The need for Partnerships in Children’s Palliative Care

In order to improve Palliative Care provision

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Co-ordinator: Palliative Care in Humanitarian Emergencies: PALCHE
Discussion

• Why we need effective partnerships

• Examples of effective partnerships in children’s palliative care

• How partnerships enhance provision of palliative care
It Takes A Village To Raise A Child
African Proverb

Illuminated Living
Palliative care is built on partnerships - with

Patients and families

Multi-Disciplinary Team

Community

Health services

Other organisations & Faith groups
What does “partnership” include in palliative care?

- participation
- association
- joint interest or common objective
- contract - formal or implied
Based on

- Understanding of purpose
- Respect
- Joint decision-making
- Honesty
- Communication
- Equality
Partnerships are built on trust.
Common goal

To improve quality of life and relieve suffering of children with life-limiting conditions
Effective partnerships

- Strengthen initiatives
- Increase reach
- Provide benefit for all
- Increase enthusiasm & commitment!
But........

• Require ongoing communication

• Problems must be sorted out quickly

• Depend on people and personalities !

• Power struggles and egos may hamper partnerships
Require work
One size does **NOT** fit all.
WHY DO WE NEED PARTNERSHIPS IN CHILDREN’S PALLIATIVE CARE?
We still have far to go to meet the need!
98% of Need is in Low and Middle Income countries (WHO 2015)

<table>
<thead>
<tr>
<th>Global Need</th>
<th>Need in Low and Middle income countries</th>
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<tbody>
<tr>
<td>Generalised</td>
<td>21 163 000</td>
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<tr>
<td>21 600 000</td>
<td></td>
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<tr>
<td>Specialised</td>
<td>7 938 000</td>
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<td>8 100 000</td>
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ICPCN & UNICEF 2015
Add to that

An estimated 93 million children under 14 with moderate to severe disabilities (UNICEF State of the World’s Children 2013)

Many of these children and their families would benefit from palliative care
Unknown number of children needing palliative care in humanitarian situations
The most insidious injustice: the pain control access divide

Non-methadone, Morphine
Equivalent opioid consumption per death from HIV or cancer in pain:
Poorest 10%: 54 mg
Richest 10%: 97,400 mg
US/Canada: 270,000 mg

Data: http://www.treatthepain.com/methodology
Calculations: HGEI/Funsalud
Knaul et al. Eds Closing the Cancer Divide.
“unnecessary, unrelieved suffering exists on a massive scale globally; and the poor suffer disproportionately yet have least access to palliative care”

(Connor & Sepulveda 2014)
98 % Provision is in High Income Countries
When we know how to provide palliative care
And pain relief- unnecessary suffering exists
A moral imperative to balance need and resources
Making a difference through EFFECTIVE PARTNERSHIPS
“When the palliative care team from the children’s hospice came to visit me, for the FIRST TIME they saw me, Lucy, as a person, and not a patient with a mixture of medical problems

Lucy Watts MBE & Molly

ICPCN Global Youth Ambassador
MATTIE STEPANEK’S DEFINITION:

“Palliative care no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently”.

Mattie Stepanek, a child who died from a life limiting neuro-muscular illness and the 4th child in his family to have the same condition
National Public-Private Partnership Uganda

Hospice Africa Uganda and the Ugandan Ministry of Health

HAU successfully advocated for

- Morphine availability
- Nurse prescribing of oral morphine
- Now prepares oral morphine for the whole country
- Inexpensive and available
A collaborative activity led by Dr Anne Merriman MBE
There has been recognition that Faith groups have an important role to play in palliative care as in developing countries they may provide over 50% of health care
Faith groups form powerful global partnerships

“Religions of the World Charter for Children’s Palliative Care”

Vatican City 2015

Signed by all major faith groups – in 8 languages so far
Includes a call for

Ethics and human rights

Professional responsibilities & definition

Patient and Family needs
World Health Assembly Resolution on Palliative and Long-term Care 67.19
May 2014

Unanimously approved by all member states of WHO

Strengthening of palliative care as a component of comprehensive care throughout the life course

Places an obligation on countries to implement the Resolution
Many of the Team that worked IN PARTNERSHIP to get the WHA Resolution passed May 2014
ICPCN – the Global Action Network to reach all children with palliative care needs

Activities:

- Advocacy
- Information Sharing including ehospice
- Education & Research
- Partnerships & Collaboration

www.icpcn.org
Thank you