INTERVENTIONS AND MODELS OF CARE IN CHILDREN’S PALLIATIVE CARE

Where are we and where are we going?

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STAGES OF PEDIATRIC PALLIATIVE CARE – TRADITIONAL MODEL

Individualised blending of care directed at underlying illness and at physical, emotional, social, and spiritual needs of the child and family with continuous re-evaluation and adjustment.

End-of-life care

Bereavement care

Hope for a cure, life extension, a miracle...

Hope for comfort, meaning...

Pediatric palliative care: challenges and emerging ideas
Stephen Liben et al    Lancet 2008
EVOLUTION OF PPC IN UK

1997
ACT “A guide to the development of Children’s palliative care services” first published definitions of children’s palliative care and the numbers and needs of LLC.

2003
Big Lottery funding grants funded development of specialist community nursing teams and hospice services.

2006
Secretary of State for Health committed £27 million over 3 years to support Children’s hospices and commissioned an independent children’s palliative care services review.

2007
Craft and Killeen palliative care services review.

2008

2009
Recognition of Paediatric Palliative Medicine as a sub-specialty by RCPCH.

2010
Department of health £30 million funding for palliative care projects.

2011
The Palliative care funding review A review of funding of the current funding mechanisms for dedicated palliative care for adults and children in England.

Charlotte Mellor, Emma Heckford, Jo Frost
Developments in pediatric palliative care
Using the 4 categories of ACH the following recommendations were made as minimum standards for PPC in Europe

1- Provision of services as per levels
   I- Palliative care approach by all Health Care professionals
   II- Generalised Palliative Care provided by Professionals who have received some training in Palliative Care
   III- Specialised Palliative Care- core activity is the provision of Palliative Care

2- Minimum core standards- including education, training and funding

3- Ethical and legal framework

Eur J Pall Care 2007:14(3)
FUTURE MODELS OF CHILDREN’S PALLIATIVE CARE DELIVERY

- Footprints model of Pediatric Palliative Care
- Integration and Developing Standards
- Together for Short lives-UK model
- IPCC Model
- Bow tie model for the 21st century
- WHA resolution on Palliative Care including children within Health Care policies
- DFID, UK- ICPCN- HtH- India & Malawi model
- ICPCN- International umbrella for CPC worldwide
SUZANNE TOCE and MARY ANN COLLINS

The FOOTPRINTS Model of Pediatric Palliative Care

JOURNAL OF PALLIATIVE MEDICINE Volume 6, Number 6, 2003
<table>
<thead>
<tr>
<th>Standard 1</th>
<th>Every family should receive the disclosure of their child's prognosis in a face to face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided both for the child and the family in language that they can understand.</th>
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<tr>
<td>Standard 2</td>
<td>Every child diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.</td>
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<tr>
<td>Standard 3</td>
<td>Every family should receive a comprehensive multi agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.</td>
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<td>Standard 4</td>
<td>Every child and family should have a multi agency care plan agreed with them for the delivery of coordinated care and support to meet their individual needs.</td>
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<tr>
<td>Standard 5</td>
<td>Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.</td>
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</tbody>
</table>
Toni Wolff, Jackie Browne
Organizing end of life care: parallel planning
Pediatrics and Child Health, 2011

**STANDARD 1**
- Decision making
- Emergency care plan

**STANDARD 2**
- Discussion of death
- Distribution of plan and Transfer

**STANDARD 3**
- Multi agency coordination
- Choices and information

**STANDARD 4**
- Multi agency coordination
- Choices and information

**STANDARD 5**
- Multi agency coordination
- Choices and information

Death

Bereavement
A CORE CARE PATHWAY FOR CHILDREN WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS

The six standards are:

Within Stage one – Diagnosis or recognition:
- 1. The prognosis – sharing significant news
- 2. Transfer and liaison between hospital and community services

Within Stage two – Ongoing care:
- 3. Multi-disciplinary assessment of needs
- 4. A child and family care plan

Within Stage three – End of life:
- 5. An end of life plan
- 6. Bereavement support

David Widdas, Katrina McNamara, Francis Edwards
US INITIATIVE FOR PEDIATRIC PALLIATIVE CARE (IPPC)

- Maximize family involvement in decision making and care planning in the ways and to the degree that each individual family finds comfortable;

- Inform children with life-threatening illnesses and involve them in decisions regarding their care and care planning as fully as possible, given their developmental abilities and desires;

- Reduce pain and distressful symptoms for children with life-threatening illnesses;

- Provide emotional and spiritual support to children and families as they cope with the multiple losses associated with life-threatening conditions;

- Facilitate the resolution of families’ practical needs, such as the need for respite, through coordination with the community;

- Facilitate continuity of care across care settings, both within and outside the hospital, by providing each family with a designated care coordinator;

- Offer bereavement support to the child and the family before and after death.
BOW TIE MODEL OF 21ST CENTURY PALLIATIVE CARE - HAWLEY P.H.

WHA has passed a resolution on palliative care calling on all member states to:

- Develop, strengthen and implement palliative care policies
- Support palliative care initiatives including education and training, quality improvement and availability of medicines essential for the provision of palliative care
- Provide support to caregivers
- Include palliative care as a part of integrated training for all healthcare workers who routinely work with people with serious illness
- Ensure access to essential medications
- Foster partnerships between government and civil society to increase access to palliative care
PROMOTE CPC in INDIA & MALAWI
DFID (UK)- ICPCN-IAPC- Tata Memorial Centre

- Advocacy
- Education
- Morphine availability
- Empowerment of children and their families

Set up 3 sites which have been used as models to promote the above

ACHIEVEMENTS
Govt. policies, Influence Palliative and Paediatric world to integrate CPC into the lives of children living for decades with life limiting conditions
Thank you.

The ICPCN's mission is to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, by raising awareness of children's palliative care, lobbying for the global development of children's palliative care services, and sharing expertise, skills and knowledge.