A NURSE-LED COMMUNITY PALLIATIVE CARE SERVICES AND EDUCATION PROGRAMME IN INDONESIA
“We are not here to add days to the children’s lives, but to add life to their remaining days.”
WHAT PROBLEMS ARE WE SOLVING?

Nearly 700,000 children are living in pain with serious and life-limiting illnesses across Indonesia.

Less than 1% of these children have access to pain relief or palliative care.*

*Hidden Lives, Hidden Patients; Worldwide Hospice Palliative Care Alliance and International Children’s Palliative Care Network; 2015
WHAT PROBLEMS ARE WE SOLVING?

1. Hospital bed crunch
2. Trained palliative care professional shortage
3. Minimum caregivers awareness

*World Bank Survey of 100 countries, 2011
We are not here to add days to the children’s lives, but to add life to their remaining days.
“We are not here to add days to the children’s lives, but to add life to their remaining days.”
OUR SOLUTIONS:
1. HOME-BASED PALLIATIVE CARE

"We are not here to add days to the children’s lives, but to add life to their remaining days."

2700 seriously-ill children and families reached since 2006.
OUR SOLUTIONS:
2. COMMUNITY NETWORK IN PALLIATIVE CARE

2400 community volunteers trained to support their seriously ill neighbors.

“We are not here to add days to the children’s lives, but to add life to their remaining days.”
OUR SOLUTIONS:
3. PALLIATIVE CARE TRAINING & EDUCATION

4100 healthcare professionals trained in palliative care.

“We are not here to add days to the children’s lives, but to add life to their remaining days.”
Utilisation of the Children’s Palliative Outcome Scale to improve outcomes of care for children with cancers

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Background

- Increasing incidence of childhood cancer from 165,000 new cases annually to 215,000 cases (for children 14 years)
- 85,000 new cases (for 15-19-year-olds)
- Many more remain uncounted and unreported due to a lack of childhood cancer registries in a large number of countries. (IARC, 2015)
Background (2)

• In developed countries, the life expectancy is increasing, but treatments are associated with morbidity and late effects (WHO, 2015)
• In resource limited settings cure rates are 10% in some countries (Bonilla et al, 2000)
• 80% childhood cancers occur in LMIC (WHO, 2015)
• Besides measuring morbidity and mortality, it is important to measure outcomes that reflect patient’s overall wellbeing
Why measure outcomes?

• Person-centered outcomes are not commonly included in measures used to assess the quality or effectiveness of paediatric palliative care. (Coombes, 2016)

• By engaging patients and families in decisions related to their care:
  – We achieve better understanding of needs greater consensus on treatment plans.
  – Better outcomes, and satisfaction with care.

  (Ekman et al, 2011; Taylor et al, 2008; Fayers and Machin 2007)
<table>
<thead>
<tr>
<th>Child version</th>
<th>Proxy version</th>
</tr>
</thead>
</table>

**SECTION A: ABOUT THE CHILD**

<table>
<thead>
<tr>
<th>Question</th>
<th>construct domain</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Can you tell me how much pain you have had since yesterday?</td>
<td>Health status</td>
<td>Physical</td>
</tr>
<tr>
<td>2. How much have other problems with your body been troubling you since yesterday? (Prompt only if needed: e.g. being sick, going to the toilet a lot)?</td>
<td>HRQoL</td>
<td>physical</td>
</tr>
<tr>
<td>3. Can you tell me how much you have been feeding since yesterday?*</td>
<td>Health status/QoL</td>
<td>Physical</td>
</tr>
<tr>
<td>4. Can you tell me how much you have cried since yesterday?*</td>
<td>Health status or QoL</td>
<td>Psychological</td>
</tr>
<tr>
<td>5. Can you tell me how often you have felt happy since yesterday?*</td>
<td>QoL</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>6. How much have you felt like playing since yesterday?*</td>
<td>QoL</td>
<td>Social</td>
</tr>
<tr>
<td>7. How much have your questions about your sickness been answered since yesterday?</td>
<td>QoL</td>
<td>other</td>
</tr>
</tbody>
</table>

**Abbreviations**: QoL – quality of life, HRQoL – health-related quality of life.

Children’s Palliative Care Outcome Scale 7 questions for children and 5 for carers

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What should we measure?

- Qualitative interviews
  - children (n=61); carers (n=59)
- Multi-country
  - Kenya, Namibia, South Africa, Uganda
- Diverse illnesses
  - Sickle cell, end stage heart disease, end stage renal disease, neurological complications,
- Thematic analysis
  - To identify themes on symptoms, concerns and health outcomes
Main themes arranged by Brofenbernner’s socio-ecological layers of child development

**Physical:** Pain, Other symptoms, Symptom distress, Physical function

**Spiritual/existential:** Indicators of spiritual well-being /peacefulness, beliefs, practices, faith, Outlook on death, existential loss, Spiritual resources, Connection to supernatural

**Psycho-social:** Emotional, behavioral, Cognitive, Outlook on self, positive and negative affects [happy, sad, smile] Self growth

**Social health:** Quality of relationships, Initiate and maintain relationships Family love and support Belonging Perspectives of others Play and have fun Attend school Isolation Trapped in hospital

**Service delivery factors:** Staff attitude, environment of care

**Life values/normalcy:** Be like normal children

**Cultural beliefs and norms:** Stereotypes, stigma

**Financial /opportunity cost concerns:** Costs associated with care

**Micro system**

**Meso system**

**Exo system**

**Macro system**
Children use ‘unique’ language

My skin is like that of a snake

I fail to breathe

I have maggots in my skull

The upper part of my chest is separated from my abdomen

My stomach is too heavy

My body is big and round

My neck is dropping
All items provide useful information on child and family wellbeing.

Item Information Functions

Theta

Information

-4 -2 0 2 4

-0.0 -0.05 0.05 0.1 0.15 0.2

pain1
feeding
happy
questions

othersymptoms
cried
play

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Acceptability

• Median completion time is 10 minutes – minimal burden

• The number of missing items was low (less than 3%)

• Cognitive interviews showed all questions were acceptable and clear
Utilisation

- It is important to capture data on age and interpret scores with age in mind.
- Children can self-report, recent work showed that children as old as 7 years can self-report.
- Proxy reporting is important.
Improving quality of life for children with cancer and their families through the provision of quality palliative care.

Facility based children’s palliative care and the use of an innovative pain assessment App for children

Prof. Julia Downing PhD RGN
Chief Executive
International Children’s Palliative Care Network
Professor in Palliative Care, Uganda
Models of CPC Service Delivery

• Variety of models for CPC have evolved
• Important that they are culturally appropriate
• Can’t just lift one model and put it elsewhere
• Important to understand existing models in order to scale up services
• Evidence of effectiveness has been lacking
Key Elements of an Effective CPC Programme

- Clear and strong leadership
- Focused on the vision
- Linked to what makes the programme unique
- Different components of care
- Holistic approach to care
- Clear strategy
- In touch with changes in the environment
- Adaptable (but not losing focus)
- Consistency in approach
- Acceptance by the community and collaboration
- Access to a variety of education programmes

*(Downing et al 2017)*
University Department/Hospital Team
Needs Assessment

- Prevalence of life-limiting disease – 46%
- Comparable European average is 5-23%
- Service development tailored to meet the needs

(Lewington et al 2012)
Link-nurse programme at Mulago Hospital

• In order to make palliative care accessible to all who need it around the hospital
• 27 link nurses trained
• Evaluation completed
• Model extended

(Downing et al 2016)
Evaluation......

FGDs

• Provision of PC
• Knowledge
• Attitudes
• Training
• Challenges/Limitations
• Future developments
Managing Pain through Technology

- Pain is an issue for many children requiring PC
- Assessment of pain is a challenge, along with sharing their pain history with the medical team
ICPCN Pain Assessment App
Location and Type of Pain
Assessment Tools
## Pain History

<table>
<thead>
<tr>
<th>Date / Time</th>
<th>Pain Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>28/05 07:08</td>
<td>Stabbing 0</td>
</tr>
<tr>
<td>28/05 07:29</td>
<td>dull 6</td>
</tr>
<tr>
<td>28/05 07:46</td>
<td>Throbbing 8</td>
</tr>
<tr>
<td>28/05 20:54</td>
<td>Stabbing 6</td>
</tr>
<tr>
<td>28/05 22:18</td>
<td>dull 6</td>
</tr>
</tbody>
</table>

**Left Back Shoulder**

- **28/05 07:46**
  - **Throbbing 8**
  - The pain: Stays in one place
  - It hurts: Sometimes
  - Does anything make it better?: No
  - Does anything make it worse?: No
  - Did the patient have pain in another place?: No

**Back to Home**
Huyaam Samuels’ experience

• “The ICPCN Pain App is a lifesaver. It is quick and easy to use, has a user friendly interface and efficient. I am no longer forgetting any important details of my pain on a day-to-day basis. It comes with me to all my appointments enabling me to get the best treatment possible. I would recommend this app to everyone suffering from pain related conditions!”
Next Steps......

• Ongoing piloting in different settings
• Ask a child/teenager to use the App for 4-6 weeks and complete a simple questionnaire
• Translate the app into another language
Improving quality of life for children with cancer and their families through the provision of quality palliative care.

Introduction

Prof. Julia Downing PhD RGN
Chief Executive
International Children’s Palliative Care Network
Professor in Palliative Care, Uganda
ICPCN......

• Is the global network of individuals and organisations working together to reach the estimated 21 million children with life-limiting conditions and life-threatening illnesses

• We believe that:
  – All children and young people and their families have the right of access to PC
  – That PC should begin at diagnosis and continues into bereavement
  – The family are the primary caregivers and need to be empowered
  – That CPC is about living life to the full
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
Lancet Commission Report
Serious Health Related Suffering (SHS)

• 2.5 million children die annually needing PC and pain relief
  – 98% from LMICs

• In low income countries:
  – 90% of childhood deaths associated with SHS are avoidable
  – Childhood deaths account for >30% of all deaths with SHS (1% High income countries)
  – >50% childhood SHS related to HIV disease
Global need for CPC

- **Total Need:** 21.644 Million
- **Specialist Need:** 8.163 Million
- 44.42 per 10,000 children
- Range – 21 - >100 per 10,000 children
- Important – not based on mortality figures

*(Connor et al 2017)*
Outline of the Session

1. A nurse-led community palliative care services and education programme in Indonesia – lessons learnt from Rachael House

2. Lessons learnt form the development of an integrated children’s palliative care service at Hospis Malaysia

3. Utilisation of the Children’s Palliative Outcome Scale to improve outcomes of care for children with cancer

4. Facility based children’s palliative care and the use of an innovative pain assessment App for children

5. My experience in receiving palliative care – a child’s perspective
Questions to Discuss

1. What can we learn from the presentations that will impact our own practice?

2. What is the advantage of empowering the nurse to strengthen the delivery of children’s palliative care service?

3. What is the biggest advantage of involving the community into palliative care?

4. How do we make sure that children’s palliative care is integrated into the health system so children and their families can get care wherever they are?