Some models of palliative care delivery in Africa

Eve Namisango

&

Emmanuel Luyirika

African Palliative Care Association

Determinants of palliative care models in Africa

Ownership: Government, Faith-based or other NGO, Private company or social enterprise

Level of service: Is it a tertiary service, intermediate or embedded in a primary health care level

Set up: Inpatient stand-alone, inpatient part of hospital, outpatient standalone, outpatient part of a hospital, Community outreach post, Home-based care or a hybrid of all or some these

Source of funding: Out of pocket, tax-payer/government, CSR of Private companies, Health insurance, relying on philanthropy (Trusts, foundations or individuals or families funding)

Geography: Urban, peri-urbarn, rural or deep rural or a hybrid

Type of services: Covering a specific disease or a general service for all conditions; only adult or children or both

Facilitators of functioning of these models

- Presence of a national association (Uganda, Kenya, Malawi, South Africa, Rwanda, etc.
- Public-Private partnerships: Uganda, South Africa, Kenya, Botswana, Eswatini, etc
- Volunteerism: Rays of Hope Hospice Jinja, the only doctor is a volunteer
- Involvement of disease survivors: advocacy and peer support
- Adoption of palliative care into local CSRs of companies
- National Palliative Care policies: Kenya, South Africa, Botswana etc
- Private donors (True Colours Trust, OSF, etc. support)
- Involvement of Academia: KCL, Leeds, UoE, etc.

Some of the models

- **The Uganda model**: Uganda provides free morphine to all health units and hospices free of charge
- Hospice Africa Uganda: An outpatient service that also reaches inpatients in Mulago government hospital and Uganda Cancer Institute and a defined geographical area around Kampala City; It runs two upcountry units in Mbarara and Hoima which also support the regional Referral Hospitals there and linking to the patients' homes.
- Rays of Hope Hospice Jinja: Links with a regional referral hospital in Jinja and the lower health units in 11 districts it serves as well as patients' homes
- **Kenya Model of hospices** in government health units sharing staff, utilities and space

- **Inpatient hospices** in South Africa, Seychelles and Botswana: These are largely non-profits but governments in these countries contribute to the costs of running them
- **Rwanda Model**: Use of Community health insurance to reach those in need

Palliative Care in Kazakhstan and Central Asia

Gulnara Kunirova, Republic of Kazakhstan

August 25, 2022 Global Palliative Care and Pain Relief Research Hub Webinar

"Comparative Models in Palliative Care: Perspectives from Africa, Asia and the Americas"

NO

TO DISCLOSE

President, Kazakhstan Association for Palliative Care (KAPC),
Board Member, International Association for Hospice and Palliative Care (IAHPC)

KAZAKHSTAN QUICK FACTS

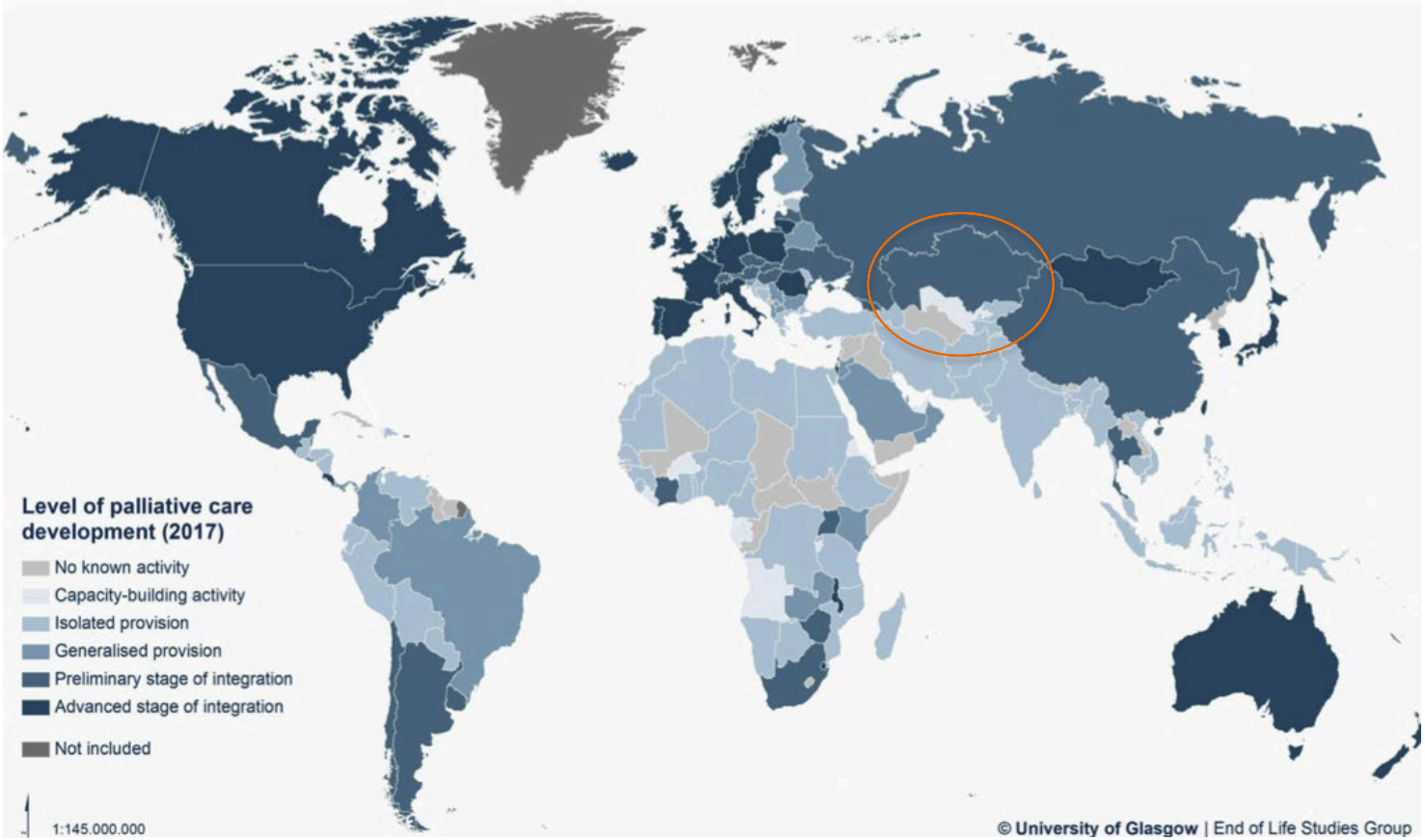
- Size - world's 9th biggest country (2,7 million км²)
- Population – among world's least populated countries (18,7 million people)
- 120 ethnic groups (47% Muslim, 44% Christian, 2% Protestant, 7% other)
- 17 provinces (including 3 cities of central submission)

Need for Palliative Care in Kazakhstan & Central Asia*

Kazakhstan	134,000 (18,7 mln)
Kyrgyzstan	26,000 (6,6 mln)
Tajikistan	32,000 (9,5 mln)
Turkmenistan	27,000 (6 mln)
Uzbekistan	108,000 (34 mln)

Knaul, Farmer, Krakauer, et al. Alleviating the access abyss in palliative care and pain relief: an imperative of UHC, Lancet 2017

Palliative Care Development in Kazakhstan & Central Asia*



Kazakhstan
GROUP 4A
Preliminary Stage of PC Integration

Kyrgyzstan, Tajikistan
GROUP 3A
Isolated PC provision

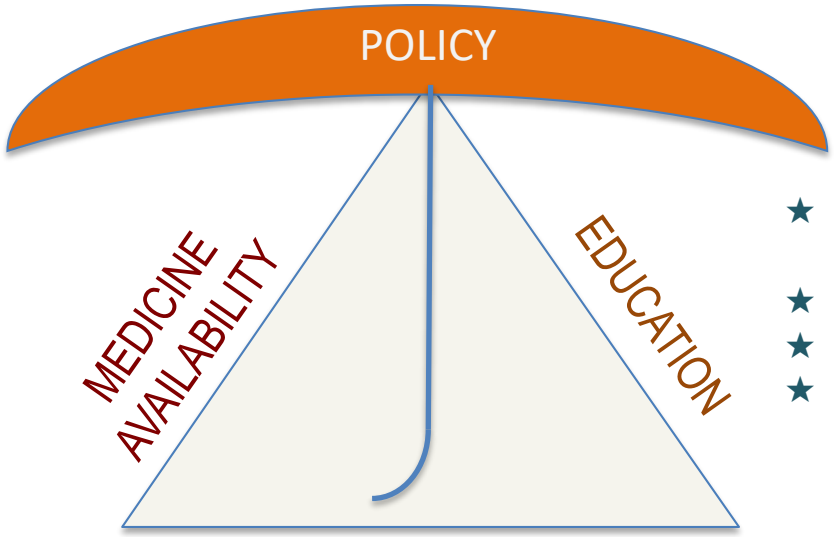
Uzbekistan
GROUP 2
Capacity-building PC activity

Turkmenistan
GROUP 1
No Known Activity

**Global Atlas of Palliative Care 2nd Edition, Worldwide Palliative Care Alliance (WHPCA), 2020*

Public Health Model for PC Development

★ PC is part of national health plan ★ Sufficient financing ★ Strategy/Standard/Regulations ★Partnership



★Opioids/Essential Medicines - affordable, accessible
★ Importation Quota – adequate
★ Range of Opioids – sufficient (non-invasive)
★ Prescribing
★ Distribution
★ Dispensing
★ Administration

★ Curricula, courses – on graduate and post-graduate levels of education
★ Media and public advocacy
★ Family and caregiver support
★ Training of non-medical specialists and volunteers

★ Opinion Leaders ★ Manpower ★ Infrastructure/Resources (services, beds) ★ Guidelines/Instruments

Based on Stephen Connor et al. Global Atlas of Palliative Care. 1st Edition. WHPCA. London, UK. 2014

POLICY – RECENT IMPROVEMENTS

1) Palliative Care (including Palliative Medical Care) is recognized as an integral part of the national health care system – Definition in the National Code on People's Health (7 July 2020)
2) Provision of PC is regulated by the National PC Standard (MoH Order, 27 November 2020)
3) PC services (including medicines) are free of charge for patients – part of the Guaranteed Benefits Package (Government Decree, 16 October 2020)
4) National Cancer Control Plan for 2018-2022 contains a PC section (Government Decree, 29 June 2018)
5) PC Budget was increased 250% between 2020 and 2022
6) PC is included in the list of services provided at the primary care level
7) Two Road Maps were adopted on the Development of PC for Adults and Establishing PC for Children (MoH Orders, 18 April 2022, 30 June 2022)

ACCESS TO ESSENTIAL PC MEDICINES

1. 17 medicines including 3 opioids are included in the list of essential medicines for PC (part of the Guaranteed Benefits Package)
2. 11 clinical protocols adopted
3. Strong opioids currently available in Kazakhstan:
   - Morphine Hydrochloride 1% (amp. 10 mg)
   - Fentanyl patches (25-50-75-100 mcg/h)
4. Procurement of opioids on primary care level is conducted by the Sole Distributor SK Farmacy (previously, through local HDs)
5. Opioids are used in palliative care units & hospices; prescribed and dispensed by primary care facilities for home-based patients

MANPOWER & EDUCATION

1. Overall need for medical and non-medical PC specialists - 6,000
2. Currently 101 nurses and 45 physicians provide in-patient PC + unknown number of physicians, nurses, psychologists and social workers provide in-home PC
3. Specialization in Hospice & Palliative Medicine (since 2021) for physicians
4. Mandatory Education and Training Standard for colleges and medical schools (since 2021) include:
    - Theory (120-150 hours) for all
    - Practice (150-180 hours) for paramedic practitioners (feldshers) & nurses, including BSN
    - Internship (90-120 hours) for GPs
    - Residential courses for oncologists, pediatricians and gerontologists
5. KazIOR + KAPC collaboration = training courses, conferences, seminars (over 11K attended)

INFRASTRUCTURE & IMPLEMENTATION

- 10 beds per 100^{000} population, according to the Standard (1,900 total need)
- 1,988 beds available in hospices + PC Units + wards/beds in general hospitals (incl. 68 pediatric)

Continuity of care:

Tertiary/secondary referral hospital

- Multidisciplinary team:
  - Physician +
  - Nurse
  - Psychologist
  - Social Worker

Primary care facility

- Medicines
- Home visits
  - GPs 1/month
  - Nurses 4/month

Hospice/Nursery or Mobile team

- Multidisciplinary
- Specialized care
- End-of-life care

In-patient Palliative Care

1988 total beds
(cancer & non-cancer)

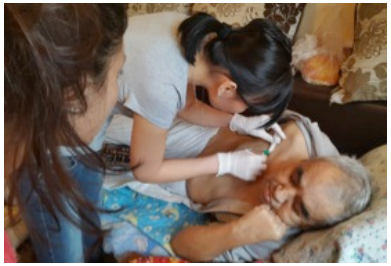
Home-based Palliative Care (Mobile Teams)

209 Mobile Teams (cancer patients)

+ 2 NGO-based Mobile Teams (all)

Best Practice Model - the Almaty Mobile Team

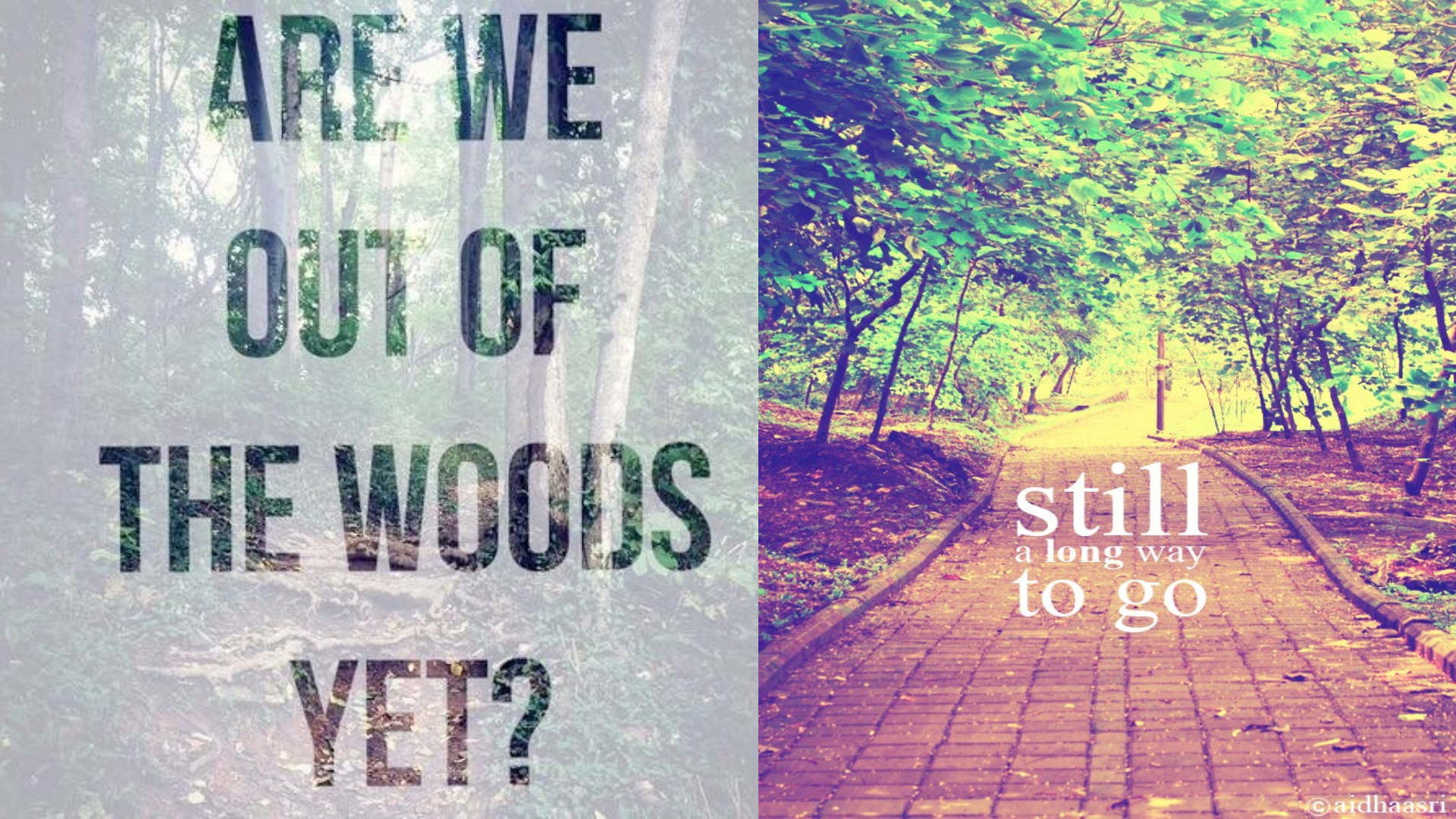
2013



A small NGO-based PC service:
1 part-time doctor and
1 part-time nurse

2022

Multidisciplinary Mobile Team
(part of the Almaty Cancer Center):
2 doctors, 3 nurses, 2 social workers, 1 psychologist,
operator, driver, working full-time...
+ 208 mobile teams across Kazakhstan


ARE WE
OUT OF
THE WOODS
YET?
still
a long way
to go
©aidhaasri

BARRIERS - POLICY

- No National Strategy on PC development
- No national registry of those in need of PC
- Legislative/regulatory base needs to be improved
- No separate licensing of PC services
- No Government policy with regards to Pediatric Palliative Care
- Underestimation of the demand, role, economic and social advantages of PC on the part of healthcare policy makers, administrations of medical organizations
- No state social procurement of NGO projects

BARRIERS – MEDICATIONS

- Limited range of strong opioids, esp. non-invasive forms
- Low quota for import of opioids for Kazakhstan with INCB
- Late/inadequate prescription of opioids by physicians (esp. GP's) due to:
  - lack of competence in pain diagnostics & treatment (Protocol)
  - fear of prosecution for prescribing opioids or harsh penalties for unintentional violations
  - «opiophobia» among physicians and general public
- Limited access to PC services/opioids in remote (rural) areas
- Opioids are rarely prescribed to children

BARRIERS – EDUCATION

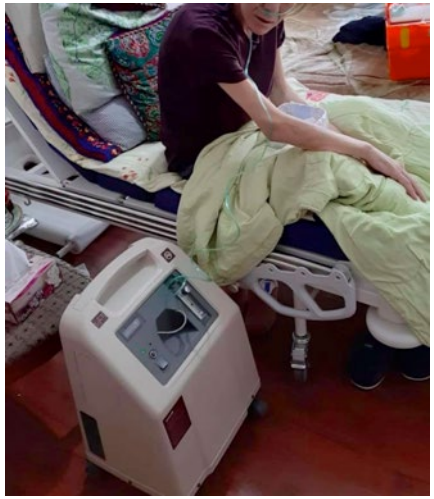
- Palliative Care Physician – not a Specialty, but Specialization
- No specialization for nurses
- Lack of training manpower (Mandatory courses exist mainly on paper, lack of practical knowledge among academic faculty)
- Scope, content, structure of courses are not standardized, inconsistent with international requirements
- Limited opportunities for hands-on training and foreign training courses
- Limited training opportunities for psychologists, social workers, volunteers
- Lack of textbooks in Kazakh language

BARRIERS – IMPLEMENTATION & INFRASTRUCTURE

- Low tariffs for in-patient PC services
- Poor material and technical condition of PC facilities
- Limited access to in-patient services and mobile teams in remote areas
- Limited to no access to PC services for children
- Scattered PC beds in general hospitals do not ensure quality care
- Low charity, volunteering and social activism
- Lack of mechanisms to assess implementation and progress

WHAT WE DO:
Government and Parliament outreach

WHAT WE DO:
Supporting services, patients and families



WHAT WE DO: Conferences, Training Courses, Webinars

WHAT WE DO:
Awareness raising, developing volunteering

World hospice & palliative care day

WHAT WE DO: International Cooperation


THANK YOU AND WELCOME TO ALMATY!
www.palliative.kz
palliative.kz@gmail.com

PALLIATIVE CARE ACCESS IN BRAZIL

- Heloísa Broggiato Matter

PhD Candidate Swansea University

Department of Arts and Humanities

- GDPO Global Drug Policy Observatory

- **Global Palliative Care and Pain Relief Research Hub Webinar 25 August 2022**

DISCUSSED TOPICS

- Low consumption of opioids in Brazil
- Barriers to adequate access to opioids for pain treatment
- Access to controlled medicines and drug traffic
- How do patients and physicians circumvent barriers?

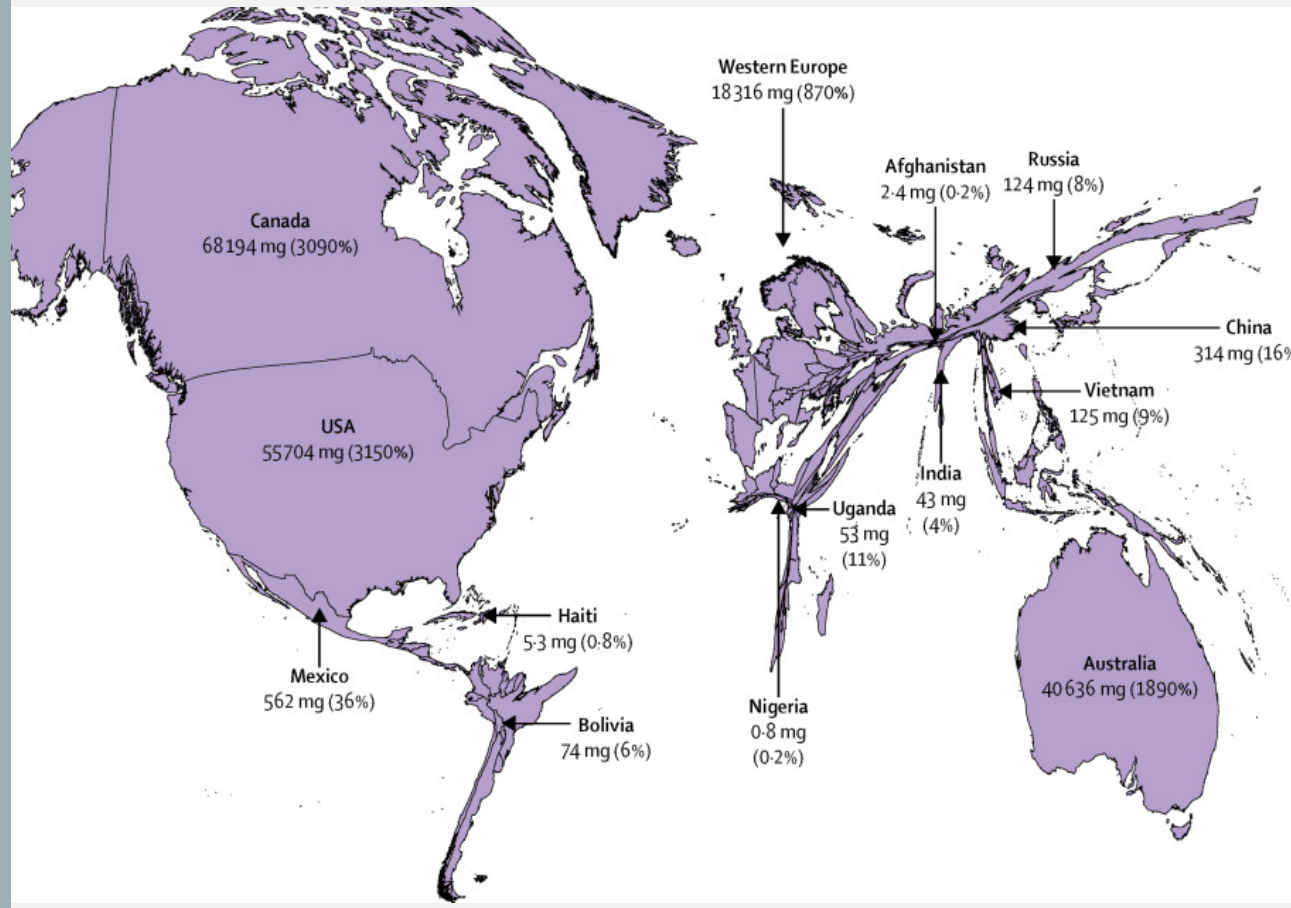
OPIOID CONSUMPTION PER YEAR (ME)

Brazil	Germany
8-10 mg/per capita	~ 500 mg/per capita

Both levels of consumption are considered adequate by the INCB.

DISTRIBUTED OPIOID MORPHINE-EQUIVALENT (AVERAGE 2010-2013)

Knaul, Felicia Marie, et al. "Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report." *The Lancet*391.10128 (2018): 1391-1454.



HEALTH IS A RIGHT FOR EVERYONE AND STATE'S DUTY

Brazilian Constitution 1988 recognizes the right to health, which is a human right

Drug trafficking is a heinous crime

BARRIERS TO ACCESS TO OPIOIDS

1. Bureaucracy
2. Gaps in education
3. Corruption and poor management
4. Cultural Attitudes

1. BUREAUCRACY

- How are opioids provided by SUS (Unique Health System)? UHC
- Opioids are part of the National List of Specialized Component of Pharmaceutical Assistance (2009)
- Protocol for Chronic Pain and Therapeutic Guidelines
- Special prescriptions
- Fear of patients to take opioids, fear of physicians to prescribe, excessive bureaucracy

2. GAPS IN EDUCATION

- Medicine based in specialities
- Gaps on the treatment of symptoms
- Few university hospitals with palliative care service

3. CORRUPTION AND POOR MANAGEMENT

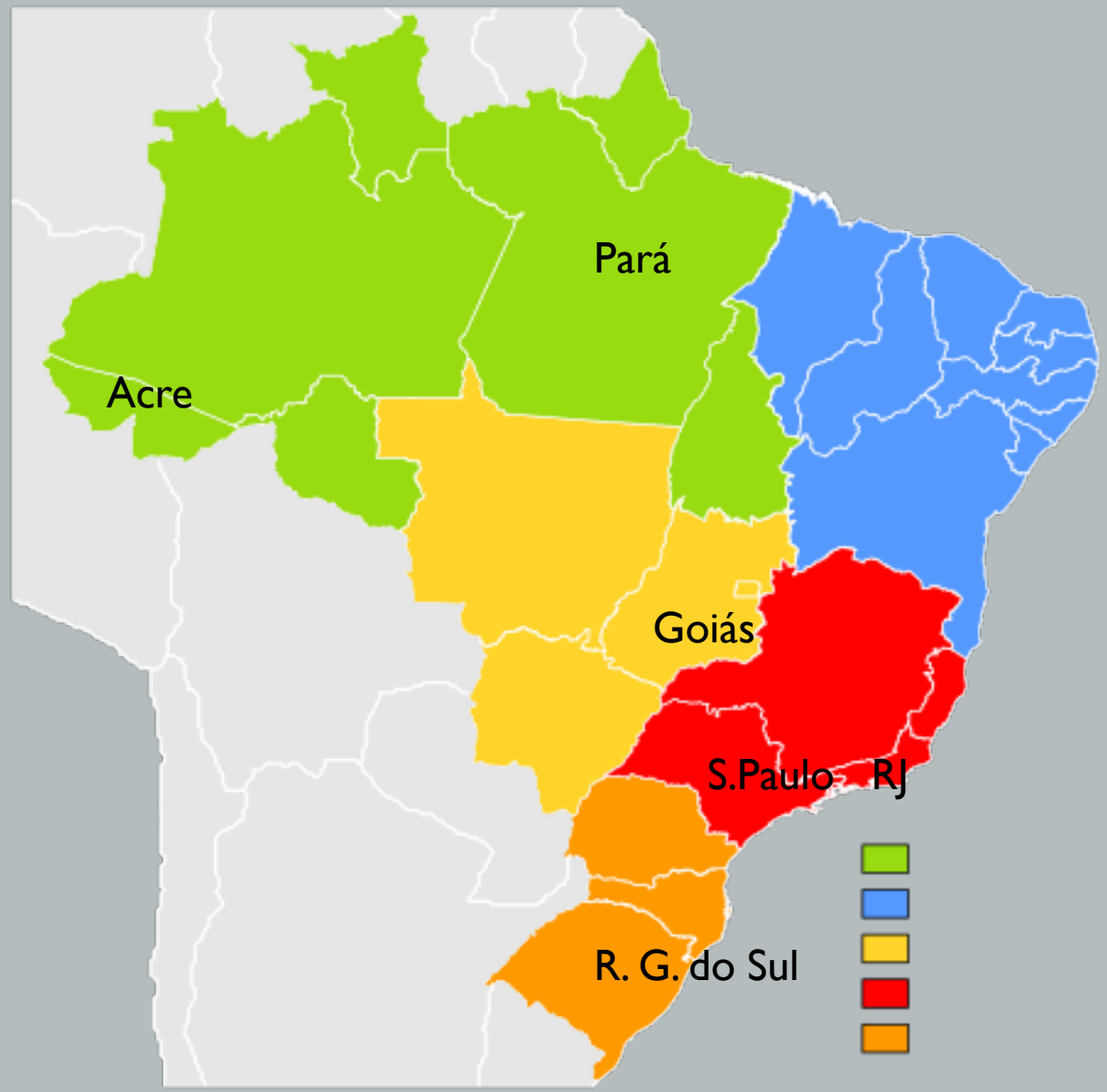
- Procurement of opioids ignores scientific evidence and epidemiology
- Non-payment and disruption of the supply chain
- Gaps in the health system

RIO DE JANEIRO

REFERENCE INSTITUTIONS FOR CANCER TREATMENT

- São Paulo accounts for 50% of opioid consumption in Brazil
- Reference hospitals are concentrated in Rio de Janeiro and São Paulo

Brazil



PRIMARY HEALTH CARE AND OPIOIDS

- Weak structure
- Less attractive for physicians
- Frequent rotation of professionals
- Bureaucracy to prescribe
- Ministry of Health do not trust that a physician in PHC can prescribe opioids correctly
- Only 2 states in Brazil have a public palliative care policy: Rio Grande do Sul and Goiás.
- No public policy that regulates the supply chain of medicines

4. CULTURAL ATTITUDE: PAIN TREATMENT IN THE AMAZON REGION

- Traditional medicines used by indigenous peoples
- Extreme poverty
- Very limited access to palliative care
- No interest of pharmacies in selling opioids

CONCLUSION

Access to opioids in Brazil could be improved by integrating palliative care and family health strategies in Primary Health Care in a descentralized public health system like SUS. This would ensure a more equitable distribution of opioids.

Thank you.
heloisa.broggiato@gmail.com

Global Healthcare

There's an elephant in the room.

It is large and squatting, so

it is hard to get around it.

Yet we squeeze by with,

"How are you?" and "I'm fine," and a

thousand other forms of trivial chatter

(Terry Kettering)

Global error of omission 1

51 million in LMICs are in serious health-related suffering.

Pain relief is available to < 4% Indians.

http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext

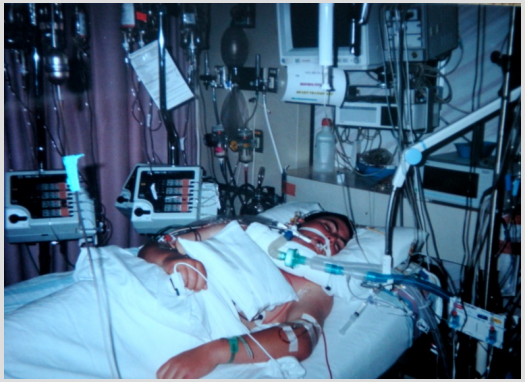
Global error of commission 1: Inappropriate end-of-life care.

In India, the poor die in

misery of neglect;

the middle class die in

misery of ignorance;



the rich die in misery on ventilators.

No one gets a pain-free and dignified death.

(Dr Sankha Mitra)

Catastrophic Health Expenditure

High income countries	84.6 million
Low-income countries	54.5 million
Low-middle income countries	423.1 million
High-middle income countries	433.9 million

https://data.worldbank.org/indicator/SH.UHC.OOPC.10.TO

Error of commission 2:

55 million Indians are destroyed by catastrophic health expenditure.

Sakthivel Selvaraj, Habib Hasan Farooqui, and Anup Karan Quantifying the financial burden of households' out-of-pocket payments on medicines in India: a repeated cross-sectional analysis of National Sample Survey data, 1994–2014 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5988077/ BMJ Open. 2018 May 31;8(5)

Focus of Palliative care:

Mitigation of serious health-related suffering

of people “where they are, when they need it.”

World Health Assembly 67 (2014) advised

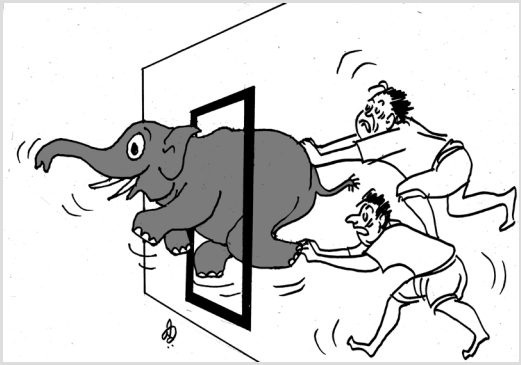
all countries to integrate palliative care

into all health care.

WHA 67.19. Strengthening palliative care as a component comprehensive care throughout the life course. 67th world health assembly, 2014. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

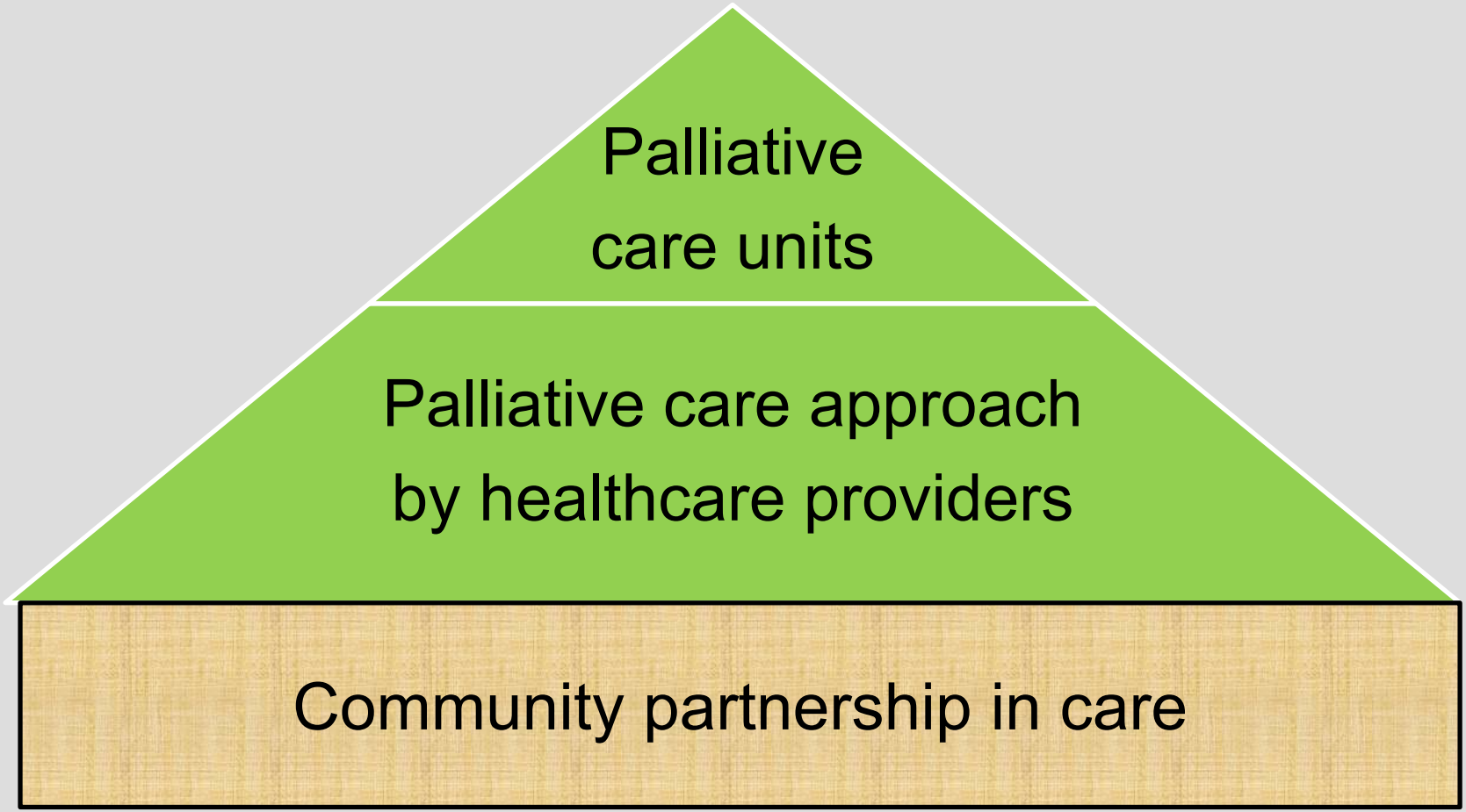
Astana Declaration 2018

We support the involvement of individuals, families, communities and civil society through their participation in the development & implementation of policies & plans that have an impact on health.



https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf

PALLIUM INDIA



Community participation - Advantages

- Adherence to treatment
- Balanced prevention, promotion, cure, rehab & palliation
- Integration of multiple sectors like education, agriculture, transport, commerce, religion, housing, trade and health
- Attention to psychosocial issues.

Community participation - management of change

- Awareness
- Training
- Stepwise implementation
- Monitoring
- Course correction
- Appreciation

Modified from: World Health Organization 2016. Planning and implementing palliative care services: A guide for programme managers. https://www.apps.who.int/iris/ handle/10665/250584

OPEN THE HEALTHCARE DOOR

Community – medical system interaction

- Mutual respect
- Ground rules & values
- Monitoring and review
- Quality assurance

Needed: facilitator

Community participation - Challenges

Look out for vested interests

- Personal
- Religious
- Political

Monitor quality of care -

Adherence to values & ethics

PALLIUM INDIA

OPEN THE HEALTHCARE DOOR

chairman@palliumindia.org