A Framework for Children that are Bereaved, Caring for a dying parent and/or Living with a life threatening illness

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Zimbabwe
Outline of Presentation

1. Island Hospice & Healthcare
2. Background & context (25)
3. Clinical Model & framework for Island’s Children’s Programme (25)
4. Questions (10)
Established in 1979 as the first hospice in Africa

Models:
- Home based care
- Hospital based care
- Rural & community outreach
- Road side services
- Therapeutic & comprehensive bereavement care
- Capacity building

Recommended to be a WHO palliative care demonstration site for region
# Service Delivery 2016

<table>
<thead>
<tr>
<th>PATIENTS SEEN</th>
<th>MALE</th>
<th>FEMALE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULTS</td>
<td>3,903</td>
<td>8,088</td>
<td>11,991</td>
</tr>
<tr>
<td>CHILDREN</td>
<td>514</td>
<td>2,047</td>
<td>2,561</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4,417</td>
<td>10,135</td>
<td>14,552</td>
</tr>
</tbody>
</table>
Background: Zimbabwe

- Population of 14 million & 1 in 60 in need of PC (WHO)
- Right to health enshrined in the constitution but health system fragile
- MMR of 614 deaths per 100,000
- 15% HIV prev. rate. Cervical cancer on the rise (4 women a day die from CC)
- 98% drugs funded by donors (GF, PEPFAR, EU, DFID etc)
- 90% need med insurance
- 6 pillars of functional health system weakened
Continuum of (Palliative) care in the developing world

- Disease-oriented care
- Supportive & Palliative Care
- Bereavement Care
- Care of orphans
- Impacts on Individual, Family, Community
- Diagnosis
- Island Care
- Primary Health Care & Specialist Care
- Death

Adapted from WHO: Defilippi, Gwyther 2002
## Orphans/CHH Data

<table>
<thead>
<tr>
<th></th>
<th>#</th>
<th>Year</th>
<th>Ref</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child headed households</td>
<td>100 000</td>
<td>2012</td>
<td>UNICEF</td>
</tr>
<tr>
<td>Orphaned due to HIV/AIDS</td>
<td>890 000</td>
<td>2012</td>
<td>UNICEF</td>
</tr>
<tr>
<td>Orphaned all causes</td>
<td>1 200 000</td>
<td>2012</td>
<td>UNICEF</td>
</tr>
<tr>
<td>Orphaned due to AIDS</td>
<td>450 000</td>
<td>2015</td>
<td>UNAIDS</td>
</tr>
</tbody>
</table>

For more information, visit the following links:

- [UNICEF Zimbabwe Statistics](https://www.unicef.org/infobycountry/zimbabwe_statistics.html)
- [UNICEF Real Lives](https://www.unicef.org/zimbabwe/reallives_7849.html)
- [UNAIDS](http://www.unaids.org/en/regionscountries/countries/zimbabwe)

- 2013, UNICEF International Children’s Palliative Care Network (ICPCN) collaborative research quantify need for children’s PC in 3 sub Saharan countries – Kenya, South Africa & Zimbabwe.

- [http://www.icpcn.org/icpcn-unicef-research/](http://www.icpcn.org/icpcn-unicef-research/)
## Estimated population need for CPC

<table>
<thead>
<tr>
<th>Country</th>
<th>Generalized CPC Need</th>
<th>Specialised CPC Need</th>
<th>Population %</th>
<th>Rate per 10,000 Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenya</td>
<td>660,717</td>
<td>264,102</td>
<td>0.68</td>
<td>120.05</td>
</tr>
<tr>
<td>S. Africa</td>
<td>801,155</td>
<td>304,441</td>
<td>0.62</td>
<td>151.92</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>312,046</td>
<td>117,231</td>
<td>0.91</td>
<td>180.63</td>
</tr>
</tbody>
</table>
### 2013 Estimated # Children reached

- **Enormous gap between need & Provision of service**

<table>
<thead>
<tr>
<th>Country</th>
<th># Reached</th>
<th>% of need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenya</td>
<td>545</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>S Africa</td>
<td>14,501</td>
<td>~5%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>5,438</td>
<td>~5%</td>
</tr>
</tbody>
</table>

- Based on the statistics provided by NGO’s, hospices, PC orgs and public facilities
Zimbabwe PC Challenges

- Essential palliative care medications available
  - However, reluctance to prescribe &/or administer opioids cited as major barrier to access to comprehensive pain management
  - Lack of appropriate pain medication formulations for children

- PC not fully integrated into National Health system
  - Funding for PC services major constraint to achieving adequate reach & quality.
Big Lottery /Island “Collaborate” project :2013/16

• A reduction in experiences of isolation & anxiety in bereaved children & other vulnerable children (including YC’s) leading to an improvement in psychosocial & emotional wellbeing.

• Improved coping ability & resilience of young carers leading to a reduction in vulnerability to infection, & improvement in opportunities for personal development
Contributed to increased coping

- During FGDs children reported
  - Reduced feelings of isolation
  - Reduction in stigma compared to 2 years prior
- Able to identify referral networks
- CHBC usually first ones mentioned, followed by CCW and schoolteachers.
“When children suffer from chronic or fatal illness, it is their right to be free of pain & to die with dignity. Sadly, all too often this is not the case. The 3 Country study is an important first step to better understand the need & gap in coverage of palliative care for children.”
Clinical Implementation of Islands Children’s Programme

- Bereavement
- Young Carers
- Paediatric palliative Care
Challenges

• Level of bereavement in Zimbabwe

• Lack of health /welfare system initiatives

• Collapse of extended family

• Poverty- having these children access services

Need to -
• Be economic in terms of $ & time

• Framework utilizes any opportunity to reach children
  – Guardian support
  – Community collaborations
  – Capacity Building...
Children’s Psychosocial Care
Bereavement

• Grief not linear progression

• Experience interpreted & reconfigured through ongoing reflection as child ages/matures

• Multiple losses

• Research Mental health prognosis
  – Adult depression etc

• Models for our context

• Stroebe & Schut Dual Purpose/ Oscillation Model
Dual Purpose Model
DPM/Oscillation Model. (Stroebe et al)
## 2 Types of Stresses

<table>
<thead>
<tr>
<th>Loss Oriented Coping strategy</th>
<th>Restoration oriented coping strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress directly associated with loss of person</td>
<td>Stress re issues resulting from the loss</td>
</tr>
<tr>
<td>• Dealing with loss itself (e.g. rumination &amp; longing for person, reliving memories, crying)</td>
<td>• Dealing with secondary consequences of the loss</td>
</tr>
<tr>
<td></td>
<td>• Attending to life changes</td>
</tr>
<tr>
<td></td>
<td>• Adjust to substantial changes that co occur - patterns of social interaction, status change etc</td>
</tr>
</tbody>
</table>
Children’s bereavement Group
"Talking to my dead father by writing a letter was very helpful and made a big difference."

Writing letters........
Young Carers (YC’s) Definition:

- Under 18 provide care to family member.
- Carry out significant caring tasks.
- Assume level of responsibility usually associated with adult.
- Patient often parent = disabled, chronic illness/condition that needs care, support, supervision.
- Lack relevant skills.

Becker S (2000)

- World wide phenomena.
- In Zimbabwe many YC’s are often themselves HIV+.
YC’s research in UK.

• Most significant Factors influence whether children become carers, is availability & effectiveness of health & social care support for ill/disabled relative.

• 4% of UK 18-24 year olds have regularly cared for ill/disabled relative during childhood (NSPCC Cawson 2002)

• 1% of all family carers in Scotland are YC’s (Scottish Executive 2001)

• CARERS UK by Chris Dearden & Saul Becker 2002
• http://www.lboro.ac.uk/microsites/socialsciences/ycrg/youngCarersDownload/yceduc%5B1%5D.pdf
Island & YC’s

- Community partners, Island staff & CHBC identified children & adolescents = caring for ill family member

- Need-Meaningful practical/psychosocial/material support

- YC’s Programme - holistic framework
  - access to support from peers & trained CHBC adults
  - address their losses
  - build coping mechanisms
  - learn how to provide adequate care
  - referral on to relevant agencies
  - Identify /manage & refer YC’s health issues
  - Follow up support from Island staff
Community Volunteer training and mentorship
Challenges faced by YC’s…

- **Access to Education**
- **Health & Nutritional Needs**
- **Psychosocial Wellbeing**
- **Lack of Adequate Knowledge/Skills to Care for the ill**

**YOUNG CARERS**
The Life of a YC..

Education
- Delayed enrolment/drop out → lack of school fees
- Absenteeism & lack of concentration

Deprived of childhood
- Play
  - Social life revolves around patient → Isolation

Not equipped with skills to care for person with life threatening illness.

Challenges of providing physical care PLUS trauma associated with impending loss of loved one.
Life of YC...

- May sell property/livestock /beg/prostitution to meet clinic/hospital/ medication/food requirements
- Minimal support in care role
  - Associated with breakdown of extended family
- Against children’s rights but due to circumstances = “acceptable”

- Issues of
  - Birth certificates
  - Nutrition
  - universal precautions
  - stigma
‘Sometimes there will be no pain killers and she will be crying’ (14 yr old girl caring for mother)
YC “workshop” Programme includes..

Adapted from Children’s Bereavement groups, feedback from children & global best practices

- Family drawings
- Patient Communication
- Discussion on losses
- Poems & Drama
- Play & games
- Working/linking with community stakeholders (CHBC attend workshops)

- Nutrition
- HIV facts
- General hygiene & protecting yourself
- Managing pain
- Signs of approaching death
- Personal experiences & biggest challenges
KUBATANA GROUP RULES

1. KEEP GROUP SECRETS 
   (NO Gossip)
2. KUWIRIRANA
3. RESPECT EACH OTHER/
4. KUTERERA (LISTEN) FAMILY
5. BE SMART
6. COME ON TIME 
   (2 O’clock)
YC’s struggle with intimate care provision.

- **SSQ -> 80 YC’s assess psychosocial wellbeing (BL 2015)**
  - **77.5% of YC’s had some psychosocial disorder.**
  - **25% of YC’s had severe psychosocial disorder.**

- **Analysis = majority of YC’s sometimes /always feel depressed, tired.**

- **Unable to concentrate or make decisions.**

- **✓ bathing, feeding, turning, lifting & carrying patient**
- **✓ attending to nutritional needs**
- **✓ changing clothes**
- **✓ cleaning toilet, diarrhoea & vomit;**
- **✓ collecting medication & ensuring it is taken**
- **✓ wound care & giving medication**
YC’s needing Physical Palliative Care (PC)

Young primary carers collect medication @ Island CPC clinic Mufakose
WHO Definition of Palliative Care for Children (summary)

- **Active total care**
  - plus family support
  - begins @ diagnosis

- Evaluate & alleviate **total** distress

- Effective PC = broad **multidisciplinary** approach
  - includes family & community

- Successfully implemented even **limited resources**

- Provided **wherever** child & family choose to be
  - @ home, hospital etc
What’s different about PC for Children

• Children are unique... not small adults
  needs & responses = different

• Effective care requires understanding difference

• PC for children involves partnership between
  child, family/guardian/land lord, teachers, health
  care professionals/ community based volunteers.

• Child should participate to fullest extent possible
Pain Management in Children

- Pain is what child says hurts
- Paediatric formulation NB

- FACT: Children feel pain same way adults & have same pain management needs!

- Child needs to trust those caring for them
YC’s Palliative Care & Adherence

- Disclosure issues: Taking ARVs can be confusing
- Ill parent under strain with own treatment/ ARVs unable to monitor YC adherence
- Overwhelmed...
- Pill fatigue....

‘It is difficult caring when there is nothing to eat’ (12 yr old boy caring for granny)
Thank you for your interest

www.islandhospice.care