Pediatric Palliative Care

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Learning objectives
At the end of this presentation the participant will be able to:
1) Support the role of pediatric palliative care in caring for children with complex illness
2) Reflect on the experience of parents and physicians in caring for children with incurable illness
3) Consider the ethical implications of care decisions

What is Palliative Care?

<table>
<thead>
<tr>
<th>Curative Model</th>
<th>Palliative Model</th>
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</thead>
<tbody>
<tr>
<td>Primary goal: cure</td>
<td>Primary goal: relieve suffering</td>
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<tr>
<td>Disease Process</td>
<td>Patients and Family</td>
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<tr>
<td>Symptoms treated as clues to diagnosis</td>
<td>Distressing symptoms treated as entities in themselves</td>
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<tr>
<td>The patient’s body is differentiated from the patient’s mind</td>
<td>The patient is viewed as a complex being comprising physical, emotional, social and spiritual dimensions</td>
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<tr>
<td>Death is the ultimate failure</td>
<td>Enabling a patient to live fully and comfortably until he or she dies is a success</td>
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WHO Definition of Palliative Care for Children

• 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 centres and even in children’s homes.

Statistics

• 81 million children in the United States
• Children represent 25% US population
• United States 2.5 million deaths annually
• About 50,000 deaths are pediatric 0-19 (2.2% of deaths)
• 100% Adults die
• 0.06% Children die
• Half of childhood deaths are in first year of life
• Half of infant deaths are in the first month of life

Disclosure
• Escobar, Veronica, DO and Medellin, Glen, MD have no relationships with commercial companies to disclose.
Prenatal Ultrasound

Diagnosis

First Conversation
Diagnoses

- Semilobar holoprosencephaly
- Dandy-Walker variant
- Severe dysplastic cerebrum and cerebellum
- Large midline cleft lip and palate
- Underdeveloped right eye
- Multiple vertebral and rib anomalies
- Diabetes insipidus
- Malrotation

Home Visit

Hospice Inpatient Center

Death
Bereavement