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

Key Findings and Overview of The *Lancet* Commission Report

http://www.thelancet.com/commissions/palliative-care

FIU 8th International Conference on Global Health
May 24, 2018

Dr. Natalia Rodriguez
on behalf of Dr. Felicia Knaul and the Lancet Study Group
University of Miami

Are we missing the real opioid crisis? (BBC News)

"From that moment commenced the shrieking fit which lasted for three days, and was so terrible that it was impossible to hear it without horror even through two doors."

Leo Tolstoy, The Death of Ivan Ilyich, 1886

"Imagine your final months, weeks, and days of life. Like most, you probably hope to be free of pain. Consider, however, a scenario in which you and those who hold you dear face those painful days with no access to the palliative care that could alleviate your suffering: Tolstoy's Ivan Ilyich bereft of even opium to calm the fear and agony.

Unimaginable? Yet this is the reality for most people. With few exceptions, poor people throughout the world live and die with little or no access to pain relief or any other type of palliative care."

Lancet Commission on Palliative Care and Pain Relief

Overview of Lancet Commission and Report

Health Systems and Global Health
+
Palliative Care Specialists

- **Chair, co-chair**
- **33 commissioners**
- **61 co-authors from over 25 countries**

Led by the University of Miami in collaboration with Harvard University

5 Key Messages

1. Alleviation of the burden of serious health-related suffering from life-threatening or life-limiting conditions and at end-of-life is a global health and equity imperative.

2. Universal access to an affordable Essential Package of palliative care can alleviate much of the burden of SHS.

3. LMICs can improve the welfare of poor people at modest cost by publicly financing the Essential Package of palliative care and through full integration into universal health coverage.

4. International and balanced collective action is essential to achieving universal coverage of palliative care and pain relief by facilitating effective access to essential medicines, while implementing measures to prevent non-medical use.

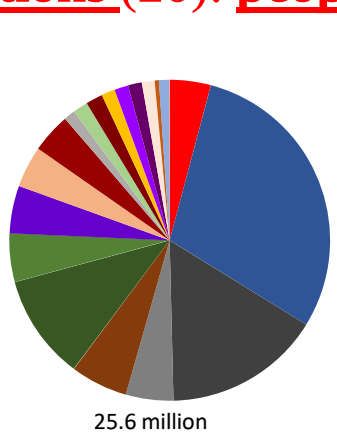
5. Better evidence and priority setting tools must be generated to adequately measure the global need for palliative care, implement policies and programs, and monitor progress towards alleviating the burden of pain and other SHS

Outline

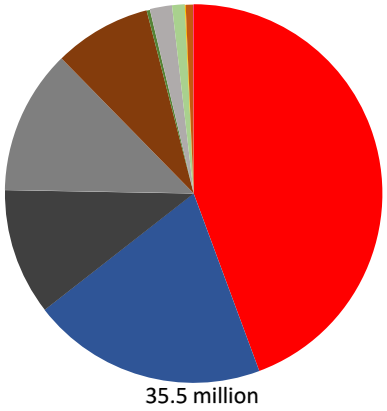
1. Global Need:
   Serious Health-related Suffering
2. Unmet need: access to pain relief
3. Intervention: an essential package
4. Strengthening the global and national health systems
5. Next steps

Global burden of serious health-related suffering (SHS) - 2015

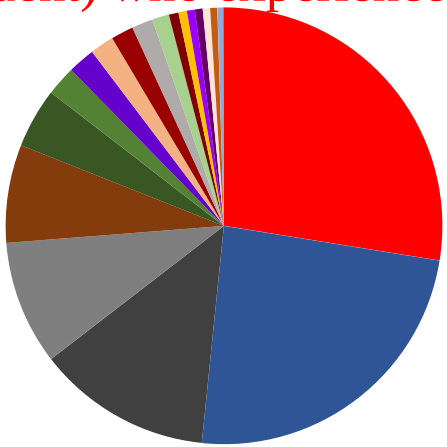
Health conditions (20): **people** (decedent and non-decedent) who experienced SHS



25.6 million



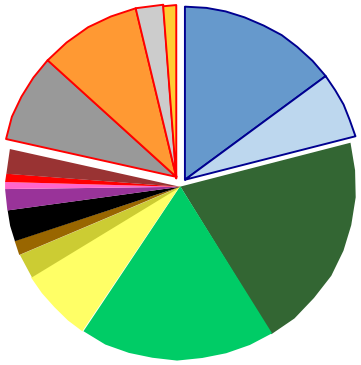
35.5 million



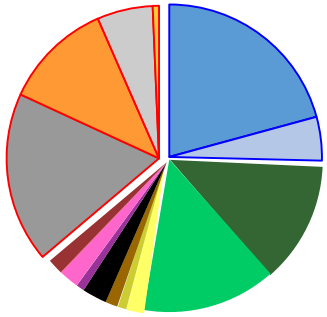
61.1 million

HIV disease
Lung disease
Degenerative CNS disease
Renal failure
Malignant neoplasm
Tuberculosis
Congenital malformation
Malnutrition
Cerebrovascular disease
Liver disease
Chronic ischaemic heart disease
Muskuloskeletal disorder
Dementia
Low birth, premature birth, birth trauma
Inflammatory CNS disease
Leukaemia
Injury
Non-ischaemic heart disease
Haemorrhagic fevers
Atherosclerosis

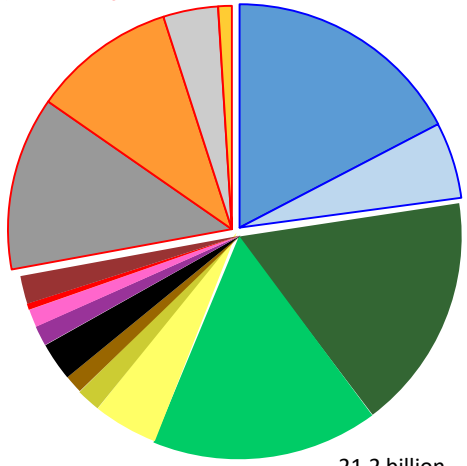
Symptoms (15): physical (11) and psychological (4); **days** with SHS



11.9 billion



9.3 billion



21.2 billion

Pain (mild)
Pain (moderate to severe)
Anxiety, worry
Depressed mood
Confusion, delirium
Dementia
Constipation
Shortness of breath
Fatigue
Weakness
Nausea, vomiting
Diarrhoea
Dry mouth
Itching
Bleeding
Wounds

Global burden of serious health-related suffering (SHS) in 2015

25.5 million deaths

- 45% of the 56.2 million deaths worldwide

And…

- at least 35.5 million people experienced SHS (non-decedents)

5.3 million children with SHS
99% are in LMICs

61.1 million people worldwide suffered

> 6 billion days of suffering (up to 21 billion days)

80% in LMICs

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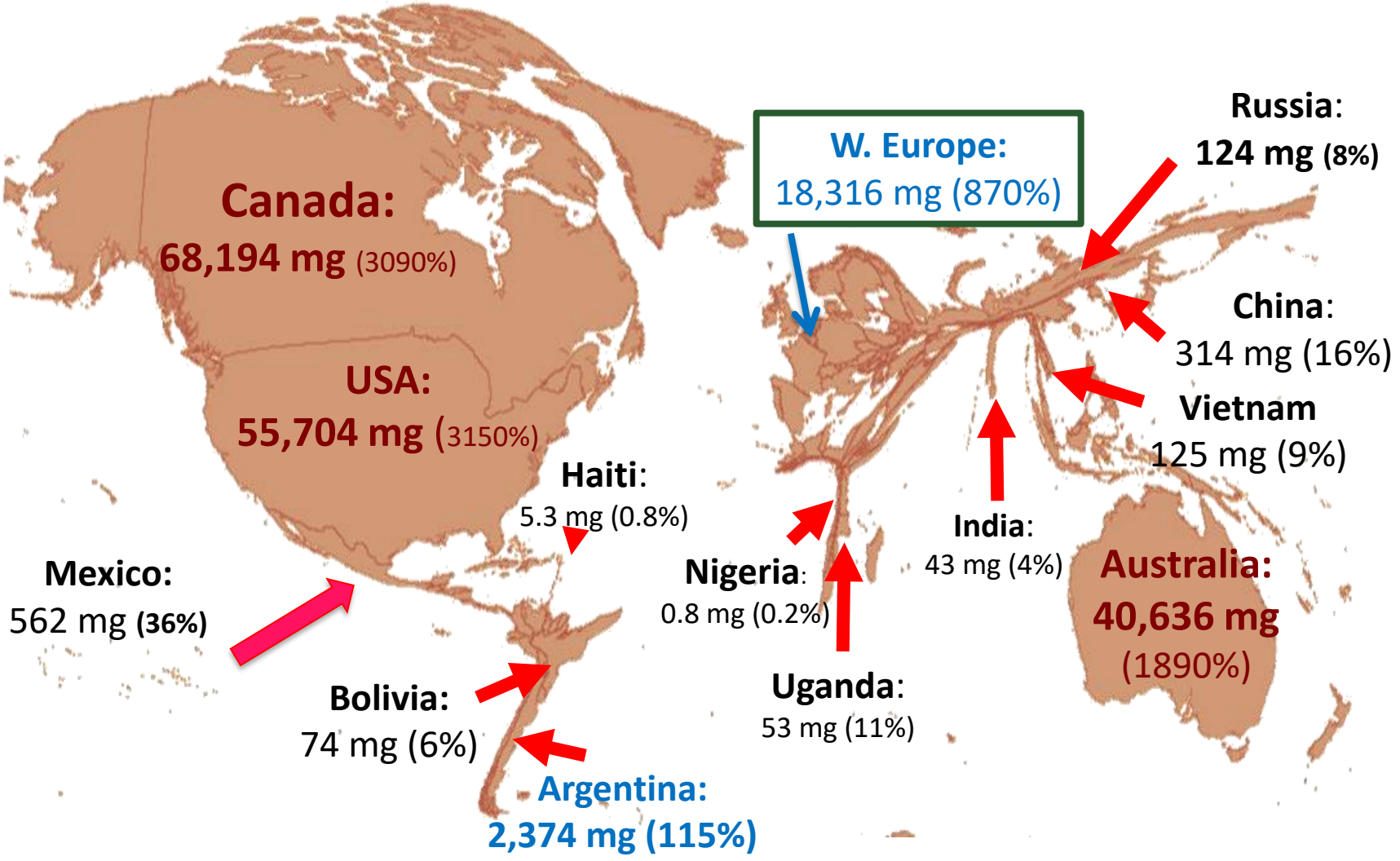
Distributed opioid morphine-equivalent

mg/patient & (% of SHS palliative care need met)



Source: Author calculations using INCB (2010-13) and GHE 2015 (www.incb.org, http://www.who.int/healthinfo/global_burden_disease/en/) . See Data Appendix for methods.

Inequity of access: distributed opioid morphine-equivalent (DOME)

- The 50% poorest: <1%
- The 10% richest: almost 90%

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Intervention: Essential Package

Medicine
Amitriptyline
Bisacodyl (Senna)
Dexamethasone
Diazepam
Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate, oral and injectable)
Fluconazole
Fluoxetine or other SSRI (sertraline and citalopram)
Furosamide
Hyoscine Butylbromide
Haloperidol
Ibuprofen (naproxen, diclofenac, or meloxicam)
Lactulose (sorbitol or polyethylene glycol)
Loperamide
Metoclopramide
Metronidazole
Morphine
Naloxone Parenteral
Omeprazole oral
Ondasetron
Paracetamol oral
Petroleum jelly

Medical Equipment
Pressure Reducing Mattress
Nasogastric drainage or feeding tube
Urinary catheters
Opioid lock box
Flashlight with rechargeable battery
Adult diapers/ Cotton and Plastic
Oxygen

Human Resources
Doctors (Specialty and General)
Nurses (Specialty and General)
Social Workers and Counsellors
Psychiatrist, psychologist or counsellor
Physical Therapist
Pharmacist
Community Health Workers
Clinical Support Staff
Non Clinical Support Staff

Aligned with Sustainable Development Goals (SDGs): Should be made universally accessible by 2030

Essential Package: cost per person with SHS Rwanda, Vietnam and Mexico by medicine prices

(US$ current value, 2015)

	Rwanda			Vietnam			Mexico		
	Reported Price	Intl Prices		Reported Price	Intl Prices		Reported Price	Intl Prices	
		Lowest	Highest		Lowest	Highest		Lowest	Highest
Medicines	52	18	78	27	23	96	122	28	119
Morphine (oral or injectable)	*20*	*8*	*50*	*14*	*12*	*76*	*90*	*14*	*84*
Equipment	31			5			31		
Palliative care team (HR)	121			78			584		
Total	**219**	**182**	**248**	**119**	**115**	**194**	**796**	**694**	**793**
% public health expenditure[4]	**8.8**	**7.3**	**9.9**	**1.0**	**1.0**	**1.7**	**1.0**	**0.8**	**1.0**

For LIMCS: =~3% of the DCP3 Essential UHC package

Annual estimated cost of closing the access abyss and meeting the global palliative care need for morphine

- At current prices: $US600 million
- At best international prices: $US145 million

- For all children with SHS in low income countries: $US 1,034,000

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4. **Strengthening the global and national health systems**
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Universal Health Coverage

All people must obtain the health services they require - prevention, promotion, treatment, rehabilitation and palliative care - without the risk of impoverishment (WHO)

Through a wave of global reforms in the difficult context of a complex epidemiological transition, and with highly fragmented health systems

Unfortunately, palliative care and pain control have been ignored in most countries

Strengthening Health Systems, by Function to Expand Access PC & PR

Stewardship

Priority setting
- Implement public education and awareness-building campaigns around palliative care and pain relief
- Incorporate palliative care and pain relief into the national health agenda

Planning
- Develop comprehensive palliative care and pain relief guidelines, programmes, and plans
- Integrate palliative care into disease-specific national guidelines, programmes, and plans
- Include palliative care and pain relief essential medicines in national essential lists

Regulation
- Establish effective legal and regulatory guidelines for the safe management of opioid analgesics and other controlled medicines that do not generate unduly restrictive barriers for patients
- Design integrated guidelines for provision of palliative care and pain relief that encompass all service providers

Monitoring and evaluation of performance
- Monitor and evaluate palliative care and pain relief interventions and programmes using an explicit outcomes scale, measuring coverage as well as effect
- Promote civil society involvement in performance Assessment

Intersectoral advocacy
- Engage all relevant actors in the promotion and implementation of palliative care interventions and programmes through ministries of health

Financing

- Explicitly include palliative care interventions in national insurance and social security health-care packages
- Guarantee public or publicly mandated funding through sufficient and specific budgetary allocations starting with the Essential Package
- Develop pooled purchasing schemes to ensure affordable, competitive prices for palliative care inputs and Interventions

Delivery

- Integrate palliative care and pain relief at all levels of care and in disease-specific programmes
- Design guidelines to provide effective and responsive palliative care and pain relief services
- Integrate pain relief into platforms of care, especially surgery
- Establish efficient referral mechanisms
- Implement quality-improvement measures in palliative-care initiatives
- Develop and implement secure opioid supply chain and ensure adequate prescription practices

Resource Generation

Human resources
- Establish palliative care as a recognised medical and nursing specialty
- Make general palliative care and pain relief competencies a mandatory component of all medicine, nursing, psychology, social work, and pharmacy undergraduate curricula
- Require that all health and other professionals involved in caring for patients with serious, complex, or life-threatening health conditions receive basic training in palliative care and pain relief

Information and Research

- Incorporate palliative care and pain relief access, quality, and financing indicators into health information systems
- Ensure that government-funded research programmes include palliative care

National palliative care and pain relief associations

Inter-institucional, multi-disciplinary national committees to advocate for implementation and monitor commitments, compliance and progress…

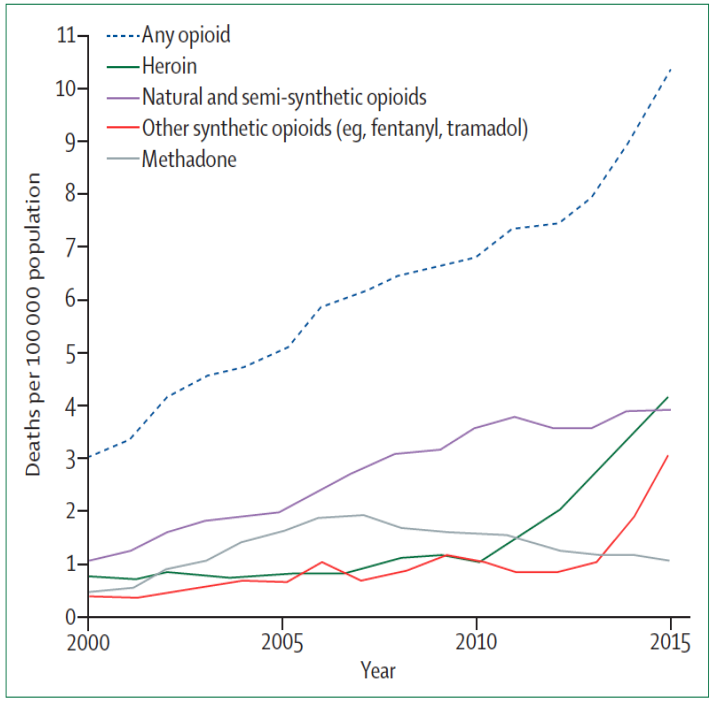
Country Case Studies

Regions	Health Systems & UHC / Models & Innovations	
Africa	Kenya Malawi Rwanda	South Africa Uganda
East Asia	Mongolia Vietnam	
Eastern Europe	Albania Romania	
Latin America and Caribbean	Chile Colombia Costa Rica	El Salvador Jamaica Mexico
Middle East	Lebanon	
North America	United States	
South Asia	Kerala, India India Nepal	

Opioid Epidemic in US: lessons and recommendations

- Monitor the supply and marketing of opioids
- Prevent direct marketing of opioid medications to health care providers by pharmaceutical companies
- Ensure that all health personnel receive mandatory, basic training for safe management of opioid analgesics
- Ensure that indications for use and prescription of opioid medications follow evidence-based practice

Deaths from opioids overdose, by type of opioid, in USA 2000-15



A balanced approach is essential – adequate attention to medical needs of all patients, as well as management of risk of non-medical use

Global Collective Action

	WHO, UNICEF, and other UN agencies	World Bank and other development banks	Bilateral agencies	Trusts or foundations	Global and regional not-for-profit organisations	Academic institutions and think tanks	For-profit and corporate multinational and transnational entities
Stewardship							
Consensus building around the importance of palliative care	+++	++	+++	+	+++	+	
Strengthening the position on global and local agendas	+++	++	+++	+	+++	+	
Monitoring and evaluation of initiatives and accountability frameworks	+++		+	++	+++	+++	
Cross-sector advocacy	+++	+++	+	+	++	+	
Interinstitutional partnerships	++	++	++	++	++	++	+
Production of global public goods							
Basic, clinical, health-systems, and ethics research	++		++	+++	++	+++	
Information and databases	+++	+++	++	+	++	+++	
Development and update of guidelines and standards for national and international regulation	+++		+++		+++	+++	
Design of training materials for countries			++		++	+++	+++
Comparative evidence and analysis of initiatives and best practices	+++	++	++	++	++	+++	
Update the WHO Model List of Essential Medicines	+++				++	++	
Management of externalities							
Guidelines to avoid cross-border use of controlled medicines and ensure safe and effective prescribing	+++				++	++	
Global solidarity							
Expansion of global financial resources	+	+++	++	++			
Humanitarian assistance	+++	++	++	+++	+++		
Technical cooperation and training	+++	+	+++	++	+++	+++	+++

The symbols denote various levels of engagement by actor in the global health system, such that + denotes minimal engagement, ++ denotes moderate engagement, and +++ denotes strong engagement.

Table 8: Actors and services to expand access to palliative care, by global health system function

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The Lancet Call-to-Action:

"... Measures of suffering have been absent, and so the need for palliative care and pain relief services has been easy to miss. That excuse no longer holds. The scale of human suffering is massive... The Commission has uncovered an appalling oversight in global health.

It is time for that oversight to be remedied."

Richard Horton, The Lancet, 2017

Four streams of work following report release:

1. Research
2. Advocacy and awareness
3. In-country implementation
4. Global collective action

Suffering-Intensity-Adjusted Life-Year (SALY)

- Complete and more robust measure of burden accounting for suffering averted
  - Include intensity level and weighting of duration
  - Expand conditions, e.g. mental health
  - Incorporate caregiver suffering
- Develop measures of value to patient and family
- Integrate or complement existing measures (QALY)
- Utilize to assess intervention efficacy
- Advance equity analysis, including gender perspective

Implementation Working Group

Anchored by the **International Association for Hospice and Palliative Care** and in collaboration with global, regional and national regional palliative care networks and associations

CARIPALCA

Four streams of work following report release:

1. Research
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"A Sea of Suffering"

Dr. Richard Horton, Editor-in-chief of *The Lancet*

April 14, 2018


Comment

Offline: "A sea of suffering"

How did it happen that palliative care lost the dignity debate? Palliative care is a discipline dedicated to improving quality of life by preventing and alleviating suffering. There can be few higher callings in medicine. Yet those who advocate "dignity in dying" have successfully claimed that the idea of dignity lies not in palliative care but in assisted dying for the terminally ill. A large majority of the public seems to agree. Those in favour of assisted dying have portrayed palliative care as somehow antithetical to patient autonomy. According to this view, palliative care is conservative and paternalistic. Part of the problem lies in the word. The common and defeatist meaning of palliation is to do something that lessens a problem but does not solve it. Short-term palliatives are negatively contrasted with long-term solutions. Palliative care specialists, despite their growing numbers and their great successes, have failed to win, even barely engaged with, these arguments.

Last week, the Lancet Commission on Alleviating the Access Abyss in Palliative Care and Pain Relief launched its findings and recommendations at the University of Miami. Led by Felicia Knaul, the Commission described how 61 million people are affected by severe health-related suffering, 80% of whom live in low and middle-income settings. 45% of those dying annually experience severe suffering, including 2·5 million children. The Lancet Commission identified a highly cost-effective package of interventions to address this neglected

of suffering afflicting communities worldwide. This discovery—and it is a discovery in the truest scientific meaning of the term—is equal to the identification of mental health as a global health priority by measuring DALYs. The story of health in the 21st century has been entirely rewritten by Felicia Knaul and her colleagues.

The consequences are far reaching. Those fighting non-communicable diseases (NCDs) must now supplement their focus on premature mortality with an equal concern for NCD-related suffering. Universal health coverage will only be universal if it includes palliative care. Those financing health programmes, from governments to foundations, must now embrace the essential package promulgated by the Commission. The forces that continue to marginalise palliative care are powerful. Stigma tops the list. Medicine regards the alleviation of suffering as someone else's problem. Palliative care is too often seen to indicate failure—the failure of medicine to cure. The hubris of modern medicine is that it cannot face up to failure. The dedication of biomedicine as a discipline dedicated exclusively to survival has created an anti-humanist and quasi-theocratic science of health. But, as the Commission makes clear, palliative care is not about failure. It is fundamental to any notion of human dignity in the face of illness or disease. The Lancet's commitment will be to work with the Commission to expand its network of supporters and collaborators, and to publish regular country-by-country assessments

"The Lancet Commission called on the entire health community, indeed the whole of society, to take pain and suffering more seriously—and to take collective action to remedy the access abyss, without question the most disfiguring inequity in health care today…

the great innovation of the Lancet Commission was to devise a new metric— severe health-related suffering—to uncover the epidemic of suffering afflicting communities worldwide. ….

The story of health in the 21st century has been entirely rewritten... Medicine can never be the same again."

Miami DECLARAcTION: to close the access abyss in palliative care and pain relief

Statement of action by critical mass gathered at the launch symposium to evoke change that commits advocates & researchers and calls to task diverse stakeholders

A ccelerate progress to provide universal access to a publicly financed and fully integrated essential package of palliative care health services.

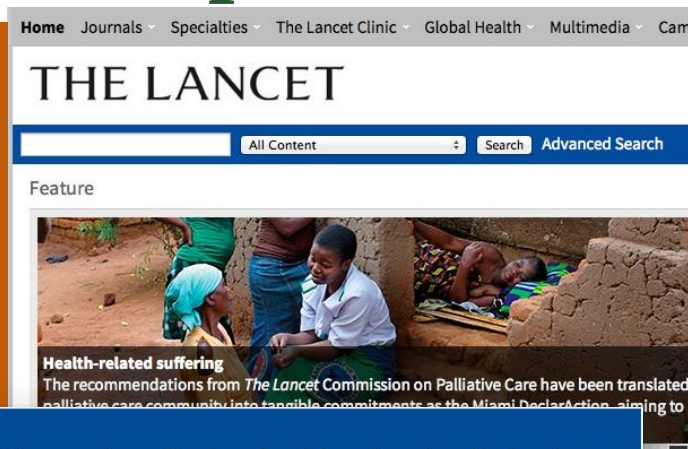
C reate balanced global and national policies on access to opioid medicines for pain relief to enable effective public health practice and policy-making.

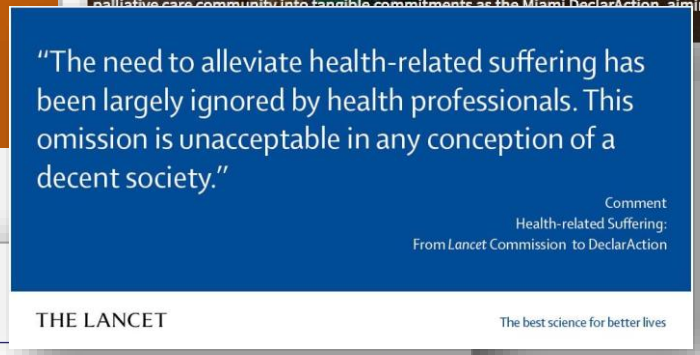
T ransition health systems to focus on volume and value in ways that incorporate palliative care and pain relief to achieve UHC.

I mplement accountability frameworks to evoke change.

O rganize and mobilize evidence through research and implementation science

N egotiate a balanced and action-oriented public health agenda that embodies global collective action.



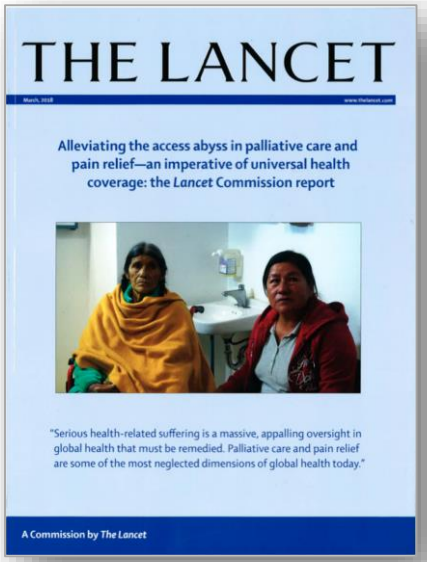


Advocacy Tool-kit and Background Resources

– Lancet Commission Publication:

thelancet.com/commissions/palliative-care

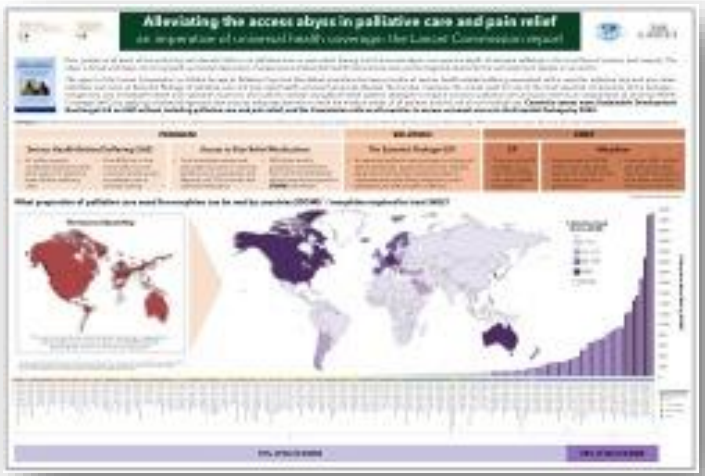
- Executive Summary and Full report
- Commentaries
- Podcast



– Advocacy Toolkit:

www.miami.edu/lancet --> background resources

- Data Appendix
- Fact sheets
- Country data sheet
- Video presentation
- Wall map



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http://www.thelancet.com/commissions/palliative-care

Cancer related burden of SHS (2015)

≃ 15 million people per year globally

- **Global**
  - **7.8 million decedents in need of PC**
  - **7.1 million patients in need of PC**
  - **2.1 billion days**
- **LMICs**
  - **5.5 million decedents in need of PC**
    - **90% of the total cancer deaths**
  - **5 million patients**
  - **~1.5 billion days**

By country income:

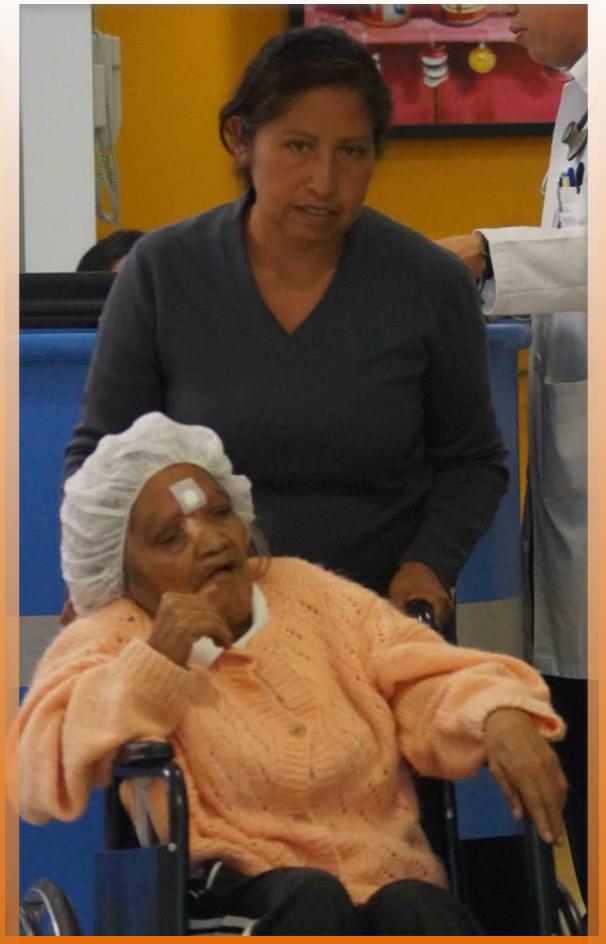
- 8% low
- 16% lower middle
- 30% upper middle
- 42% high

Mexico: The burden of SHS (2015)

≃ 470,000 people per year

- 230,000 deaths
  - 37% of the total
- 240,000 patients
- 150 million days

- Cancer, HIV/AIDS, injuries, dementia, liver and lung diseases



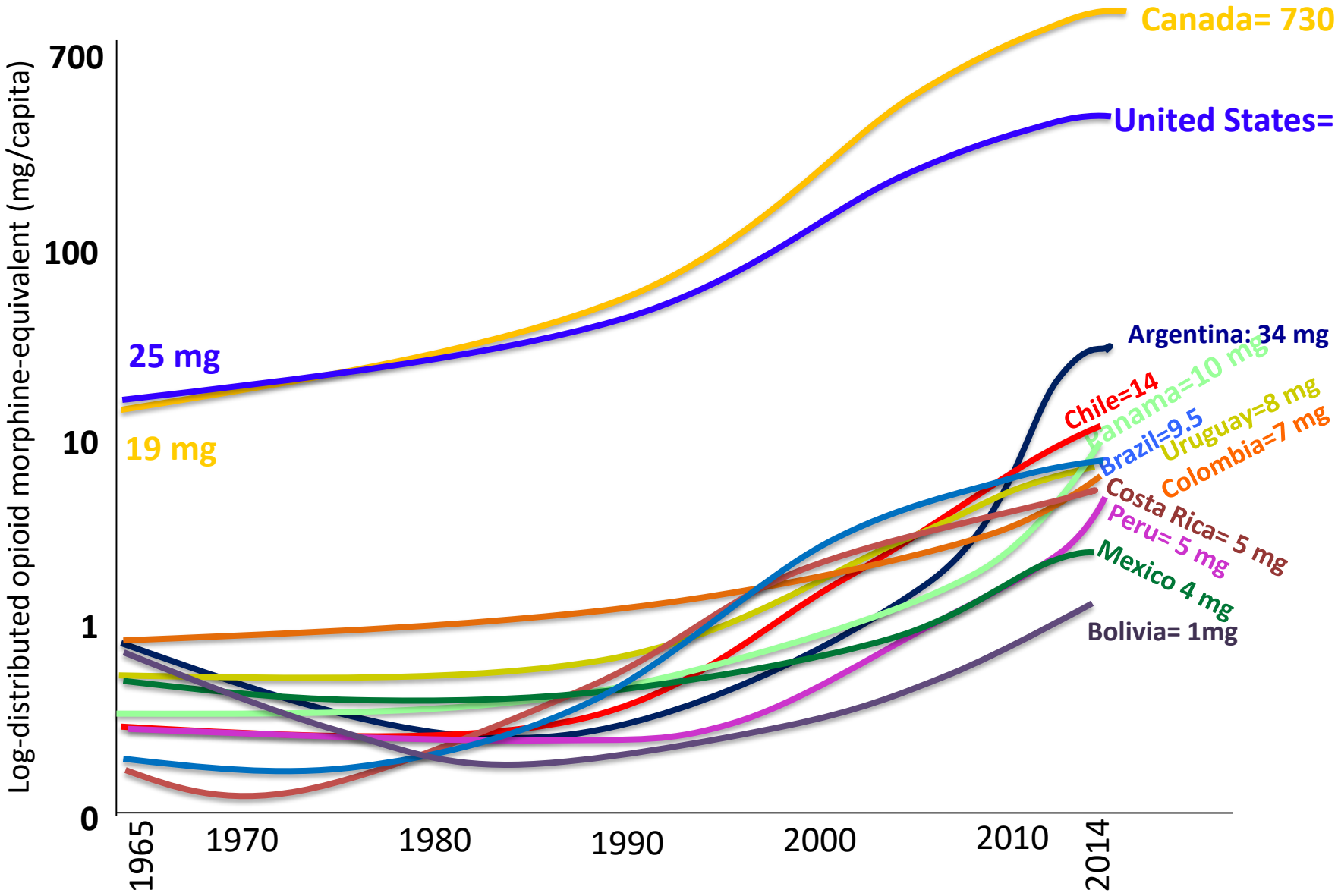
Avoidable Mortality and SHS: LMICs

- Low income countries: 81%
- Lower-middle-income countries: 69%
- Upper-middle-income countries: 46%

- Children in LMICs: 88%

- Infectious diseases and health conditions associated with poverty have the highest percentage of PC decedents that are avoidable
  - Tuberculosis, HIV, inflammatory diseases of CNS, and malnutrition: >95%

DOME in the Americas, 1965–2014

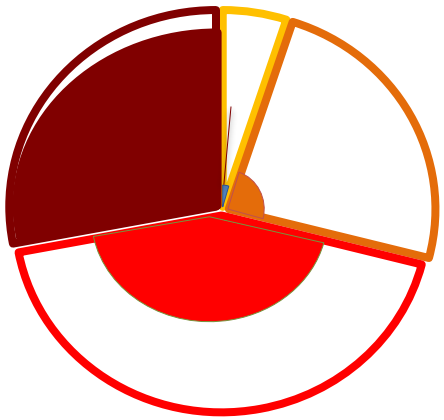


Source: Knaul, Farmer, Krakauer et al, 2017. http://www.thelancet.com/commissions/palliative-care.

Total medical and palliative care unmet need for opioid analgesics (in DOME)

Benchmark: Western Europe High-Income

Palliative Care need

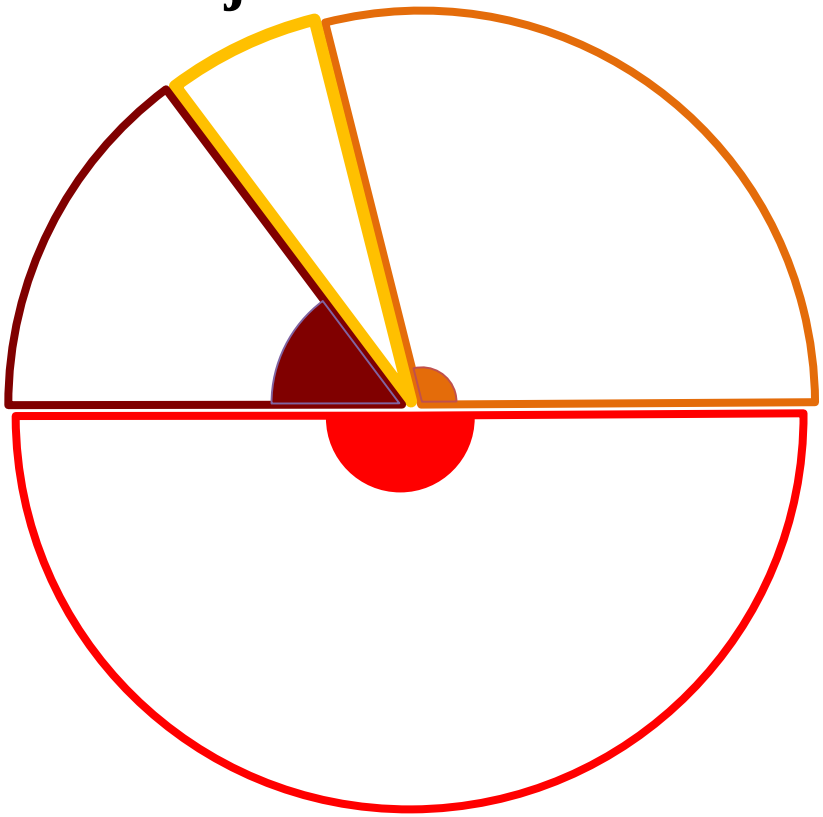


Total need: 82 Tons
(Unmet need = 49 Tons)

Income regions

- Low
- Lower middle
- Upper middle
- High

Projected total need



Total need: 581 metric tonnes
(Unmet need: 548 metric tonnes)

Western Europe High Income Countries:

Austria
Belgium
Denmark
Finland
France
Germany
Greece
Iceland
Ireland
Italy
Luxembourg
Malta
Netherlands
Norway
Portugal
Spain
Sweden
Switzerland
United Kingdom

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

Mexico: the pain relief access abyss

- 562 mg per patient with SHS in need of palliative care
- Average requirement for palliative care: 1,561 mg
- At least 64% of palliative care must go unmet
- Ranking: 64/172 countries

- Estimate to meet total medical need for pain relief: 13,164 mg /patient
- Unmet need: 95%

Universal Health Coverage in Mexico

- **“Mexico reached a truly immense landmark in its pioneering journey of health reform: achieving UHC for its 100 million citizens”**
- **“ Mexico has showed how UHC, as well as being ethically the right thing to do, is the smart thing to do.”**

Mexico: celebrating universal health coverage.

The Lancet, August 2012.

Mexico, Palliative Care in 2013

- Innovative legislative framework approved in 2009 as part of the General Health Law and updated in 2013

…necessary, but not sufficient

…ignored…

Advocacy played a key role in evoking policy and legislative breakthroughs

- Advocacy by a large group of local NGOs in collaboration with a Supreme Court Judge, a Minister of Health, and Human Rights Watch drove policy change

1. Law was enacted by the Ministry of Health
2. Palliative care and pain relief services added to the Seguro Popular essential package
3. Electronic prescribing replaced paper for controlled mediciones – opioids -; a major policy shift