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.

Lancet Commission on Palliative Care / Disease Control Priorities 3rd Ed. (World Bank)

- **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)

Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage. Lancet 2017. Available at: http://dx.doi.org/10.1016/S0140-6736(17)32513-8

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

- 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

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

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

Cancer-Related Suffering – Global Estimate (2015)

		Malignant neoplasms			Leukemia	
		Decedents	Non-decedents	Combined	Deced.	Non-deced.
TOTALS	Number	8,417,884	32,600,000		288,470	NA
	% need	90%	22%		90%	
	Number in need	**7,576,096**	**7,131,250**	**14,707,346**	**259,623**	**NA**
Pain mod / severe	% / number	80% / 6,060,877	20% / 1,426,250	7,487,127	35% / 90,868	NA
	Duration (days	90	90		60	
Dyspnea	% / number	35% / 2,651,634	15% / 1,069,688	3,721,322	50% / 129,812	NA
	Duration (days	90	90		60	
Nausea or vomiting	% / number	20% / 1,515,219	15% / 1,069,688	2,584,907	20% / 51,925	NA
	Duration (days)	120	21		60	
Depressed mood	% / number	47% / 3,560,765	18% / 1,283,625	4,844,390	47% / 122,023	NA
	Duration (days)	150	150		90	

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?

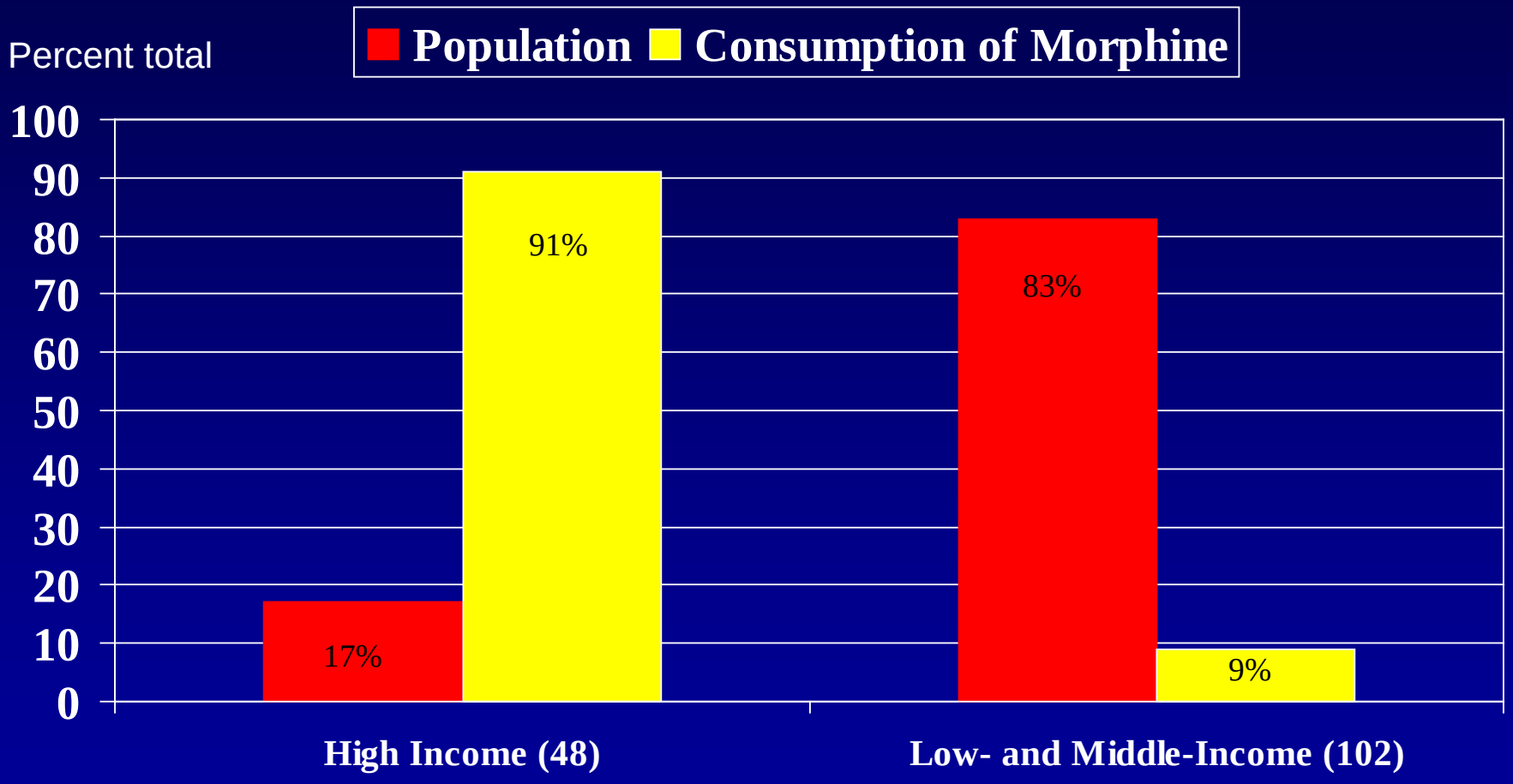
Accessibility of opioids pain medicines is a surrogate indicator.

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

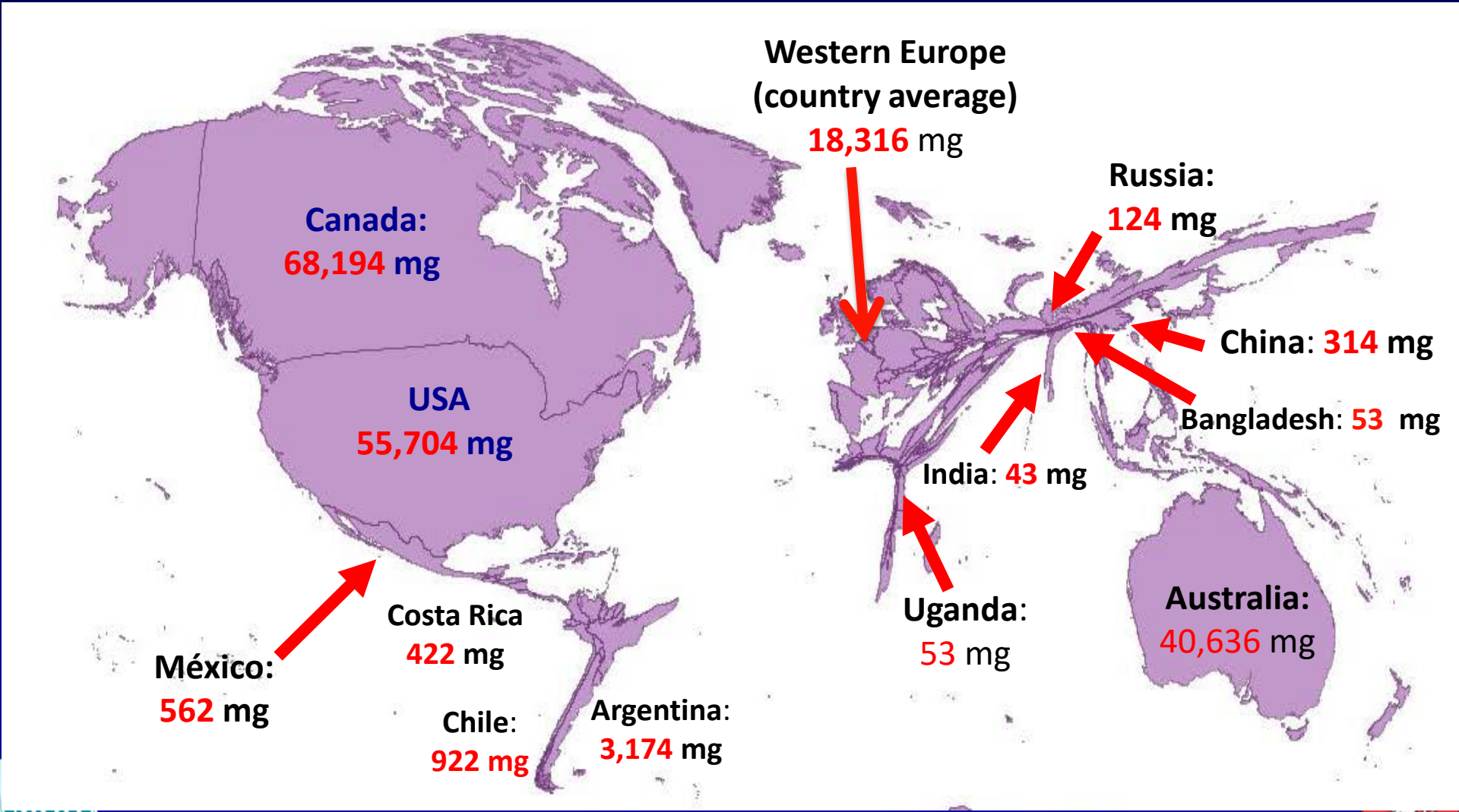
Global Consumption of Morphine

High-Income vs. Low/Middle-Income Countries, 2013



Source: International Narcotics Control Board; United Nations Population Data, 2007; World Bank Income Classification, 2013.
By: Pain & Policy Studies Group, University of Wisconsin /WHO Collaborating Center, 2013.

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



Knaul, Farmer, Krakauer et al, 2017. http://www.thelancet.com/commissions/palliative-care

Consequences of no PC: MILLIONS of vulnerable patients suffer needlessly

Thank you

An essential package for palliative care

M.R.Rajagopal

www.palliumindia.org

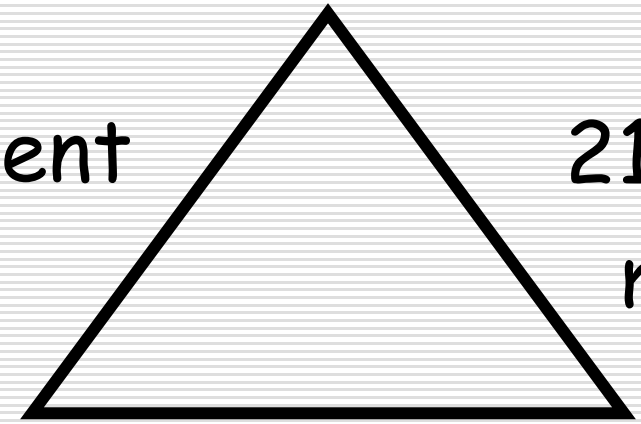
chairman@palliumindia.org

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".

Knaul FM et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *The Lancet, 2017*, 391:10128

Components of essential package



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.

Temel JS; Greer JA; Muzikansky MA; Gallagher ER et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med Med 2010;363:733-42.

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".

WHO Medicines Strategy: 2000:2003. Framework for action in essential Drugs and Medicines Policy (Cited 21 Jan 2014).Available from www.who.int/medicinedocs/pdf/whozip16e/whozip16e.pdf.

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".

Xu et al. 2007; World Health Organization 2010 (Cited 20 Jan 2014). Available from http://www.who.int/health_financing/documents/dp_e_11_02-ncd_finburden.pdf

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.

Selvaraj S, Farooqui HH, Karan A. Quantifying the financial burden of households' out-of-pocket payments on medicines in India, 1994–2014. BMJ Open. 2018 May 31;8(50 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5988077/

Lopsided availability

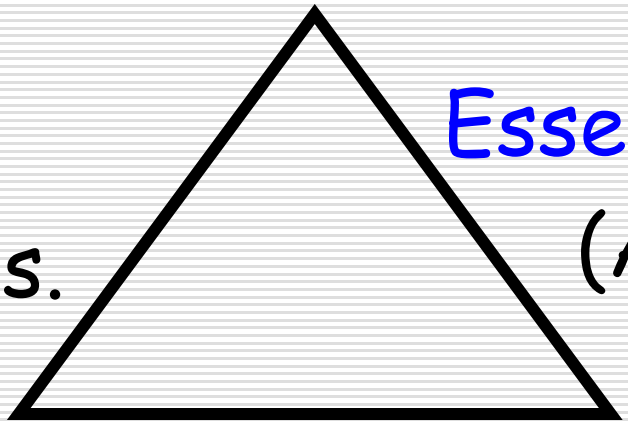
- In Rwanda, injectable morphine costs 6 times more than international price.
- Many countries and many institutions have expensive opioids (transdermal fentanyl, sustained release tablets); but not immediate release morphine.

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

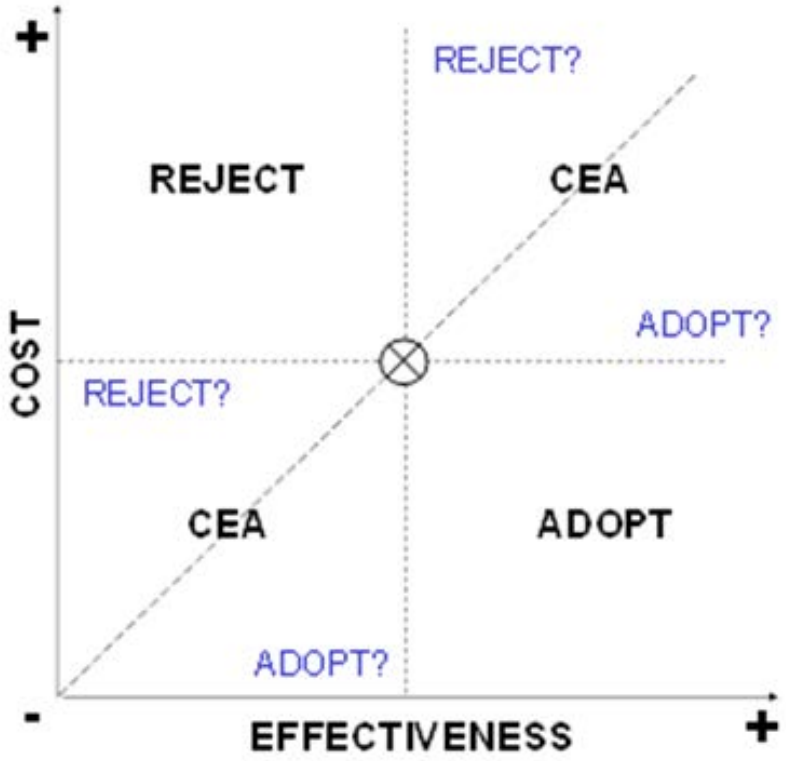
- 67% 60+ / 8.6% children
- 80% LMIC
- 93.5% NCD
- ~75% of countries no or limited delivery of PC
- only 8% of countries good integration
- 92% of morphine used by 17% of world population

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)


+
REJECT?
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BENEFITS
COSTS
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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]

- 1 Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, Morrison RS. Cost and utilisation outcomes of patients receiving hospital-based palliative care consultation. Journal of Palliative Medicine 2006; 9(4):855–860.
- 2 Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. Palliative Medicine 1998; 12(5):317–332.
- 3 Morrison RS, Penrod JD, Litke A, Meier DE, Cassel JB, Caust-Ellenbogen M, Spragens L. Cost savings associated with US hospital palliative care consultation programs. Archives of Internal Medicine 2008; 168(16):1783–1790.
- 4 Morrison RS, Meier DE, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J. The care span: Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. Health Affairs 2011; 30(3):454–463.

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]

- 5 Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: Evidence from Catalonia. Palliative Medicine 2001; 15(4):271–278.
- 6 Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, Gonzalez J. Increased satisfaction with care and lower costs: Results of a randomised trial of in-home palliative care. Journal of the American Geriatrics Society 2007; 55(7):993–1000.
- 7 Enguidanos SM, Cherin D and Brumley R. Home-based palliative care study: site of death, and costs of medical care for patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer. J Soc Work End Life Palliat Care 2005; 1: 37–56.
- 8 Wright AA, Trice E, Zhang B, Ray A, Balboni T, Block SD, Maciejewski PK. Associations between end of life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA – Journal of the American Medical Association 2008; 300(14):1665-1673.
- 9 Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Prigerson HG. Healthcare costs in the last week of life: Associations with end of life conversations. Archives of Internal Medicine 2009; 169(5):480–488.

Recent Review Article

- 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 [10]

10. Smith, Brick, O'hara, Normand. Evidence on the cost and cost-effectiveness of palliative care: A literature review *Palliative Medicine*. 2014, 28(2):130-150

Evidence in Low & Middle Income Countries[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.

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

The Lancet Commissions

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*, Liliana De Lima, Afsan 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 Rajagopal†, 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

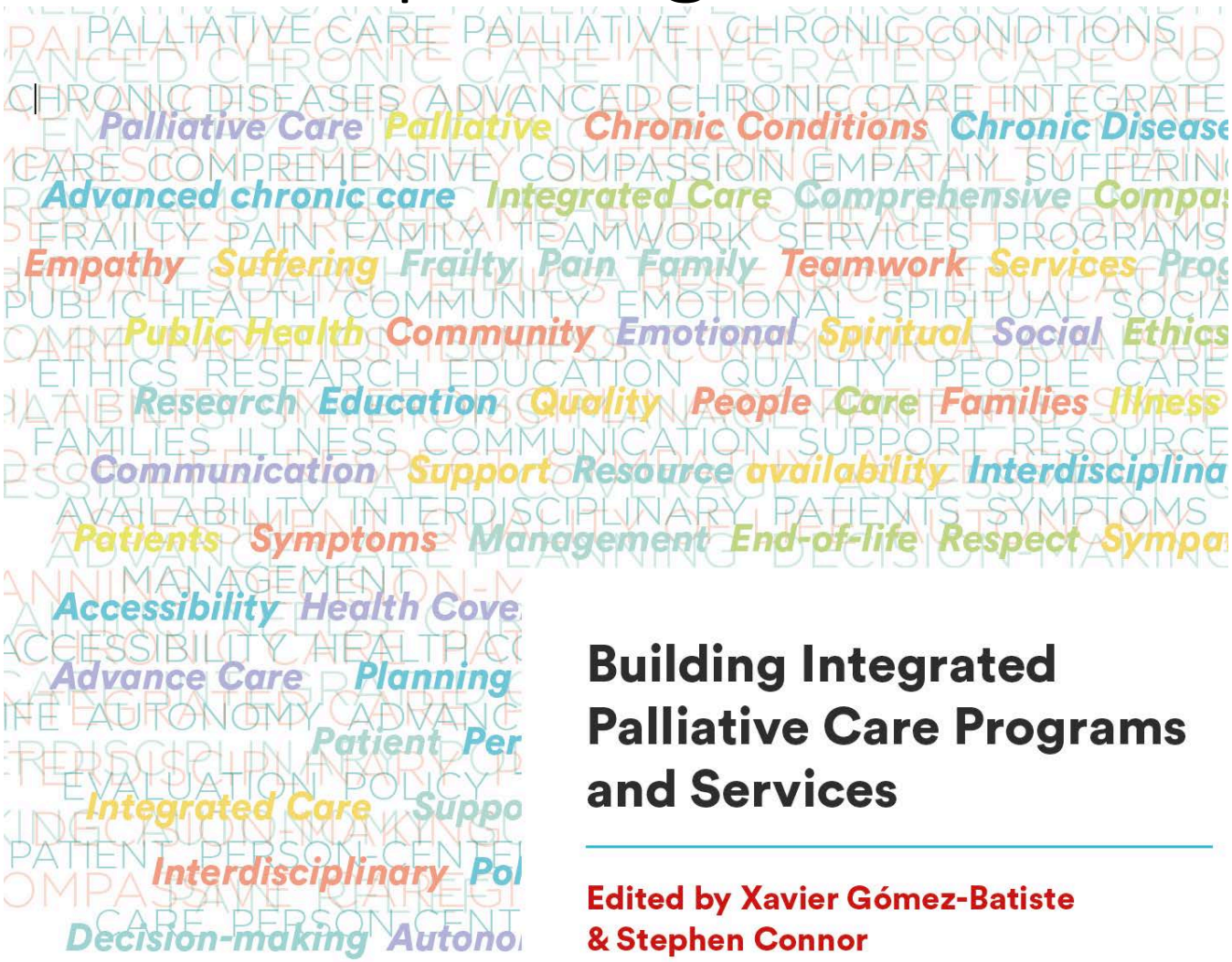
Strengthening Health Care Systems

- 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



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worldwide hospice palliative care alliance

Palliative Care #BecauseIMatter

Toolkit 2018

World hospice & palliative care day

Thank you!

For questions about this presentation contact me at

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