Palliative and Healthcare Environment: Global Community Based Palliative Care Development A progress report and way forward

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Disclosure

• No conflicts of interest
The need - a global perspective

- >1 million deaths/week
- >60 million need PC
  - 25.6M at EOL
- Families (at least 2-4 each)
- <10% of need for PC met, 14% @ EOL
- at least 18 million die in pain
The need - a global perspective

- 67% 60+ / 8.6% children
- 80% LMIC
- 93.5% NCD
- ~75% of countries no or limited delivery of PC
- only 8% of countries good integration
- 92% of morphine used by 17% of world population
Content

• Global Need for PC – Lancet Commission & WHO
  • Serious Health Related Suffering
• Global Development of PC
• Advocacy for PC
• Community Based Palliative Care
  • Creative & Innovative Models
• Challenges and Vision for the Future of PC
Global Need for Palliative Care

Global Atlas of Palliative Care at the End of Life

Lancet Commission Report on Palliative Care & Pain Relief

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

Global Need for Palliative Care

Global Atlas

• 20.4 million at EOL
• 40 million total need
  • 1M children
• 18 major Dz groups
• Pain as surrogate for PC

Lancet Commission Report

• 25.6 million at EOL
• 61.1 million total need
  • 5.3M children
• 20 major Dz group
  • Inclusion of Injury
• Suffering as surrogate
  • 15 types

Need for PC in China (Lancet)

Decedents (10,139,831)
• 5,501,000

Non-Decedents
• 4,978,000

Hong Kong 22nd out of 80 on the 2015 EIU Quality of Death Index (China 71st)
Serious Health-Related Suffering

<table>
<thead>
<tr>
<th>Categories of serious health-related suffering</th>
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<tbody>
<tr>
<td>Physical</td>
</tr>
<tr>
<td>Psychological</td>
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<tr>
<td>Social</td>
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<tr>
<td>Spiritual</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Health conditions or stage of disease</th>
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</thead>
<tbody>
<tr>
<td>End of life</td>
</tr>
<tr>
<td>Chronic or acute life-threatening or life-limiting disease, ill health, and injury</td>
</tr>
<tr>
<td>Not associated with a life-threatening or life-limiting health condition</td>
</tr>
</tbody>
</table>

- **Palliative care health-related interventions; described in this Report**
- **Palliative care interventions primarily outside of health care; not covered in depth in this Report**
- **Health conditions that generate serious health-related suffering mitigated by other health and social interventions, and preferably not managed by palliative care, yet often are in impoverished settings; not covered in this Report**

*Figure 3: Serious health-related suffering, palliative care, and scope of this Report*

Serious Health Related Suffering (SHS) – Lancet Commission Report

**Number of deaths/patients**
1. Mortality associated with SHS (decedent)
2. Patients in need of palliative care (total, decedent and non-decedent)

**Number of suffering days**
1. Total number of days with any suffering (sum of duration in days of each symptom) = **upper bound**
2. Number of days with symptom of longest duration (duration in days of longest lasting symptom as an “at least” estimate) = **lower bound**
Categories & Types: Patients’ Suffering

• Physical (11 symptoms)
  • Bleeding, constipation, diarrhea, dry mouth (xerostomia), shortness of breath (dyspnea), fatigue, nausea and/or vomiting, pain (mild vs. moderate or severe), itching (pruritus), weakness, wounds

• Psychological (4 symptoms)
  • Anxiety/worry, depressed mood, confusion/delirium, dementia
Magnitude of the Burden of SHS

- 25.6M of 56.2M deaths experienced SHS
- 35.5M experienced SHS before year of death
- In LMIC’s 10 Dx = >90% of people dying with SHS
  - Cancer, cerebrovascular, lung, injury, TB, premature birth & trauma, HIV, liver, heart disease, & dementia
- 21.2B SHS days/year for all patients worldwide
  - Cancer almost 50% of SHS
  - HIV, CVD, & COPD = ~10%
  - Pain >20% of total SHS days
- Lower bound 6 billion SHS Days
Lancet Commission
Essential Package of PC Services

• Medicines – all those in the WHO model list
• Medical Equipment – pressure mattress, NG tubes, urinary catheters, lock box, flashlight, diapers, O2
• Human Resources – MD, RN, SW, Psych, PT, Pharm, CHW, Support staff (clinical & non-clinical)
• Basic Needs/Social Support
Components of the Essential Package

<table>
<thead>
<tr>
<th>Medicine</th>
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<tbody>
<tr>
<td>Amitriptyline</td>
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<tr>
<td>Bisacodyl (senna)</td>
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<tr>
<td>Dexamethasone</td>
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<tr>
<td>Dexamethasone</td>
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<tr>
<td>Diazepam</td>
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<tr>
<td>Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)</td>
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<tr>
<td>Fluconazole</td>
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<tr>
<td>Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)</td>
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<tr>
<td>Furosemide</td>
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<tr>
<td>Haloperidol</td>
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<tr>
<td>Hyoscine butylbromide</td>
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<tr>
<td>Ibuprofen (naproxen, diclofenac, or meloxicam)</td>
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<tr>
<td>Lactulose (sorbitol or polyethylene glycol)</td>
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<tr>
<td>Loperamide</td>
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<tr>
<td>Metaclopramide</td>
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<tr>
<td>Metronidazole</td>
</tr>
<tr>
<td>Morphine (oral immediate-release and injectable)</td>
</tr>
<tr>
<td>Naloxone</td>
</tr>
<tr>
<td>Omeprazole</td>
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<tr>
<td>Ondansetron</td>
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<tr>
<td>Paracetamol</td>
</tr>
<tr>
<td>Petroleum jelly</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Equipment</th>
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<tbody>
<tr>
<td>Pressure-reducing air mattress</td>
</tr>
<tr>
<td>Nasogastric drainage or feeding tube</td>
</tr>
<tr>
<td>Urinary catheters</td>
</tr>
<tr>
<td>Opioid lock box</td>
</tr>
<tr>
<td>Flashlight with rechargeable battery (if no access to electricity)</td>
</tr>
<tr>
<td>Adult diapers (or cotton and plastic, if in extreme poverty)</td>
</tr>
<tr>
<td>Oxygen</td>
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<tr>
<th>Basic Needs/Social Support</th>
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</thead>
<tbody>
<tr>
<td>Cash payment and housing</td>
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<tr>
<td>Food package</td>
</tr>
<tr>
<td>Funeral support</td>
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<tr>
<td>In-kind support</td>
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<tr>
<td>Transportation costs</td>
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</tbody>
</table>
Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering (Lancet Commission Report 2017)
Distribution of major causes of death worldwide (2011*)

Communicable, maternal, perinatal and nutritional conditions 25%
Injuries 9%
Non-communicable diseases 66%

*Excluding tuberculosis patients who need PC (i.e. 153,000).
N=54,591,414

*WHO Global Health Estimates Deaths by Age, Sex, & Cause
Distribution of major causes of death worldwide (2016*)

N = 56,874,000

*WHO Global Health Estimates Deaths by Age, Sex, & Cause
Adult Need for PC Worldwide

- Cancer: 34.01%
- Cardiovascular diseases: 38.47%
- HIV/AIDS: 5.71%
- Chronic obstructive pulmonary disease: 10.26%
- Diabetes mellitus: 4.59%
- Kidney disease: 2.02%
- Cirrhosis of the liver: 1.70%
- Alzheimer’s and other dementias: 1.65%
- Multi-drug-resistant tuberculosis: 0.80%
- Parkinson disease: 0.48%
- Rheumatoid arthritis: 0.27%
- Multiple sclerosis: 0.04%

N = 19,228,760
Decedent Need for Palliative Care by Diagnosis

- Cancer: 30%
- Cerebrovascular: 16%
- Lung Disease: 11%
- Injuries: 6%
- Dementia: 5%
- TB: 5%
- Liver Disease: 5%
- Premature birth and trauma: 4%
- HIV: 4%
- Non-Ischemic Heart Disease: 4%
- All other: 11%

N=25.6M
Distribution of children in need of palliative care at the end of life by disease groups

- Neurological conditions (not including epilepsy): 2.31%
- Kidney diseases: 2.25%
- Cancer (Malignant Neoplasm): 5.69%
- Endocrine, blood, immune disorders: 5.85%
- Cardiovascular disease: 6.18%
- Cirrhosis of the liver: 1.06%
- Congenital anomalies (not including 1/2 heart): 25.06%
- HIV/AIDS: 10.23%
- Meningitis: 12.62%
- Protein energy Malnutrition: 14.12%
- Neonatal conditions (several adj): 14.64%
80% of the need for palliative care is in LMIC’s.

But 80% of existing PC services are in high income countries.
Global Development of Palliative Care*

- +16,000 services
- +3 million patients
- 6-12 million family
- ~14% of EOL need met
- >10% of total need

*Global Atlas of PC 2014
PC Services by 1M Population

Palliative care services given by providers
number of services per 1,000,000 population

- 0.01 - 0.20
- 0.21 - 1.23
- 1.24 - 4.85
- 4.86 - 681.20
PC All Levels of Development

Level of Palliative care Development (PCD)
- Level 1: not known activity
- Level 2: capacity building
- Level 3a: isolated provision
- Level 3b: generalized provision
- Level 4a: preliminary integration
- Level 4b: advanced integration
- Not applicable

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Mapping Levels of Palliative Care Development Globally

- Six Levels of Development
  1. No interest or development 32%
  2. Interest but no service provision 9.8%
  3a. Isolated provision of services 31.6%
  3b. Generalized Provision 7.3%
  4a. Preliminary Integration 10.7%
  4b. Advanced Integration 8.6%

Lynch, Connor, & Clarke, 2012
Aging

• The Elderly Sub-Population
  • Young old 65-74
  • Old 75-84
  • Old Old 85+

• For the first time in history, people aged 65 and over outnumber children under the age of 5.

• By 2050, the U.N. estimates that the proportion of the world's population age 65 and over will more than double, from 7.6% today to 16.2%
Children’s PC All Levels of Development

Levels of Pediatric Palliative Care provision and services
- Level 1. Not known activity
- Level 2. Capacity building
- Level 3. Localized provision
- Level 4. Preliminary to advanced integration
- Not applicable
- Data not available
17 Sustainable Development Goals
Important Considerations

• Universal Health Coverage
• Gender & Age
• Human rights
• Disability
• Vulnerable and Marginalised Populations (leave no-one behind)
• Poverty Reduction
Advocacy

- Policy
- Education
- Medication Access
- Implementation
EVIDENCE BASED REPORTS

DIPLOMATIC ENGAGEMENT AT THE UN

PUBLIC ACTION

WORLD HOSPICE AND PALLIATIVE CARE DAY

TARGETTED COLLABORATIVE ACTION

BUILDING PARTNERSHIPS AND CO-PRODUCING SOLUTIONS AND ACTION
Collaborative Global Advocacy Highlights

2005 – First World Hospice Palliative Care Day
2008 – UN Special Rapporteur on right to health report includes palliative care as neglected issue to UN GA
2011 – PC in Non-Communicable diseases global plan, UN political declaration and first PC indicator in WHO global monitoring framework
2013 – PC included in Universal Health Coverage definition
2014 – First Global Atlas on End of Life Care (WHO/WHPCA)
2014 – WHA palliative care resolution adopted
2017 – Palliative care included in Global Action Plan on Dementia and WHA cancer resolution
Community Based Palliative Care Development – Innovative Models

Three Examples

1. Neighborhood Network in PC – Kerala, India
2. Compassionate Communities – Korail Slum, Dhaka, Bangladesh
Model Palliative Care Programs Globally - Kerala

- Neighborhood Network in Palliative Care
Compassionate Korail
Compassionate Individuals

- Mindful Awareness & Intention
- Attunement to Self and Others
- Kindness & Courage
- Knowledge & Skills
- Wisdom & Fortitude for Presence and Action

Compassionate Relationships

- Between Family Members
- Between Patient-Caregiver
- Between Team Members
- Between Organizations
- Between Systems

Compassionate Communities

- Solidarity
- Social Attitudes
- Shared Values
- Sense of Belonging
- Interoceptivity

Compassionate Organizations

- Policy & Structure
- Leadership & Governance
- Guidance & Accountability
- Economic Sustainability

Connectedness & Shared Humanity
Kibera Community Self Help Program - KICOSHEP

• Grafting palliative care into a CBO
Decent Care Values in PC

- **Individual**
  - Agency
  - Dignity

- **Social**
  - Interdependence
  - Solidarity

- **Systemic**
  - Subsidiarity
  - Sustainability
What have we learned from low & middle income countries?

- Community Involvement/owners
- Home based care focus
- Task shifting
- Continuity of caring
- Our barriers are universal and mostly self-created
- Top down & bottom up
Community based palliative care development

What do these models have in common?

- Importance of leadership
- Focus on home based care
- Community Health Workers
- Volunteerism
- Community Ownership
- Family Caregiver Training/Empowerment
- Professional Back Up
- Compassionate Communities
Australian Population-based Palliative Approach Model

Groups

C

B

A

Needs

Complex

Intermediate

Primary care

←←← = Patient movement between levels

Australian Palliative Approach Model (modified)

- What We Flagged - using database flags to identify all various palliative type patients
- What we Know - patients already receiving one or more dedicated palliative services & providers
- What is New - previously unknown palliative patients now picked up by flags
- What is Unclear - remains to be decided what dedicated services best fit in Group B or Group C
- What is Unknown - patients who died but no palliative flags or services. Not know if need for HPEOL
Challenges and Vision for the Future of Palliative Care

• Challenges
  • 75% of countries have severely limited access to opioids
  • The world has two opioid crises
  • 42% of countries had no PC services
  • Over 61 million need PC but less than 10% receive it
  • 80% of this need is in resource limited settings
  • Children are less likely to receive PC services than adults
  • Slow progress in educating and retaining workers
  • Lack of public awareness of hospice & PC
Challenges and Vision for the Future of Palliative Care

How do we get to a more integrated model of palliative care?

• Increasing the capacity of primary care providers to integrate palliative care (PC) into practice
  • Increased PC education for all health professionals
  • Shifting existing resources from acute to primary palliative care – advanced illness management
• Increased capacity to deliver home based care
• Available, accessible, and affordable medicines
Challenges and Vision for the Future of Palliative Care

How do we get to a more integrated model of palliative care?

• Integration of specialized PC into existing health care delivery structures, not stand alone
• Better continuity of care between levels of care
• More community involvement/ownership and volunteerism
• Palliative care as a model for the health care system of the future
Challenges and Vision for the Future of Palliative Care

- **Vision for the future**
  - Opioids for palliative care patients are available in all countries
  - Public financing for palliative care extends to all LMIC’s
  - Palliative care is included in all country Universal Health Coverage schemes by 2030
  - Palliative care indicators & evidence measure the impact & value of palliative care in health care systems
  - All who need palliative care receive at least the essential package integrated into existing health care by 2030
Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor
Lucy’s Story – Public Engagement by Direct Stakeholders
Thank you!

For questions about this presentation contact me at sconnor@thewhpca.org