Paediatric Palliative Care and SA’s New Policy Framework + Strategy for Palliative Care

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Introduction
Overview of talk

- Paediatric Palliative Care: Myths and Stigma in children’s oncology
- The advocacy journey
- The New SA Palliative Care Policy Framework and Strategy
Paediatric Palliative Care: Myths and Stigma in children’s cancer
Myth #1: Palliative care is for the dying cancer child...

Are we there yet?
Myth # 2: Palliative care means giving up + stopping chemo...
Myth #3: Palliative care is just TLC

Nothing more we can do!

Doom and gloom!
Truths about palliative care....

WHO definition of palliative care

- Palliative care is an **approach** that improves the **quality of life** of patients and their families facing the problem associated with **life-threatening illness**, through the prevention and **relief of suffering** by means of early identification and **impeccable assessment** and treatment of pain and other problems, physical, psychosocial and spiritual.
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.

- Figure 1: Traditional palliative care services model
It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Figure 2: Modified integrated palliative care services model (Frager, 1997)
Definition continued...

- 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 centers and even in children's own homes.
Mattie Stepanek 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”. 
The advocacy journey...
Formation of the Alliance: 2009

Alliance for Access to Palliative Care

Terms of Reference

Aim: The Alliance for Access to Palliative Care is a network of like-minded individuals with individual or organizational representation working collaboratively to advance palliative care in South Africa to ensure that this care is accessible, affordable, available to all persons in South Africa.

5th June, 2009
WHA resolution: 2014
Landmark resolution for palliative care...

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY
Agenda item 15.5

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

WHA67.19
24 May 2014
Key components of WHA 67 resolution

Fig. 1. WHO Public Health Model.
National Steering Committee for Palliative Care Policy- SA: Appointed August 2016
Guiding Principles for Palliative Care in South Africa

- Right to health
- Patient centred and ethical care
- Equitable access
- Holistic, comprehensive continuum of care throughout the life course
- Integrated within the health system
- Patients and families as partners
- Enacting of enabling legislation and development of new legislation
- Multi-sectoral
- Quality and evidence based
WHO Health System Building Blocks
Health Promotion
Disease Prevention
Treatment
Care and Support

Community Health Centres
District Hospitals
Health Posts
Satellite Clinics
Mobile Clinics

Health Promotion
Disease Prevention
Treatment
Care and Support

Rehabilitation
Palliative Care

Environmental Health

Continuum of Care

Dimension of Place
ECD/School
 Household
 Workplace

Dimension of Time
Pre-birth
0 – 28 days
1 – 5 years
6 – 18 years
19 – 45 years
46 – 65 years
+ 65 years
End-of-life

Clinics
Community Health Centres
Satellite Clinics
Mobile Clinics
Health Posts
Workplace
District Hospitals

Environmental Health

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District Hospitals

Environmental Health
Primary Health Care engineering
Diagram 9. Service Delivery Platform. (DHS Strategy 2015 with modification to include integrated palliative care services at hospital, district and community levels)
The majority of patients (A) will have needs that can be adequately addressed at a community or primary health care level.

Some patients (B) may have an acute exacerbation of pain or symptoms or experience psychosocial distress that requires a more specialized level of health care intervention (district or regional) to alleviate the need and will then continue care in the community.

A very small proportion of patients (C) will have ongoing complex needs which require ongoing specialist level interventions – either at regional or tertiary level of care.
Patient pathways through levels of care
Levels of Palliative care expertise:

<table>
<thead>
<tr>
<th>Levels of Palliative Care Expertise</th>
<th>Skills of Health Care Workers</th>
<th>Level of Health Service Delivery</th>
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</table>
| Palliative Care Approach (All health care workers)   | A Palliative care approach can be offered by any cadre of health care worker (HCW) at all levels of the health system. The palliative care approach should be included in all pre-service and in-service trainings. The undergraduate curricula of health professionals should include the palliative care approach. Most patients will have needs that can be adequately met by HCWs with this level of skill. | Community  
Primary care clinics  
Community Health Centres  
District hospitals  
Regional Hospitals  
Tertiary Hospitals (Non-Palliative Care Specialists) |
# Goals of the National Strategic Plan for PC

<table>
<thead>
<tr>
<th>Goals</th>
<th>Challenges</th>
<th>Alignment to WHA</th>
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<tbody>
<tr>
<td>Goal 1: To strengthen palliative care services across all levels of</td>
<td>Addresses the challenges of service delivery, and provision of medical products including medicines.</td>
<td>Aligned to WHA PC Resolution: Member state 1, 2, 3, 5, 6, 7.</td>
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<td>the health system from the tertiary hospital to the patient in the</td>
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<td>home to provide integrated and equitable care.</td>
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<td>Goal 2: Ensure adequate numbers of appropriately trained health</td>
<td>Addresses the challenges of an adequately trained health workforce in adequate numbers to provide</td>
<td>Aligned to WHA PC Resolution: Member state 4 (a), (b), (c).</td>
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<td>care providers to deliver palliative care at all levels of the</td>
<td>palliative care services.</td>
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<td>health service.</td>
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<td>Goal 3: Establish and maintain systems for monitoring and evaluation</td>
<td>Addresses the challenges of data available for planning and evaluating progress against plans</td>
<td>Aligned to WHA PC resolution: Member state 9</td>
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<td>of South Africa’s palliative care program.</td>
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<td>Goal 4: Ensure appropriate allocation of financial resources to</td>
<td>Addresses the challenges of funding of South Africa’s palliative care program</td>
<td>Aligned to WHA PC resolution: Member state 2</td>
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<td>strengthen and sustain South Africa’s palliative care program.</td>
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<td>Goal 5: Strengthen governance and leadership to support</td>
<td>Addresses the challenges of governance and leadership required to ensure implementation of the</td>
<td>Aligned to WHA PC Resolution: Member state 8, 9.</td>
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<td>implementation of the policy.</td>
<td>palliative care policy.</td>
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Special considerations: vulnerable populations

Age extremes
Disabilities
Rare diseases
Infection risk
Harm risk - other patients or themselves
Escape risk

Outside public health care system
In institutions - DOH, DSD, DOE, DCS, NGO’s
Homeless
Access problems (Home Affairs)
Transport difficulties

Specialist Support Teams
District/Sub-district Management Team
Contracted Private Providers

District Hospital
PHC Clinics
Community Health Centres

Doctor
PHC Nurse
Pharmacy Assistant
Counselor

PHC Outreach Teams

Households
Community based health Services
- Environmental
- Health Promotion
- Epidemics
- Community Mobilisation

Local Government
- Environmental Health
- Water Sanitation
- Refuse removal
- Pest and vector control

Schools
ECD

Workplace
A GENERIC APPROACH TO PALLIATIVE CARE FOR VULNERABLE POPULATIONS

<table>
<thead>
<tr>
<th>Children</th>
<th>Elderly</th>
<th>Inmates</th>
<th>Psychiatric</th>
<th>Infectious (TB)</th>
<th>Refugees</th>
<th>Homeless</th>
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**DISABLED**

Step 1: Situational analysis- MRC and Questionnaires to facilities

Step 2: Guidelines : research/revision/development

Step 3: Central Training and dissemination of Guidelines: National meeting Plenary – principles and basics of palliative care + Parallel tracks

Step 4: Self evaluation + audits (PC teams)- baseline assessments

Step 5: Development of networks and pathways to alternate care

Step 6: Ongoing mentorship and support- telemedicine contact with COEs.

Step 7: Monitoring and evaluation- follow up annual meetings
Provincial Palliative Care Policy Making