Estimating the Global Burden of Cancer-Related Suffering:

The Report of the Lancet Commission on Global Access to Palliative Care & Pain Relief

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Disclosures

• None
At the end of this presentation, participants will be able:

1. To describe estimates of cancer-related suffering and need for palliative care using a new detailed method.

2. To discuss global agreements stating relieving suffering by assuring access to palliative care is a medical and ethical imperative.
Estimated global burden of health-related suffering:

- Identified the serious conditions in the *International Classification of Diseases* (ICD)-10 that most commonly result in physical, psychological, or social, or spiritual suffering among:
  
  **“Decedents”** (patients with health-related suffering associated with one of these conditions who *died in 2015*)

  **“Non-decedents”** (patients with health-related suffering associated with one of these conditions who *did not die in 2015*)

<table>
<thead>
<tr>
<th>Condition (ICD-10 numbers)</th>
<th>Decedents in need of palliative care in 2015</th>
<th>Non-decedents in need of palliative care in 2015</th>
<th>Total patients in need of palliative care in 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>A96,98,99: Hemorrhagic fevers</td>
<td>16,629</td>
<td>16,629</td>
<td>33,258</td>
</tr>
<tr>
<td>A15-19: M/XDR TB</td>
<td>173,895</td>
<td>101,591</td>
<td>275,486</td>
</tr>
<tr>
<td>A15-19: Drug-sensitive TB</td>
<td>1,079,064</td>
<td>0</td>
<td>1,079,064</td>
</tr>
<tr>
<td>B20-24: HIV disease</td>
<td>1,059,626</td>
<td>15,761,933</td>
<td>16,821,559</td>
</tr>
<tr>
<td>C00-97: Malignant neoplasms (except C91-95)</td>
<td>7,576,096</td>
<td>7,131,250</td>
<td>14,707,346</td>
</tr>
<tr>
<td>C91-95: Leukemia</td>
<td>259,623</td>
<td>0</td>
<td>259,623</td>
</tr>
<tr>
<td>F00-04: Dementia</td>
<td>1,227,084</td>
<td>4,400,000</td>
<td>5,627,084</td>
</tr>
<tr>
<td>G00-09: Inflammatory disease of CNS</td>
<td>348,726</td>
<td>31,997</td>
<td>380,722</td>
</tr>
<tr>
<td>G20-26; G30-32; G35-37; G40-41; G80-83 Other CNS disorders: movement, degenerative, demyelinating; epilepsy; cerebral palsy, other paralytic dz</td>
<td>288,649</td>
<td>669,100</td>
<td>957,749</td>
</tr>
<tr>
<td>I60-69: Cerebrovascular disease</td>
<td>4,043,697</td>
<td>3,855,000</td>
<td>7,898,697</td>
</tr>
<tr>
<td>I05-09; I25; I42 &amp; I50: Chronic rheumatic heart diseases; Cardiomyopathy &amp; Heart failure</td>
<td>1,021,720</td>
<td>0</td>
<td>1,021,720</td>
</tr>
<tr>
<td>I25: Chronic ischemic heart disease</td>
<td>436,384</td>
<td>0</td>
<td>436,384</td>
</tr>
<tr>
<td>J40-47; J60-70; J80-84; J95-99: Chronic lung dz</td>
<td>2,709,076</td>
<td>0</td>
<td>2,709,076</td>
</tr>
<tr>
<td>K70-77: Diseases of liver</td>
<td>1,226,013</td>
<td>0</td>
<td>1,226,013</td>
</tr>
<tr>
<td>N17-19: Renal failure</td>
<td>355,407</td>
<td>0</td>
<td>355,407</td>
</tr>
<tr>
<td>P07; P10-15: Low birth weight &amp; prematurity; Birth trauma</td>
<td>1,069,086</td>
<td>0</td>
<td>1,069,086</td>
</tr>
<tr>
<td>Q00-99: Congenital malformations</td>
<td>387,616</td>
<td>387,616</td>
<td>775,232</td>
</tr>
<tr>
<td>S00-99; T00-98; V01-Y98: Injury, poisoning, external causes</td>
<td>1,477,212</td>
<td>2,954,424</td>
<td>4,431,636</td>
</tr>
<tr>
<td>I70: Atherosclerosis</td>
<td>359,679</td>
<td>0</td>
<td>359,679</td>
</tr>
<tr>
<td>M00-97: Musculoskeletal disorders</td>
<td>108,422</td>
<td>216,844</td>
<td>325,266</td>
</tr>
<tr>
<td>E40-46: Protein-Energy Malnutrition</td>
<td>330,105</td>
<td>0</td>
<td>330,105</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>25,553,808</strong></td>
<td><strong>35,526,384</strong></td>
<td><strong>61,080,192</strong></td>
</tr>
</tbody>
</table>
• Then determined:
  – The **categories and specific types of suffering** resulting from each condition (physical or psychological symptoms, social distress, spiritual distress).
  – The **prevalence of each type of suffering** associated with each condition.
  – The **duration of each type of suffering** associated with each condition.

• **All estimates were:**
  – Based on thorough literature review;
  – Reviewed / adjusted by a panel of experienced PC physicians from LMICs.
4 Categories and Specific Types of Suffering

PHYSICAL
- Pain Chronic Mild
- Pain Chronic Moderate/Severe
- Dyspnea
- Fatigue
- Weakness
- Nausea and/or vomiting
- Diarrhea
- Constipation
- Dry Mouth
- Pruritus
- Bleeding
- Wounds

SOCIAL
- Homelessness / Inadequate housing
- Lack of adequate food
- Legal problems
- Feeling stigmatized / discriminated against
- Social isolation
- Lack of transportation

SPIRITUAL
- Loss of sense of meaning of life
- Loss of faith
- Angry with God or higher power

PSYCHOLOGICAL
- Anxiety / worry
- Depressed mood
- Confusion / delirium
- Dementia

<table>
<thead>
<tr>
<th></th>
<th>Malignant neoplasms</th>
<th>Leukemia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Decedents</td>
<td>Non-decedents</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>8,417,884</td>
<td>32,600,000</td>
</tr>
<tr>
<td>% need</td>
<td>90%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Number in need</strong></td>
<td>7,576,096</td>
<td>7,131,250</td>
</tr>
<tr>
<td><strong>Pain mod / severe</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% / number</td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>Duration (days)</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td><strong>Dyspnea</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% / number</td>
<td>35%</td>
<td>15%</td>
</tr>
<tr>
<td>Duration (days)</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td><strong>Nausea or vomiting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% / number</td>
<td>20%</td>
<td>15%</td>
</tr>
<tr>
<td>Duration (days)</td>
<td>120</td>
<td>21</td>
</tr>
<tr>
<td><strong>Depressed mood</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% / number</td>
<td>47%</td>
<td>18%</td>
</tr>
<tr>
<td>Duration (days)</td>
<td>150</td>
<td>150</td>
</tr>
</tbody>
</table>
World Health Assembly Resolution 67.19 (2014) “Strengthening of Palliative Care (PC)"

1) PC “is an ethical responsibility of health systems.”
2) “… it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured …”
3) It is especially important to integrate PC into primary care.
4) Efforts to minimize risk of diversion of controlled medicines for illicit purposes must “not result in inappropriate regulatory barriers to medical access to such medicines.”
5) “… adequate training [in PC is needed] …”
So, how accessible is palliative care?

Accessibility of opioids pain medicines is a surrogate indicator.
Patients in Low and Middle Income Countries (LMICs) Rarely Have Access to Pain Relief & Palliative Care

- **83%** of world’s 7 billion people in LMICs (~5.8 billion)
- > 5.5 million terminal cancer patients per year in LMICs
- Millions with other serious chronic illnesses (cardiovascular disease, liver or renal failure, lung disease, AIDS, etc.)
- Yet only **9%** of world’s opioids consumed in LMICs
Global Consumption of Morphine
High-Income vs. Low/Middle-Income Countries, 2013

<table>
<thead>
<tr>
<th></th>
<th>High Income (48)</th>
<th>Low- and Middle-Income (102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>17%</td>
<td>83%</td>
</tr>
<tr>
<td>Consumption of Morphine</td>
<td>91%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Morphine equivalents in mg per patient with serious health-related suffering (SHS)

Western Europe (country average) 18,316 mg

USA 55,704 mg

Canada: 68,194 mg

Mexico: 562 mg

Costa Rica: 422 mg

Chile: 922 mg

Argentina: 3,174 mg

India: 43 mg

Uganda: 53 mg

China: 314 mg

Russia: 124 mg

Bangladesh: 53 mg

Australia: 40,636 mg

Consequences of no PC: MILLIONS of vulnerable patients suffer needlessly
Thank you
An essential package for palliative care

M.R. Rajagopal

www.palliumindia.org

chairman@palliumindia.org
Serious Health-related suffering (SHS)

“Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social or emotional functioning”.

Components of essential package

- Medical equipment
  - 7 items
- 21 essential medicines
- Human resources
Cost of the essential package…

…as percentage of cost of Universal Health Coverage (UHC):

0.6 – 3%
Will it not save money?

By making palliative care available, inappropriate disease-specific treatment can be avoided when futile, thus reducing health care costs.

A challenge to the essential package:

Could the low cost of the essential package be a deterrent to its availability?
Challenge:

“Despite the relatively low prices that can be obtained on the international market, availability of essential drugs remains deficient, and over half the poorest people in Africa and Asia still do not have access to these drugs”.

The impact of cost

“100 million people are pushed into poverty and 150 million people face financial hardship because they have to pay directly for the health services they use at the point of delivery”.

The impact of *health* care

Catastrophic out-of-pocket health expenditure pushed more than 4% of population of India and Bangladesh below poverty line in a year.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5988077/
Lopsided availability

- In Rwanda, injectable morphine costs 6 times more than international price.
- Many countries and many institutions have expensive opioids (transdermal fentanyl, sustained release tablets); but not immediate release morphine.

Morphine manifesto. Available at: http://palliumindia.org/manifesto
Organization of palliative care: WHO model

Education of professionals.

Essential medicines. (Affordability)

Policy

Accepting suffering as a focus & strategizing.
Quality of life
Can palliative care reduce healthcare costs and strengthen healthcare systems?

Dr. Stephen R Connor
Executive Director - WHPCA

World Cancer Congress – Kuala Lumpur – 2 Oct 2018
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
Definitions

- Palliative Care
- Cost Effectiveness Research
- Serious Health Related Suffering
- Quality of Life
- Decedents & Non-decedents
- End-of-Life
Cost Effectiveness Research

• Cost Effectiveness Analysis
  • a form of *economic analysis* that compares the relative costs and outcomes (effects) of different courses of action. Often visualized on a plane consisting of *four-quadrants*, the cost represented on one axis and the effectiveness on the other axis. Often used in the field of health services, where it may be inappropriate to *monetize* health effect.

• Cost Benefit Analysis
  • assigns a monetary value to the measure of effect. Typically the CEA is expressed in terms of a ratio where the denominator is a gain in health from a measure (QALY’s).
In the context of decision-making, especially in healthcare, Cost-Effectiveness Analysis (CEA) is a crucial tool. CEA helps in determining whether the cost of a particular intervention is justified by its effectiveness. The graph on the left illustrates the relationship between cost and effectiveness, with 'REJECT?' and 'ADOPT?' as decision points.

The right side of the image shows a balance scale, symbolizing the weighing of costs against benefits. This visual representation underscores the importance of considering both cost and effectiveness when making decisions.
Serious Health Related Suffering

• Suffering is health-related when it is associated with illness or injury of any kind. Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social or emotional functioning.

• Palliative care should be focused on relieving the SHS that is associated with life-limiting or life-threatening conditions or the end of life.
Quality of Life

• A very subjective concept that is determined by a person’s internal perception of what’s important at a given time. Difficult to use for accountability

• At the end of life a number of domains usually are most important including:
  • Functional Status
  • Symptom burden
  • Well being
  • Interpersonal relations
  • Transcendent
How could palliative care reduce costs?

• Basic premise – Cost Avoidance
  • Small increases in costs for home based care more than offset by reductions in acute care hospitalization
  • Palliative care also reduces ER use, excessive lab and diagnostics, cost of futile treatment
  • Unnecessary hospitalization, testing, treatment
  • Preventive approach
  • Family education, empowerment, & poverty reduction
  • 24 hour / 7 day-week access to multi-professional team
80/20 Rule

• 80% of health care funds are used for acute care
• 80% of the need for health care is for chronic care

• 80% of the need for palliative care is in low and middle income countries, 20% in high income
• 80% of currently available palliative care is in the 20% high income countries

• We need to reverse both
What does the evidence say?

- Mainly from high income settings
- Supports the basic premise
- Ethical concerns limit RCT evidence
- Growing number of research trials
- Examine each assertion
  - Reduced hospitalization
  - Reduced ER, testing, & treatment costs
  - Increased cost for home care
Reduced Hospitalization

• Studies of hospital based palliative care consultations\(^1,2\) show reductions in hospital costs for patients that die during their last admission ($4908 - $7563)\(^3,4\) and in most studies for patients discharged alive ($1696 – $4098).\(^3,4\)

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Reduced Cost of Care

- Studies of home based palliative care show reductions in overall cost of care (Euro 436)\(^5\), (USD 7552)\(^6\), (USD 5936)\(^7\) per cancer patient.

- Palliative care includes having consistent conversations with patients about goals of care that lead to improved outcomes and reduced expenditures (USD 1041), \(^8,9\)


Despite wide variation in study type, characteristic and study quality, there are consistent patterns in the results. Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant.  

Evidence in Low & Middle Income Countries\textsuperscript{11}

- While proven to be ‘cost-effective’ in high-income settings based on principles of cost avoidance, the costs of illness for incurable disease in low-resource settings is largely unknown.

- The critical absence of palliative care services in low-resource settings results in significant costs being absorbed by the individual, family and local community. This results in intractable, devastating and perpetuating financial losses that are passed on to future generations and function as a catalyst in the poverty cycle while stunting local economic growth.

- Palliative care should be considered as a poverty-reduction strategy.

\textsuperscript{11} Anderson RE, & Grant L. What is the value of palliative care provision in low-resource settings? BMJ Global Health 2017;2:e000139.
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

Felicia Marie Knaul, Paul E Farmer*, Eric L Krakauer*, Lillana De Lima, Afshan Bhadelia, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodriguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diederik Lohman, Lukas Radbruch, María del Rocío Sáenz Madrigal, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopalan†, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group†
Strengthening Health Care Systems

• 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
Strengthening Health Care Systems

• 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
Free to Download
www.thewhpca.org/resources

Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor
Palliative Care #BecauseIMatter

Toolkit 2018

World hospice & palliative care day
Thank you!

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