The Essence of Paediatric Palliative Care

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O CANADA, OUR HOME AND CLICHÉ LAND
A geographical guide to Canadian stereotypes

IRELAND ACCORDING TO DUBLINERS

MACLEAN'S
Dr Devins:

“Families are often anxious ... They see us as end-of-life care only. However, if we are involved from an earlier stage, we can then be seen as an extra resource in supporting the child and family”.

In the USA and Canada, paediatric palliative care is one of the first teams a family meets in hospital once a child has been diagnosed with a potentially life-threatening or life-limiting illness. The team are there in the background throughout the illness trajectory, regardless of the outcome.”
Parent of child with Cancer:

“We were extremely lucky to have been connected with the Palliative Care Team just hours after our daughter's diagnosis. However, this connection was only made after a close family friend who knew people in that team advocated for it. [The hospital] did not offer this to us.

My biggest concern is for families who receive a cancer diagnosis that is usually fatal, and they are not connected with palliative care until it is clear 'there is nothing more to be done'. The whole philosophy of this type of care needs to be made available to families just after diagnosis so that there is time to develop a full, trusting relationship with the caregivers.”
Essence of PPC

“The intrinsic nature or indispensable quality of something, especially something abstract, which determines its character” O.U.P definition

Your 1 word?
1. Pain & symptom management
2. Communication/decision-making
3. Coordination care: Home, Hospital, Hospice
Essence of PPC

Relationships
Communication
1. Pain & symptom management
2. Communication/decision-making
3. Coordination care: Home, Hospital, Hospice
The challenge of pain & symptom control.

The challenge of pain & symptom control.
“Nothing would have a greater impact on the quality of life of children with cancer than the dissemination & implementation of the current principles of palliative care, including pain relief and symptom control”

W.H.O. 1998
1. Pain & symptom management
2. Communication/decision-making
3. Coordination care: Home, Hospital, Hospice
Isn’t it better just to not talk about these things... (death)...?
Talking about death with children who have severe malignant disease.


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**Number of parents**

- **Talked**: 147
- **Did not talk**: 258
- **Regret**: 69
"We talked about Snow White, the Lion King and Bambi. We watched the movies together. She saw that dying was nothing to be afraid of, though she never understood that dying was forever. She was only 3 years and 9 months, but her life-wisdom was much greater. She was a very ‘grown-up’ child"
Essence of PPC

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Essence of PPC

1. Pain & symptom management
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Relationships – Communication
“...the human connection that is the essence of pediatric palliative care”

Interdisciplinary Textbook PPC: Wolfe Hinds & Sourkes
OBJECTIVE: To describe demographic and clinical characteristics and outcomes of patients who received hospital-based pediatric palliative care (PPC) consultations.

DESIGN, SETTING, AND PATIENTS: Prospective observational cohort study of all patients served by 6 hospital-based PPC teams in the United States and Canada from January to March 2008.

RESULTS: There were 515 new (35.7%) or established (64.3%) patients who received care from the 6 programs during the 3-month enrollment interval. Of these, 54.0% were male, and 69.5% were identified as white and 8.1% as Hispanic. Patient age ranged from less than one month (4.7%) to 19 years or older (15.5%). Of the patients, 60.4% lived with both parents, and 72.6% had siblings. The predominant primary clinical conditions were genetic/congenital (40.8%), neuromuscular (39.2%), cancer (19.8%), respiratory (12.8%), and gastrointestinal (10.7%). Most patients had chronic use of some form of medical technology, with gastrostomy tubes (48.5%) being the most common. At the time of consultation, 47.2% of the patients had cognitive impairment; 30.9% of the cohort experienced pain. Patients were receiving many medications (mean: 9.1). During the 12-month follow-up, 30.3% of the cohort died; the median time from consult to death was 107 days. Patients who died within 30 days of cohort entry were more likely to be infants and have cancer or cardiovascular conditions.

CONCLUSIONS: PPC teams currently serve a diverse cohort of children and young adults with life-threatening conditions. In contrast to the reported experience of adult-oriented palliative care teams, most PPC patients are alive for more than a year after initiating PPC.