THE GLOBAL NEED FOR CHILDREN’S PALLIATIVE CARE

& The Challenges of Developing the Evidence Base

World Cancer Congress
Melbourne, Australia
3-6 December
Overview of the Presentation

• Defining children’s palliative care
• Present status of development
• Identifying the need?
• Strategies to improve access
• Challenges to developing an evidence base
• Conclusion
DEFINING PALLIATIVE CARE FOR CHILDREN

WHO 2001
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 [own] homes.

WHO 2002
Statement on Hospice and Palliative Care for Children

Children and young people with life-limiting conditions have very specific palliative care needs which are often different to those of adults.

If these children’s and young people’s physical, emotional, social, spiritual and developmental needs are to be met, the carers require special knowledge and skills.

We ask that the voice of these children and young people is heard, respected and acknowledged as part of the expression of hospice and palliative care world-wide.

Seoul, South Korea
March 2005
Representatives from 15 countries and Mary Callaway OSF
PRESENT STATUS OF CHILDREN’S PALLIATIVE CARE

ICPCN 2005 -2015
The Lottery of Life in access to health care
IDENTIFYING THE NEED
Research to identify the need for CPC

Need in UK 32: 10 000
• Seeing less than 30%

Kenya 130:10 000
• Seeing less than 1%

South Africa 150:10 000
• Seeing 4.8%

Zimbabwe 180:10 000
• Seeing 4.7%

November 2013
• The greatest need is in the developing countries – especially Africa with almost half of under 5 deaths

• The slowest development and the greatest challenges are in the developing world

• Even in developed countries, access to services is poor – less than 10%.

• Globally we estimate that over 20 million children would benefit from palliative care
6.3 00 00 0 under 5 deaths in 2013

Half in India (21%), Nigeria (13%), Pakistan, DRC, China
- preterm birth complications 17%
- pneumonia (15 percent)
- intrapartum-related complications 11%
- Diarrhoea 9%
- Malaria 7%

Globally, nearly half of under-five deaths are attributable to undernutrition.

Children in Sub-Saharan Africa and Southern Asia most at risk

UN inter agency task group 2014
We have excellent Guidelines and Pathways

We need to review and make them useful in developing countries

ICPCN Special Task Team on Neonatal Palliative Care

NEONATAL PALLIATIVE CARE

ICPCN Special Task Team on Neonatal Palliative Care
STRATEGIES TO INCREASE ACCESS
World Health Assembly approved Resolution 67.19 in May 2014

“Strengthening of Palliative Care as a component of comprehensive care throughout the life course”

Calls on the Director General

(8) to collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children;

• WHO has advertised for a Palliative Care lead
• Technical Advisory Group meets in Barcelona 10& 11 December to identify strategies to implement the Resolution at country level.
www.elearnicpcn.org

- English
- French
- Spanish
- Portuguese
- Russian
- Mandarin
- Hindi
- Serbian
- Dutch
- Arabic, German in 2015
Pain management

- ICPCN e-Learning recommended in the guidelines
- Research to be coordinated by ICPCN

WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses
ICPCN edits the International Children’s Edition

Promotes the work of children’s palliative care around the world
Series of short films from different countries. Mike Hill & Sue Collins of Moonshine Movies

1 short film to be released every 2 weeks for a year

Longer film in production with narration by David Suchet

www.littlestars.tv
Palliative care is a human right

ICPCN Charter on the Right to Palliative Care

1. Every child should expect individualised, culturally and age appropriate palliative care as defined by the World Health Organization. The specific needs of adolescents and young people shall be addressed and planned for.

2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child’s illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.

3. The child’s parents or legal guardians shall be acknowledged as the primary care givers and recognised as full partners in all care and decisions involving their child.

4. Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.

5. A sensitive but honest approach will be the basis of all communication with the child and the child’s family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.

6. Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.

7. Where possible, the child and the family shall be given the opportunity to consult with a paediatric specialist with particular knowledge of the child’s condition and should remain under the care of a paediatrician or a doctor with paediatric knowledge and experience.

8. The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.

9. The child’s home shall remain the centre of care whenever possible. Treatment outside of the home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children.

10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual care in order to meet their particular needs. Bereavement support for the child’s family shall be available for as long as it is required.

AVAILABLE IN 24 LANGUAGES

ADVOCACY
CHALLENGES TO DEVELOPING THE EVIDENCE BASE
Challenges to developing the evidence

• We don’t really know the size of the problem – present research indicates over 20 million globally

• Fewer children than adults needing palliative care – can depend on where you are in the world

• Other priorities – palliative care for aging populations

• Lack of funding for research

• Few researchers in developing countries
Are we not curious enough?

A need for more concern from the palliative care and related communities
Delphi Study

• ICPCN undertook a Delphi study to identify the priorities for CPC research around the world

• Results will be presented later in the session and will inform the development of a research agenda and strategy for ICPCN
CONCLUSION
• We have excellent programmes, education and practitioners

• We don’t have enough - and they are mainly in developed countries

• The number of children needing palliative care is achievable

• Collaboration & generosity is key
We need to remember - Life-limited Children in Humanitarian Crises

- ICPCN Pilot study planned within Refugee situations
- We need a Strategy
- ICPCN Special Task Team established
Save the dates for the 2nd ICPCN Conference 18 – 21 May 2016 Buenos Aires Argentina
NOW
For children with life limiting conditions
icpcn