Objectives

• Define palliative care

• Discuss gaps and opportunities for palliative care capacity building and development globally

• Explore examples of interventions in sub-Saharan Africa to improve palliative care capacity and integrate palliative care within health systems
  – Local engagement
  – Interdisciplinary and nursing engagement
An Introduction to Palliative Care in Global Settings

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“Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.”

- International Association for Hospice and Palliative Care

Serious Health-Related Suffering (SHS):

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

Definitions

Severe Illness:

- Any acute or chronic illness and/or condition that causes significant impairment, and
- May lead to long-term impairment, disability and/or death.

Integrating Palliative Care with Disease-Modifying Therapy

Explicitly recognized under the human right to health

Integrated within health systems as part of Universal Health Coverage and primary care (Sustainable Development Goal 3.8)

Delivered by interdisciplinary teams

Required for a wide range of diseases and prognoses, not just at end of life
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 Bhadéla, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodríguez, 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‡

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext
https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30082-2/fulltext
In 2015, 25.5 million experienced SHS prior to death (45% of global deaths)

Overall burden of SHS among the living is >61 million worldwide
- SHS will ↑ significantly with ↑ life expectancy
- ↑ dementia, debility, cancer, and chronic disease (accounting for >75% of deaths in LMICs)

• >80% of people living with SHS are from LMICs → tremendous chasm in access to palliative care and pain relief

• In LMICs, *children account for >30% of all deaths associated with SHS (vs <1% in HICs)*

A Low-Cost Essential Package for Palliative Care

- Called for a low-cost **Essential Package** of medicines to be made universally available to relieve SHS

- Emphasized **universal access to immediate-release morphine**
  - Proportions of individuals experiencing moderate to severe pain lasting >90 days
    - Cancer: 80%
    - Cardiovascular and chronic lung disease: 67%
    - HIV/AIDS: 50%

Profound Gaps in Opioid Access

Of the 298.5 metric tons of opioids distributed worldwide each year, only 0.1 metric tons (0.03%) are distributed to LICs.

Poorest individuals receive <2% of the necessary opioids to relieve SHS

Integration of Palliative Care Throughout Health Systems

• Integration with Universal Health Coverage throughout all levels of the health system

• Strengthen the overall performance of health systems

• Reduce risk of catastrophic health-care expenditures (main cause of impoverishment in LMICs)

• Potential cost-savings for health systems in LMICs by reducing end-of-life hospital admissions/costs


International Association for Hospice and Palliative Care (IAHPC): https://hospicecare.com/home/

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Interdisciplinary Approaches to Optimizing the Palliative Care Workforce

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Optimizing the Interdisciplinary Workforce

- Identifying multidisciplinary stakeholders
  - SWs, pharmacists, chaplains, nurses, APRNs, PAs, PT/OT, nutritionists, MDs, integrative medicine practitioners, policy makers, organizational leadership, others...

- *Lancet Global Health* commentary:\(^1\)
  1) Aligning with professional optimization initiatives
  2) Adapting models of education to contextual needs of global settings
  3) Building long-term, mutually beneficial partnerships based on inclusivity and respect
  4) Full engagement of all team members in planning and delivery

---

1. Rosa, Krakauer, Farmer, et al. (in press)
Nurses Lead in Palliative Care in the Community in Rural Liberia

The community nursing team at a PIH-supported site in Liberia travel well beyond health care facilities and use all means possible to provide end-of-life care to patients.

Source: PIH Liberia Newsletter_Q2_2019
Liberia: Planning Considerations

- In a country where there are no reliable palliative care services?
- Inconsistent access to strong opioids, nonopioid analgesics, or symptom management medications
  - Global opioid disparities
  - No regulatory mechanisms for narcotics
  - Opioidphobia
- Stigma (e.g., HIV/AIDS, LGBTQ+ population)
- Cultural concerns in discussing serious illness, death, and dying
- Overall service goals?
Liberia: Education Initiative

• End-of-Life Nursing Education Consortium (ELNEC)\(^2,3\)
  – Adapted to the Liberian context
  – Train-the-Trainer
  – Modules in palliative care philosophy; pain and symptom management; final hours; loss, grief, bereavement; communication; culture and spirituality; ethics; leadership;
  – Over 24,500 RNs trained in over 100 countries
  – Estimated close to 800,000 RNs and other providers have received ELNEC training from certified trainers

• International palliative care literature
• Scholarly writing workshop
• Self-care skills (e.g., reflective practice, mindfulness)
• Interdisciplinary team workshop

Harper,
Maryland County,
Liberia

-May 2019-

Source: W. Rosa
# Liberia: Team Response

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To what extent was the course content relevant to your palliative care work in Liberia.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.30</td>
<td>.70</td>
</tr>
<tr>
<td>2. How helpful were the discussions about African and international palliative care reports/initiatives?</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.50</td>
<td>.50</td>
</tr>
<tr>
<td>3. Were the self-care exercises of benefit to you?</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.20</td>
<td>.80</td>
</tr>
<tr>
<td>4. To what extent did the case presentations contribute to your knowledge of palliative care communication?</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.20</td>
<td>.80</td>
</tr>
<tr>
<td>5. How effective was the instructor?</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.10</td>
<td>.90</td>
</tr>
</tbody>
</table>

**Evaluation Instructions:**

Please circle the number that best describes your response.

1 = not at all
2 = somewhat
3 = moderately
4 = very
5 = extremely
Liberia: Next Steps

- Sustaining partnership

- Additional training to meet lack of resources

- Possible integration of palliative care education into noncommunicable disease trainings across international sites
  - Sierra Leone, Malawi, Rwanda, Haiti, Peru

- Ongoing dissemination of work

Conceived by Rwandan MOH in partnership with 16 academic medical centers, 9 schools of nursing, 2 schools of public health and a school of dentistry\textsuperscript{5,6}

Seven-year initiative with goals to:
- Increase number of nurses and physicians
- Increase quality of their education
- Decrease overall dependence on foreign aid

“Twinning” model\textsuperscript{7}

Rwanda: Curricular Integration

• First official integration of palliative care education in Rwandan nursing curricula

• Pediatric palliative care course in the University of Rwanda MScN program included the following content:
  – Intro to palliative care
  – Pain management in palliative care
  – Symptom management in palliative care
  – Neonatal palliative care
  – Palliative care at the time of death
  – Loss, grief and bereavement
  – Complementary therapies
  – Transformational leadership in palliative care

Rwanda: Palliative Care Research

- Aim: To explore nurses/midwives’ and physicians’ palliative care and end-of-life (EOL) educational needs at 5 Rwandan hospitals
- Cross-sectional, descriptive design
- Conducted between April-August 2017
- N=420 participants (248 nurses/midwives; 17 physicians) providing care across several unit types
- Primary measure: End-of Life Professional Caregiver Survey (EPCS)
- EPCS analyzed using descriptive statistics and independent sample t-tests between the groups

Rwanda: Preliminary Findings

- 53% of participants reported caring for patients at EOL and nearly 90% endorsed palliative care methods were used.
- Physicians were more likely than nurses/midwives to receive EOL training during education (63 vs. 38%).
- Only 39% of sample received training in the past 5 years.
  - Length of training ranged from 1 day to more than 4 weeks.
- Lowest mean self-competence scores for both groups:
  - Resolving family conflicts about EOL care; knowledge of relevant cultural factors; being familiar with hospice services; having personal resources to meet needs in caring for dying patients and their families.
Rwanda: Next Steps

- Disseminate findings
- Ongoing collaborations
- Identify opportunities to advance palliative care integration in education, research, practice, and policy domains
Botswana: Emerging Work

- Botswana lacks clearly delineated cancer control plan
- Cancer mortality roughly 75% due to myriad factors (e.g., poor screening, late presentation, lack of resources)\(^{10-12}\)
- Number of factors impacting delivery of palliative care
  - Chronic shortages of medications\(^{13}\)
  - Lack of trained healthcare workers; mythology surrounding death\(^{14,15}\)
  - Symptoms burdens not effectively managed\(^{16}\)
  - Spiritual and religious needs unmet\(^{17}\)

Botswana National Response to Cancer Study

Partnership between Botswana government, Botswana MOH, and Rutgers University, NJ, USA

Aim: To conduct a comprehensive cancer needs assessment to grasp opportunities to strengthen capacity to provide effective population-based cancer care, including high-quality palliative care

Pending grant: To better understand the palliative care learning needs of the Botswana workforce, as well as experiences of cancer patients and their families

In alignment with Lancet Oncology commission report recommendations

A Vision for the Global Expansion of Palliative Care

• Use palliative care as an invitation to rehumanize healthcare
• Integrate palliative care services further upstream in the chronic disease process for client and interdisciplinary team relationship-building and improving quality of life
• Dismantle interprofessional hierarchies that prevent seamless delivery of patient- and family-centric care
• Advance research to support cost-effectiveness of palliative care models in resource-poor settings
• Ensure universal palliative care services for all, particularly morphine access for symptom burden management
• Train all healthcare workers in primary palliative care skills to promote effective communication, ethical care planning, timely pain relief, and holistic approaches to alleviating serious health-related suffering worldwide
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“Local is Global”: Re-thinking Palliative Care Approach in Africa to Value Expertise by Experience – Case study of Rwanda

Feb 5th, 2020

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It's far more important to know what person the disease has than what disease the person has.

(Hippocrates)
Country of “Thousand hills”

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Population</td>
<td>12.3 million</td>
</tr>
<tr>
<td></td>
<td>84% rural</td>
</tr>
<tr>
<td>Per capita GDP</td>
<td>$772,968</td>
</tr>
<tr>
<td></td>
<td>($125 in 1994)</td>
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<tr>
<td>GNI per capita</td>
<td>$780</td>
</tr>
<tr>
<td></td>
<td>($160 in 1994)</td>
</tr>
<tr>
<td>Human Development Index</td>
<td>0.524 (158th)</td>
</tr>
<tr>
<td>Physician: Patient Ratio</td>
<td>1:20,000</td>
</tr>
</tbody>
</table>

1. NISR 2017  
2. World Bank 2017  
3. UNDP 2017
“Humanity itself seemed lost…”

April 1994 - April 2020: 26 years Post-genocide against the Tutsis

1 Million people killed during 100 days

“Resilience” in Rwandan Society
“...Rose up from ushers...”

Improvements in Health Indicators

Maternal Mortality in Rwanda 1990 – 2015

Maternal deaths per 100,000 live births

Rwanda

Sub-Saharan Africa

World

The HIV Epidemic in Rwanda, 1990—2012

AIDS-related mortality rate (deaths per 100,000 pop.)

Adults and children on ART


Economist Intelligence Unit, “Sub-Saharan African healthcare: the user experience; A focus on non-communicable diseases.” September 2014, in The Economist, (Supported by Novartis).
1. Local as “the weak beginning”
Background

- Around **15,800** patients (HIV/Cancers) died with moderate & severe pain from 2007-2009 (PPSG, UW)
- **Morphine equivalent kg (2007-2009): 0,2**
- Per capita(mg): < **0,1**
- Per death in pain (mg): **10,6**
- **0,2kg** is enough to treat **27 people**
- Coverage of death in pain with treatment: **0,2%**
- Morphine needed~ demand: **97kgs**
- **Estimation of patients suffered from pain: > 85%**
Past Challenges

- Opiophobia “Fear of Opioids”
- Doctors' attitudes regarding PAIN
- Protocol: Red Ink+3 signatures for 1 Amp of Morphine
Past Challenges

- Overly restrictive laws governing use of narcotics
- All opioids are imported except morphine reconstitution
- Dysfunctional national and international bureaucracies
- Lack of knowledge in pain assessment and management
- Doctor/patients ratio: 1/20,000
From surgery dream to palliative care passion
2. “How to reach the unreachable...”
Rwanda one year on, what has changed since the launch of a stand-alone palliative care policy?

October 23, 2012
Policy
B. “Integration=Equity”

DISTRICT
HOSPITAL
Nurse
General practitioners
Internist, Pediatrician (if)

Social worker
Psychologist
Nutritionist
Physiotherapist*

HEALTH CENTER
Nurse
Social worker
Nutritionist

COMMUNITY
HBCPs per village

B. “Integration=Equity ”
Rwanda To Hire 1000 Palliative Caregivers

By Oswald Niyonzima February 08, 2018 at 6:50 pm
D. “Treat the Pain, relieve suffering”

Rwanda decided to produce its own liquid morphine.

- Imported morphine powder, and initiated manufacturing of oral morphine since Nov. 2014.

- Oral morphine is free of charge
Local production in Rwanda leads to increased access to oral liquid morphine for patients

Between 2013-2016, Rwanda’s quota increased over 3-fold from 800 to over 37,000 grams and total use increased from nearly zero to 10 Kg.

In 2016, a steady supply and distribution persisted, with produced morphine shipped countrywide, 99% for cancer related-pain; 1% for post-operative & other pain management.
Rwanda avoids US-style opioids crisis by making own morphine
F. “...Supply Chain, supply of hope...”
G. “Task shifting”

**Official Gazette n° 15 of 09/04/2012**

ITEGEKO Nº03/2012 RYO KUWA 15/02/2012
RIGENA IMIKORESHEREZE Y’IBIYOBYABWENGE N’URUSOBE RW’IMITI IKORESHA NKA BYO MU RWANDA

**LAW Nº03/2012 OF 15/02/2012 GOVERNING NARCOTIC DRUGS, PSYCHOTROPIC SUBSTANCES AND PRECURSORS IN RWANDA**

**LOI Nº 03/2012 DU 15/02/2012 PORTANT REGLEMENTATION DES STUPEFIANTS, SUBSTANCES PSYCHOTROPES ET PRECURSEURS AU RWANDA**

**Ingingo ya 17 : Abafite uburenganzira bwo kwemeza gutanga ibiyobyabwenge**

Ibiyobyabwenge n’imiti ikoresheya nka byo nitibishobora kugira uwo byemererwa bitari mu rwego rwo kugenerwa imiti kandi bikoziwe n’aba bakurikira:

1° umuganga ubufitije uruhushya;
2° umuganga w’amemo yo ubufitije uruhushya mu rwego rwo gukora umwuga wo kuvura amenyo;
3° umuvazi w’amutungo ubufitije uruhushya;
4° umubyaza cyangwa umufuromo ufite impamabyumenyi kandi ufite uruhushya rwo

**Article 17: People authorised to prescribe narcotic**

Narcotic drugs and psychotropic substances shall be prescribed to any person unless it is a medical prescription and issued by the following people:

1° medical practitioner authorised to exercise;
2° dentist authorized to exercise dental art;
3. veterinary doctor with authorisation;
4° qualified midwife or nurse authorized to exercise the profession and within the limits established by the Minister in charge of health.

**Article 17: Personnes autorisées à prescrire les stupéfiants**

Les stupéfiants et les substances psychotropes ne peuvent être prescrits à une personne que par une ordonnance médicale établie par des personnes médicales suivantes:

1° un médecin titulaire d’une autorisation;
2° un dentiste titulaire de l’autorisation d’exercer l’art dentaire;
3° un médecin vétérinaire titulaire d’une autorisation;
4° une sage-femme ou infirmier/infirmière diplômé(e) et titulaire d’une autorisation d’exercice de la profession et dans les limites établies par le Ministre ayant la santé dans ses attributions.

---

**Consortium of Universities for Global Health**
H. “Comprehensive model of care”

- Policy & Governance
- Partnerships
- Education & Training (local context)
- Drug Availability (Procurement & Distribution)
- Academic Research
- Monitoring & Evaluation
- Clinical Care (Assessment & Prescription)
3. “Culture Matters”
Current models for advanced care planning and end-of-life care decision-making have grown out of the Euro-American clinical and cultural experience.

Our Education System

Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.
“Education doesn’t necessarily mean duplication but rather adaptation” (Christian Ntizimira)
“When you are well, you belong to yourself but when you are sick, you belong to your family”

(Christian Ntizimira)
“Role of family members...crucial”
“Ubuntu philosophy” (understanding resources beyond funding)

“We define as “a Soul”
- Humanness
- Caring
- Sharing
- Respect
- Compassion

“When people are everything, money is nothing” (patient's quote)
# Culture matters

<table>
<thead>
<tr>
<th></th>
<th><strong>Western culture</strong></th>
<th><strong>African culture</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personhood</td>
<td>Individualism, Autonomy, Privacy</td>
<td>Familial self, Extended Family</td>
</tr>
<tr>
<td>Family values</td>
<td>Nuclear family, Equality</td>
<td>Extended family, respect for elders</td>
</tr>
<tr>
<td>Disease and illness</td>
<td>Caused by specific agent</td>
<td>Imbalance between person, ancestral world, circumstances</td>
</tr>
<tr>
<td></td>
<td><strong>Western culture</strong></td>
<td><strong>African culture</strong></td>
</tr>
<tr>
<td>----------------</td>
<td>----------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Pain</td>
<td>Concept of total pain</td>
<td>Stoicism important</td>
</tr>
<tr>
<td>Death</td>
<td>Funeral private family event, community support</td>
<td>Funeral a major social event</td>
</tr>
<tr>
<td>Bereavement</td>
<td>Community support, bvt counselling</td>
<td>Extended family support</td>
</tr>
</tbody>
</table>
“The way people die can reflect how the society lives”

(Ntizimira C)
“Naked but ashamed...” (Christian Ntizimira)
In Africa, the model of care in Palliative care should consider

*the social context, the cultural values, the local perception of death and dying* from the patients and their families as local value expertise for the global experience.
Acknowledgments

❖ Rwanda Ministry of Health
❖ Rwanda Biomedical Center
❖ City Cancer Challenge Foundation
❖ Rwanda Palliative Care and Hospice Organization (RPCHO)
❖ Harvard Medical School/GHSM
❖ Eric Krakauer MD, PhD
❖ OSIEA
❖ IAHPC
❖ WHPCA
❖ Hospice Without Borders
❖ RoRos Foundation
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