Palliative Care in Pediatric Cancer

Nassawee Vathana, M.D.

Department of Pediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok 10700, Thailand.

Siriraj Med J 2009;61:266-270
E-journal: http://www.sirirajmedj.com

All over the world children are living with and dying from life-threatening illnesses in a wide social, economic and health environment. Pediatric palliative care has the potential to help enormously in the care and relief of suffering of these children and their families. A pediatric palliative care approach should include psychosocial care, spiritual care, physical care and pain management.

WHO Definition of palliative care

Palliative care is an approach that improves the quality of life of patients and 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, psychological and spiritual.

WHO Definition of palliative care for children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO definition of the palliative care appropriate for children and their families is as follows; these principles also apply to other pediatric chronic disorders (WHO; 1998a):

- 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.

Goals of 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;

Palliative care for pediatric cancer patients (WHO recommendation)

Palliative care is an essential part of cancer control and can be provided relatively simply and inexpensively. Palliative care for children represents a special, albeit closely related field to adult palliative care. 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.

Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

The WHO definition includes all pediatric cancer patients in the criteria of palliative care. The Department of Pediatrics, Faculty of Medicine, Siriraj Hospital has developed palliative care by setting up a pediatric palliative care committee which cooperates to develop flow charts for pediatric patients in the department. The pediatric palliative care flowchart has been used in the teaching ward and the results are satisfactory. At the present we use pediatric palliative care flow chart of the pediatric department. (see Flowchart) Therefore the division of hematology and oncology, of the department of pediatrics is interested in using palliative care for pediatric cancer patients of our department. We plan to develop palliative care practical guidelines especially for pediatric cancer patients by following up on the WHO recommendation.
# Palliative Care

## Palliative Care Overview

### Screening

- Uncontrolled symptoms or
- Moderate to severe distress related to cancer diagnosis and/or
- Serious comorbid physical and psychosocial conditions or
- <12 month life expectancy or
- Patient/family concerns about course of disease and decision-making or
- Patient/family requests

### Assessment

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial or spiritual distress
- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care
- Criteria for early consultation with a pain care specialist

### Estimated Life Expectancy

- Years
- Year to Months
- Months to Weeks
- Weeks to Days (Dying patient)

### Palliative Care Interventions

- Anticancer therapy
- Appropriate treatment of comorbid physical and psychosocial conditions
- Promote coordination of care
- Symptom management
- Advance care planning
- Psychosocial and spiritual support
- Culturally appropriate care
- Resource management/social support
- Response to request to withdraw or withhold life sustaining treatment
- Care of imminently dying patient
- Palliative sedation
- Hospice care
- Response to request for physician assisted suicide and euthanasia

### Reassessment

- Unsatisfactory:
  - Intensify palliative care efforts
  - Consult or refer to specialized palliative care services or hospice

- Satisfactory:
  - Patient satisfied with response to anticancer therapy
  - Adequate pain and symptom control
  - Reduction of patient/family distress
  - Acceptable sense of control
  - Relief of caregiver burden
  - Strengthened relationships
  - Optimized quality of life
  - Personal growth and enhanced meaning

### After Death

- **Death (A “good death”)**
  - For family and caregivers:
    - Immediate after-death care
    - Bereavement support
  - For healthcare team:
    - General support
    - After-death support

---

*Adapted with permission from the NCCN 2009 Palliative care Clinical Practice Guideline in Oncology. © National comprehensive Cancer Network, 2009. Available at [http://www.nccn.org](http://www.nccn.org). Accessed May 5, 2009. To view the most recent and complete version of the guideline, go online to www.nccn.org. These guidelines are work in progress that will be refined as often as new significant data becomes available. The NCCN Guidelines are a statement of consensus of its authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult any NCCN guideline is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way. These Guidelines are copyrighted by the NCCN. All rights reserved. These Guidelines and illustrations herein may not be reproduced in any form for any purpose without the express written permission of the NCCN.*
Pediatric Palliative Care Flowchart

Indication of this patient
- Oncology patients
  - Phase 1: Failure induction phase, relapse.
  - Phase 2: All oncology patients
- The patient who turns terminal stage or dying.
  - Phase 1: Any cases who is admit to 10 cases
  - Phase 2: All patients that turn terminal stage or dying.
- The diseases that their nature is "unbearable, life threatening and limited life expectancy."

Assessment: Patient and family (with in 7 days)
(Interdisciplinary team)

Positive findings summary
1. Physical needs
   - Pain management
   - Nutrition
   - Other symptoms concerns (e.g., sleep, elimination)
   - Other
2. Psychological needs
   - Child life program
   - Consult psychology
   - Other
3. Socioeconomic needs
   - Social insurance
   - Consult D/C manager
   - Consult social worker
   - Other
4. Spiritual needs
   - Pastoral care
   - Other

Conference Team meeting
- Ward attending/residents
- Discharge coordinator nurse
- Discharge manager nurse
- Other
- Other

Plan of management
- Counseling
- Spiritual support
- Pain management
- Child life program
- Symptom control
- D/C planning, Home care
- Record data in progress note by residents

Family Meeting & Counseling
- Family
- MD
- Discharge coordinator
- Other

Review & Revise regularly

Patient care
- Refer other hospital
- Discharged
- Dead in hospital
- Dead at hospital
- Readmission
- F/U OPD
- Home care
- Death at home
● 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 counseling, if indicated;
● will enhance the 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.

In most of the world, the majority of cancer patients are in advanced stages of cancer when first seen by a medical professional. For them, the only realistic treatment option is pain relief and palliative care. Effective approaches to palliative care are available to improve the quality of life for cancer patients.

The WHO ladder for cancer pain is a relatively inexpensive yet effective method for relieving cancer pain in about 90% of patients.

Therefore we have to use specific palliative care guidelines for pediatric cancer patients, so we try to develop a new guideline by adapting from the NCCN (National Comprehensive Cancer Network) clinical practice guidelines in oncology. (see OVERVIEW)

Palliative care screening

All pediatric cancer patients should be screened for palliative care needs at their initial visit, at appropriate intervals and as clinically indicated. The guidelines using should be considered for pediatric patients who have the following conditions: uncontrolled symptoms, moderate to severe distress related to cancer diagnosis and therapy, serious co-morbid physical and psychological conditions, advanced or progressive disease for which there is no effective curative therapy, patient or family’s concerns about course of disease and decision making or a special request by the patient or family for palliative care. Management of any patient with positive screening requires a care plan developed by an interdisciplinary team of pediatricians, pediatric oncologists and nurses. The pediatric oncologists should integrate palliative care into general oncology care for patients who meet screening criteria. If the availability of palliative care screening is not presented, we should inform patients and families of the role and benefits of palliative care services by discussion about anticipation and prevention of symptoms or rescreening in the next visit.

Palliative care assessment

A comprehensive palliative care assessment should evaluate the benefits and risks of anticancer therapy, physical symptoms, psychosocial or spiritual distress, personal goals and expectations, education and information needs and culture factors affecting care. The assessment of the benefits and risks of anticancer therapy is based on the existing the palliative care guidelines, for that patient’s cancer. Special attention should be given to the natural history of that specific tumor, the potential for response to further treatment, the meaning of anticancer therapy to the patient and family, the impairment of vital organs, the performance status and serious comorbid conditions. Symptom assessment should look for common symptoms, such as pain, dyspnea, anorexia, cachexia, nausea, vomiting, fatigue, weakness, sleep disturbance and sedation. Assessment of psychosocial distress should focus upon psychosocial, spiritual and the belief of patients and their families. Special problems with social support and resources must be addressed and managed. The patient and family should be asked about their personal goals and expectations; priorities for palliative care; goals and meaning of anticancer therapy and quality of life; and the patient’s eligibility for hospice based upon needs that might be met by the hospice model of palliative care. Patients and families should also be assessed for their educational and informational needs and cultural factors which may affect to the patient care, and communication and perception of the patient’s disease status. Criteria for early consultation with a palliative care specialist are based on patient characteristics, social circumstance and anticipatory bereavement issues.

Estimated life expectancy

The panel has divided the patients into four groups to address the effect of life expectancy on the delivery of palliative care interventions: patients with years to live, patient with years to months to live, patient with months to weeks to live and dying patients in their final weeks to days.

Palliative care intervention

The intervention depends on the estimated life expectancy. Management of palliative care interventions should evaluate benefits and risks of anticancer therapy, appropriate treatment of comorbid physical and psychosocial conditions, promote coordinated care, symptom management, advance care planning, psychosocial and spiritual support, response to request to withdraw or withhold life sustaining treatment, care of an imminent-ly dying patient and palliative sedation, hospice care and response to request for physician assisted suicide and euthanasia. (According to the Thai law, there is no administration of justice which can enforceable in law.)

Reassessment

The outcome reassessment of palliative care should be measured. Satisfactory palliative care should provide the following: patient is satisfied with the response to anticancer therapy, adequate pain and symptom control, reduction of patient and family distress, acceptable sense of control, relieve the caregiver burden, strengthened relationships, optimized quality of life and personal growth and enhanced meaning. In the case of unsatisfactory palliative care the palliative care efforts should be intensified. Both satisfactory and unsatisfactory palliative care should be measured by ongoing assessment.

After death interventions

A “good death” has been defined as “one that is free from avoidable distress and suffering for patient, families and caregivers, in general accord with patient’s and family’s wishes and reasonably consistent with clinical, cultural and ethical standards”. Palliative care
for patient’s family and caregivers continues after the patient’s death and should provide immediate after-death care and bereavement support. The healthcare team should obtain psychosocial support after the patient’s death.

If cancer can be effectively treated and a cure or life prolongation is accomplished, there are always physical, psychological, or spiritual concerns that must be measured to maintain function and optimize the quality of life. For patients whose cancer cannot be treated, palliative care must be the dominant mode and focus intensively on the control of distressing symptoms. Planning for the end of life and ensuring that death occurs with a minimum of suffering and in a manner consistent with the values and wishes of the patient and family are important parts of this care. The goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient.

REFERENCES