



Pediatric Palliative Care: Where We Stand

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Introduction

Palliative care is a philosophy of care that has evolved from the hospice philosophy to a holistic approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. It not only aims at providing relief from sufferings, treatment of pain and other distressing symptoms, but also integrates the psychological and spiritual aspects of patient care. Palliative care for children represents a special, closely related, field to adult palliative care. The international literature indicates a prevalence of incurable disease annually affecting 10/10,000 young people from 0 to 19 years old, with an annual mortality rate of 1/10,000 young people from birth to 17 years old. [1] Global Atlas of Palliative Care at the End of Life [2], estimated that 6% of the global need for palliative care (based on mortality figures) is in children i.e. 12 million children or 63 children out of every 100,000 will require Palliative Care at the end of life. As the needs of children are quite unique and different from those of adults receiving palliative care, Pediatric palliative care has emerged as a specialized medical care which aims at addressing these complex issues related to the care of children and families facing chronic life limiting and life threatening illnesses.

What is pediatric Palliative Care?

The WHO defines pediatric palliative care as follows; (WHO; 1998a): [2]

- **Palliative care for children is 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.

The above definition stresses on the importance of 'total care' that is based on medical, psycho-social, spiritual and economic needs of patients and their families, implemented throughout the illness course, from the point of diagnosis to bereavement, involves all aspects of the health care system, from hospital to hospice, to community, to home and is provided through an interdisciplinary team of caregivers.

Difference from Adult Palliative Care

The timescale of childhood illness is generally different from adults; palliative care may last only a few days, weeks or months for life threatening illnesses or may be delivered on and off for a number of years for certain life limiting illnesses.

- Young children are unable to self-report their problems; Preverbal patients cannot communicate their pain the standard, subjective manner. This inability to express and quantify their pain places preverbal children at (risk) for inconsistent identification of pain and inadequate pain relief. [4] Therefore assessment of pain and other, physical symptoms is a critical issue in Pediatric palliative care.
- Pediatric Palliative care extends to embrace the whole family. Family members, especially parents and siblings, may face tremendous stress as they go through changes in life that the child's diagnosis creates, and as they anticipate bereavement.
- Parents legally represent their offspring in all clinical, therapeutic, ethical and social decisions.
- Pediatric palliative care providers need to be aware of the continuing physical, emotional and cognitive development throughout childhood and respond to each child's changing levels of communication and their ability to understand.
- Provision of education and play when a child is ill is also essential. This introduces an additional dimension which adds to the complexity of care provision.

Children benefitting from Pediatric Palliative Care:

Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Life threatening conditions are those for which curative treatment may be feasible but can fail. Life-limiting and life-threatening

conditions affecting children can be divided broadly into four-groups according to the Association for Children with Life-threatening or Terminal Conditions and the Royal College of Pediatrics and Child Health [5]:

- Conditions where curative treatment may be feasible but can fail, e.g. cancer. In these cases access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life.
- Conditions requiring intensive long-term treatment aimed at maintaining the quality of life allowing participation in normal activities, e.g. severe immunodeficiency, cystic fibrosis, Muscular dystrophy.
- Progressive conditions without curative treatment options were treatment is exclusively palliative and may commonly extend over many `years, e.g. Progressive metabolic disorders.
- Irreversible but non progressive conditions causing severe disability, e.g. cerebral palsy, where there remains a high risk of an unpredictable life-threatening event.

Assessing their needs

Children with life-limiting conditions and their families have a range of specific needs (clinical, psychological, social and spiritual) and services should be provided on a needs-led basis, not on the basis of resources available locally.

Physical needs:

Common symptoms in children with advanced cancers are pain, fatigue, nausea, vomiting, cough, anorexia and psychological symptoms (feeling sad, feeling nervous, worrying and feeling irritable).

Pain is arguably the most feared symptom and occurs commonly in children receiving end of life care. Due to lack of self-reporting and non-availability of proper assessment tools children's pain is often under-recognized, ignored and consequently undertreated. [6] Accurate assessment of pain in children is essential for correct management. Pain can be measured in young children by behavioral response (e.g., facial expression, abnormal posturing, increased irritability, sleep disruption, anger). Older children can describe their pain and can even define its intensity. A framework to assess pain is called QUEST [7]; i.e. Question the child, use a pain rating scale, evaluate behavior and physiological changes, secure parental involvement, take the cause of pain into account, take action and evaluate results. There are reliable pain scales available depending on the child's age, for assessment of pain, and include the following: [6]

Description	Age group	Pain Scale
Faces are line drawings ranging from a neutral expression to one of intense pain but without tears	4-12 years self-report by child	Faces Pain Scale Revised (FPS-R)
Poker chips placed in front of child - each is a piece of hurt	4-12 years self-report by child	Poker Chip tool
A colour photographic scale of a child's face With different pain expressions for younger children and (b) a NRS of 0-10 for older children.	3-12 years Above 8 years- Self reported	The Oucher photographic 0-10 Numerical Rating Scale
Assess cry, facial expression, verbal, torso, touch, legs	1-5 years	Children's Hospital Of Eastern Ontario Pain Scale CHEOPS)

Psychosocial and spiritual needs:

Unique aspect of pediatric palliative care is-that the complex experience of life-threatening illness occurs, by the very nature of the child as patient, within the context of growth and development - physical, emotional, social, psychological, and spiritual [8]. Age dependent cognitive abilities of children affect their perception of their illness- child up to 2 years of age does not have any concept of death, and treatment must be aimed at providing physical comfort, from 2 to 7 years, children may see death as a reversible process; it is important to minimize separation anxiety and to deal with guilt feelings, children between 7 and 12 years of age is likely to understand the permanence of death, and may suffer from guilt, abandonment and fears of body mutilation adolescents are capable of self-reflection and to them body image and self-esteem have paramount importance. Therefore while assessing and managing the child's psychological needs, caregiver and palliative care provider should possess fundamental knowledge and expertise in child development and family systems. [7].

Spirituality in childhood is also developmentally defined. To them spirituality is an approaches by which they understands life. Common spiritual concerns include unconditional love, forgiveness, hope, safety and security, loneliness (separation from the important elements of their world, such as parents, siblings, school, and pets) and loss of wholeness (being unable to do what they want to do). Assessment of these spiritual needs is very important in Pediatric Palliative Care [9].

Need of the Family:

The family is a fundamental part of any pediatric palliative care program. The needs of the family are numerous and include: [10]

- Educational needs, i.e. Training on various aspects of patient care and support;
- Psychological needs: they require assessment, support and treatment for sentiments such as guilt, rage, depression, anticipatory grief, and escape;
- Spiritual needs: a competent source of answers, open to an exchange of ideas and respectful of people's cultural background and religious beliefs;
- Financial and social needs: practical proposals for coping with a situation of isolation, loss of identity and financial insecurity (for families whose members often lose their jobs as well as supporting the cost of patient treatment and care).

Addressing the needs:

Management of pain and other physical symptoms:

Management of pain includes both pharmacologic and non-pharmacologic measures. The guiding principles of analgesic administration are "by the clock," and "by the mouth" and "by the child." According to the WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical illnesses [6], it is recommended to use two step approach to provide adequate analgesia. This two-step strategy consists of a choice of category of analgesic medicines according to the child's level of pain severity for children assessed as having mild pain, paracetamol and ibuprofen should be considered as first options and in children assessed as being in moderate to severe pain, the administration of an opioid should be considered. They are widely available in child-appropriate dosage forms, such as oral liquids, and are relatively inexpensive.

Morphine is the medicine of choice for the second step, although other strong opioids should be considered and made available to ensure an alternative to morphine in case of intolerable side effects. The starting dose of morphine is 0.15--0.3 mg/kg every 4 h. The duration of action is 3-4h and hence every three to four hourly dosing is advised to maintain blood levels and prevent breakthrough pain. The dose should be titrated till it produces adequate pain relief. Non drug measures for pain control are techniques for distraction like singing, going watching TV, which makes pain more tolerable. Long-term opioid use is usually associated with constipation and child should also receive a combination of a stimulant laxative and a stool softener prophylactically.

There is lack of sufficient data for the use of adjuvant drugs (antidepressant, anticonvulsant, anesthetics) for pain management in pediatric patients.

For nausea and vomiting Prochlorperazine (0.1-0.15mg/kg orally), Ondansetron (0.15 mg/kg) can be used every 6-8 hrs.

Management of fatigue includes rest, leaving the treatment center, distraction, medical/pharmacologic relief of treatment related complications.

Addressing psychosocial and spiritual need:

These needs can be addressed in the following ways-

- Addressing child and family's fears and concerns honestly.
- Adjusting care plan to meld with child and family's coping and communication styles
- Communicating with child in a developmentally appropriate fashion.
- Explaining death concepts and developmental stages of death understanding.
- Consider referring child to culturally appropriate spiritual care provider and allowing time for child and family to reflect on life's meaning and purpose.
- Establishing child and family's preferences for location of care.
- Offering assistance from social services, financial counselors, or other supports as available in the community.

Talking to children:

Communication with children requires familiarity with their normal emotional and spiritual development. Working at the child's developmental level mandates the use not only of oral communication, but also of body language and symbolic (expressive) methods of interacting. Commonly used techniques of expressive communication with children include drawing pictures, playing with stuffed animals, writing stories or journals, playing-or writing music, and creating rituals, Meeting the child at his or her level of development will encourage the child to express hopes, dreams, fears, and reflections. [10] A study carried out at the Tata Memorial Hospital, parental anxiety and collusion were the major barriers to open communication with the children. [11] **When the prognosis is not directly revealed to children, they have extremely high levels of generalized anxiety and suffer from loneliness and separation. Therefore, parents should be explained about the need of open communication with the child.**

Ethical Issues

When the patient is a child, it is not always easy to speak of freedom of choice, respect for the patients' wishes, and their right to honest communications. The legal reference is the child's parent or guardian. They only look at benefit from treatment point of view, doesn't acknowledge

the burdens. Therefore shared decision making is preferred where physician and parent engage in mutual exchange of information about achievable treatment and patient goals.

Bereavement support

The grief associated with the incurable disease and death of a child has devastating, long-term implications for the whole family. The child's siblings have special needs during the child's illness and after their death. Therefore support to the child's family should be given with telephonic follow ups, individual meetings and one to one counseling or self-help groups.

Pediatric palliative care in India

The exact number of pediatric patients requiring palliative care is not available in India. 1, 200,000 new cancer patients are being diagnosed every year. in India, of which 1.6 - 4.8% are pediatric cancer patients. The pediatric HIV population is around 220. 000 [12].In India, pediatric palliative care is provided as part of general palliative care, no separate pediatric palliative care centers have been established. In 2007 the Mehdi Nawaj Jung (MNJ) Institute of Oncology, in Andhra Pradesh, started a pediatric palliative care unit in collaboration with the International Network for Cancer Treatment and Research (INTCR) and Pallium India. Through the training of medical personnel and volunteers there has been an improvement in the provision of palliative care to pediatric oncology patients.

A pediatric palliative care programme was launched by the IAPC in 2010, which focused on pain relief in HIV positive children, children suffering from cancer, thalassemia and neurological disorders. This project was launched in the Maharashtra state and was funded by the Department of International Development. The International Children's Palliative Care Network (ICPCN) and Help the Hospices became partners of this programme, and the Tata Memorial Hospital provided mentorship.

The International Children's Palliative Care Network (ICPCN) held its first international conference on children's palliative care, in conjunction with Tata Memorial Centre, in Mumbai, India, from February 2014. The theme of the conference was transforming children's palliative care from ideas to action.

Though there are few centers that are doing exemplary work, medical personnel and the society at large still lacking a basic knowledge of pediatric palliative care, we still have miles to go before reaching every needy child in India.

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