, No.1, 12-21.
- Walker, S., & MacLeod, R. (2005). Palliative care knowledge of some South Island GPs. *New Zealand Family Physician*, Vol.32, No.2, pp. 88-93.
- Wolfe, J., Grier, H.E., Klar, N., Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S., Emanuel, E.J., & Weeks, J.C. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine*, Vol.342, No.5, pp. 326-333.
- World Health Organization, (1998). Cancer Pain Relief and Palliative Care in Children. Geneva, WHO.
- York Health Economics Consortium/Department of Health Independent Review Team: Independent Review of Palliative Care Services for Children and Young People: Economic Study. Final Report (2007). Retrieved November 15, 2007 from: <http://www.york.ac.uk/inst/yhec/downloads/Final%20Report-may07v1.pdf>



## **Contemporary and Innovative Practice in Palliative Care**

Edited by Prof. Esther Chang

ISBN 978-953-307-986-8

Hard cover, 302 pages

**Publisher** InTech

**Published online** 10, February, 2012

**Published in print edition** February, 2012

This book is designed to provide a comprehensive insight into the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

### **How to reference**

In order to correctly reference this scholarly work, feel free to copy and paste the following:

Huda Abu-Saad Huijer (2012). Palliative Care in Children, Contemporary and Innovative Practice in Palliative Care, Prof. Esther Chang (Ed.), ISBN: 978-953-307-986-8, InTech, Available from:

<http://www.intechopen.com/books/contemporary-and-innovative-practice-in-palliative-care/palliative-care-in-children>

**INTECH**  
open science | open minds

### **InTech Europe**

University Campus STeP Ri  
Slavka Krautzeka 83/A  
51000 Rijeka, Croatia  
Phone: +385 (51) 770 447  
Fax: +385 (51) 686 166  
[www.intechopen.com](http://www.intechopen.com)

### **InTech China**

Unit 405, Office Block, Hotel Equatorial Shanghai  
No.65, Yan An Road (West), Shanghai, 200040, China  
中国上海市延安西路65号上海国际贵都大饭店办公楼405单元  
Phone: +86-21-62489820  
Fax: +86-21-62489821

© 2012 The Author(s). Licensee IntechOpen. This is an open access article distributed under the terms of the [Creative Commons Attribution 3.0 License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.