Improving Access to Palliative Care

Interdisciplinary Approaches to Ease Serious Health-Related Suffering

Speakers: William Rosa, MS, APRN-BC, FCCM, FAANP, FAAN
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February 5, 2020

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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

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An Introduction to Palliative Care in Global Settings

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IAHPC Definition of Palliative Care

"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

https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/

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Definitions

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.

https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/

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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.

https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/

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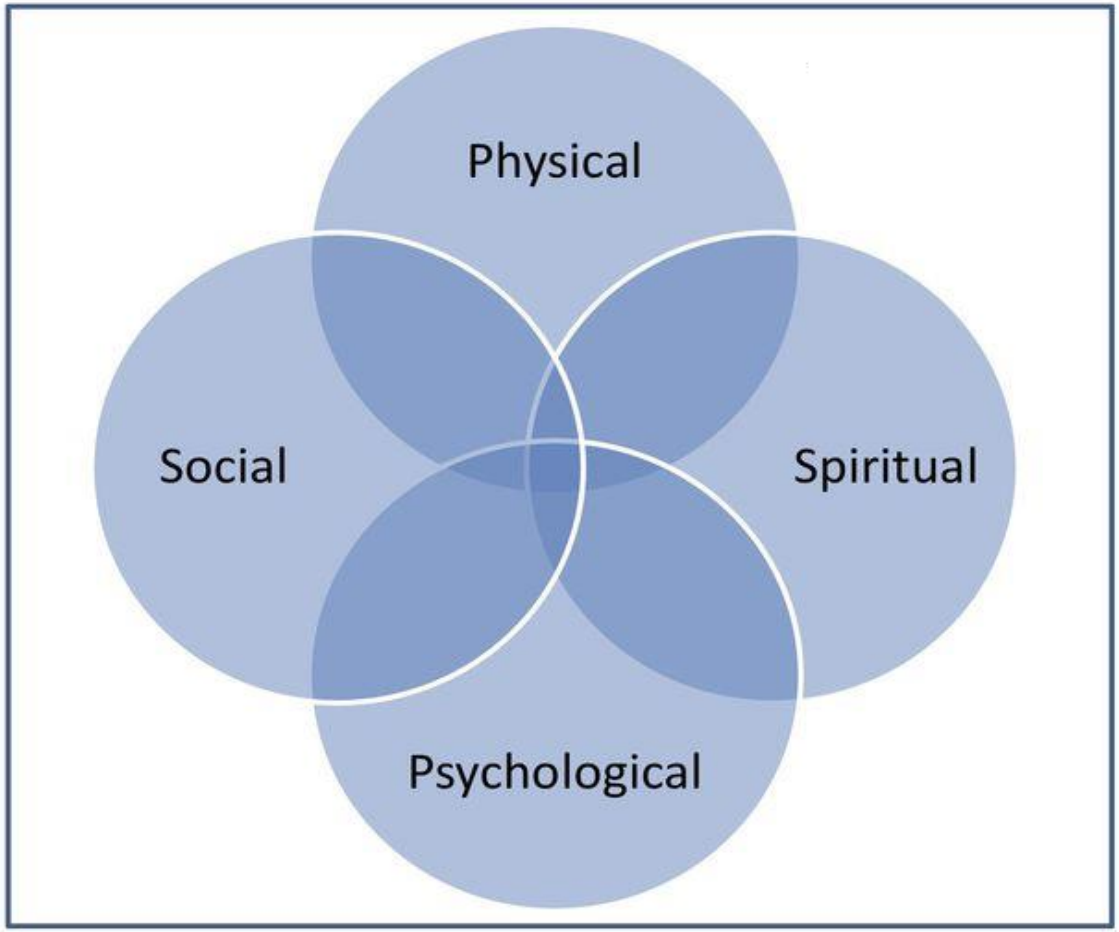
Cicely Saunders: “Total Pain”



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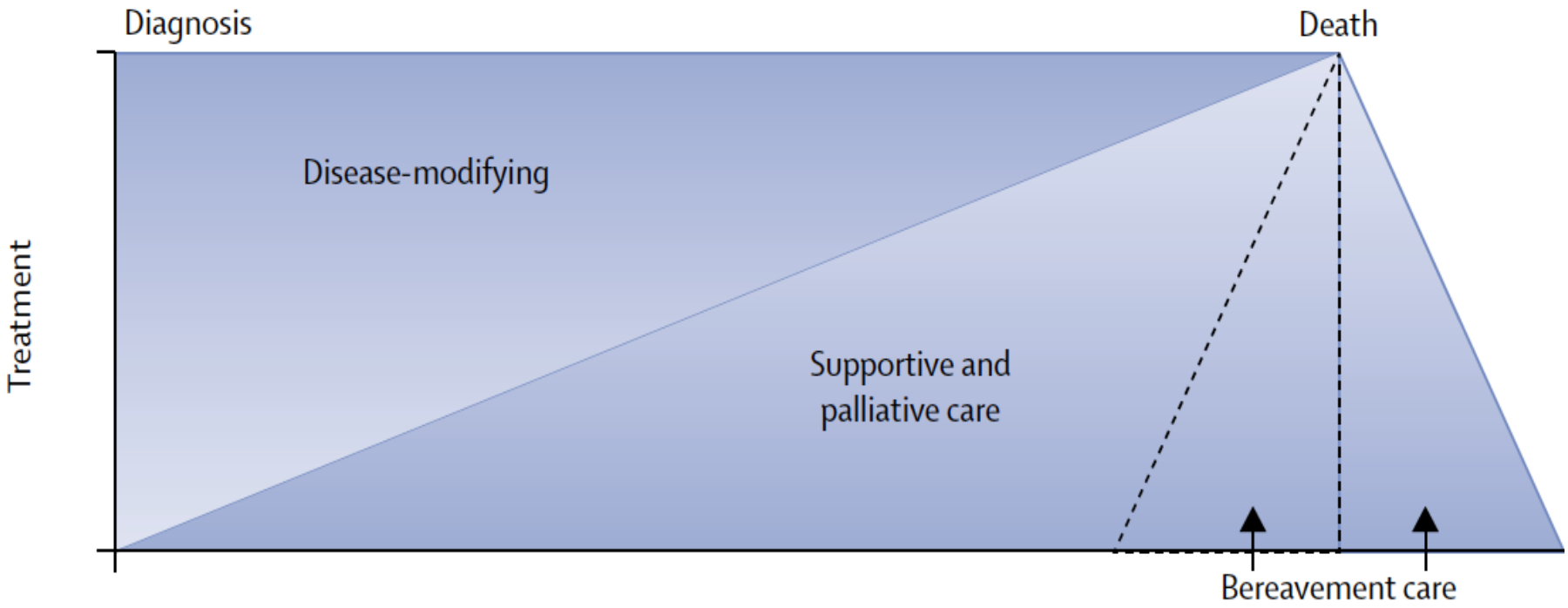
Integrating Palliative Care with Disease-Modifying Therapy



Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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Palliative Care

- 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**

World Health Organization. Palliative Care Fact Sheet (2018).

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The Lancet Commission Report on Palliative Care and 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‡*

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

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The Global Burden of Serious Health-Related Suffering

- **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)

Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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The Global Burden of Serious Health-Related Suffering

- **>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)

Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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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%

Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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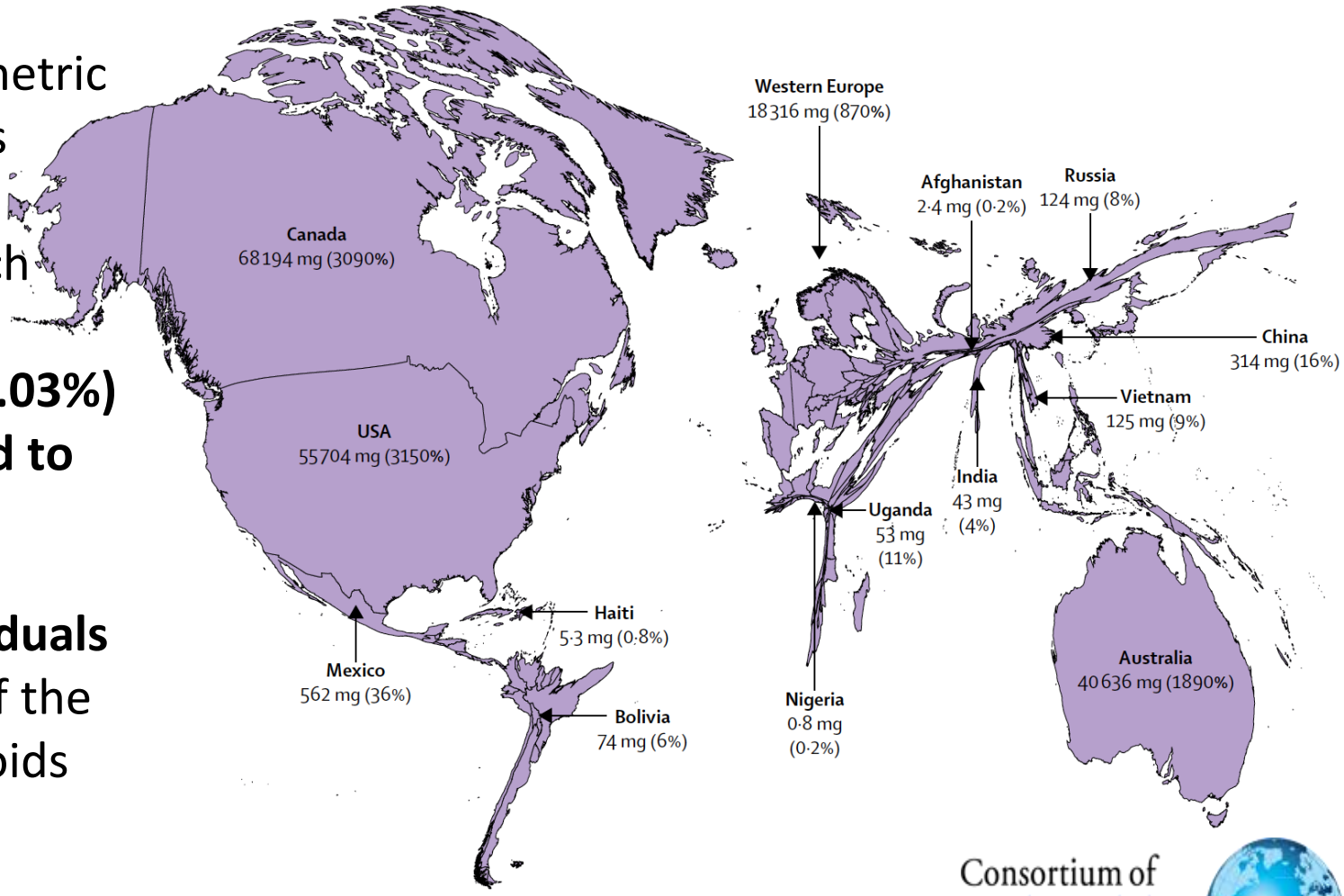
Profound Gaps in Opioid Access

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



Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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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

Knaul F *et al,* on behalf of *the Lancet* Commission on Palliative Care and Pain Relief Study Group. *The Lancet* (2017).

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Thank you

***The Lancet* Commission Report by Knaul F *et al*:**
https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext

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)

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Liberia: Partners in Health

Photo: Palliative care community nursing team travel by canoe in River Gee County, Liberia to reach a patient for end-of-life care.

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.

Julius D.N. Kpoeh, RN
Maryland County,
Liberia, West Africa

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?

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Liberia: Education Initiative

- End-of-Life Nursing Education Consortium (ELNEC)[2,3]
  - Adapted to the Liberian context
  - Train-the-Trainer
  - Modules in pal 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

2. Ferrell, Buller, Paice, et al. (2019); 3. Buller, Virani, Malloy, et al. (2019)

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Harper,
Maryland County,
Liberia

-May 2019-

Source: W. Rosa

Source: W. Rosa

Source: W. Rosa

Liberia: Team Response

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

Evaluation Instructions:

Please circle the number that best describes your response.
1=not at all
2=somewhat
3=moderately
4=very
5=extremely

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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[4]

4. Rosa, Karanja, Kpoeh (2019)

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Rwanda: Human Resources for Health (HRH) Program

- 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[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[7]

Source: W. Rosa

5. Binagwaho, Farmer, Nsanzimana, et al. (2013);
6. Uwizeye, Mukamana, Relf, et al. (2018)
7. Ndenga, Uwizeye, Thomson, et al. (2016)

Rwanda: Curricular Integration

- First official integration of palliative care education in Rwandan nursing curricula[8]

- 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

8. Rosa, Male, Uwimana, et al. (2018)

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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)[9]
- EPCS analyzed using descriptive statistics and independent sample *t*-tests between the groups

9. Lazenby, Ercolano, Schulman-Green, et al. (2012)

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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

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Rwanda: Next Steps

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

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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]

10. WHO (2018); 11. Efstathiou, Bvochora-Nsingo, Gierga, et al. (2014);
12. Botswana MOHW (2019); 13. Chabner, Efstathiou, Dryden-Peterson (2013);
14. Matula (2019); 15. LaVigne, Gaolebale, Maifale-Mburu, et al. (2018);
16. Lazenby, Sebego, Swart, et al (2016); 17. Philips, Lazenby (2013)

Botswana: Current and Future Research

- 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[18] report recommendations

18. Kaasa, Loge, Aapro, et al. (2018).

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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

Thank you

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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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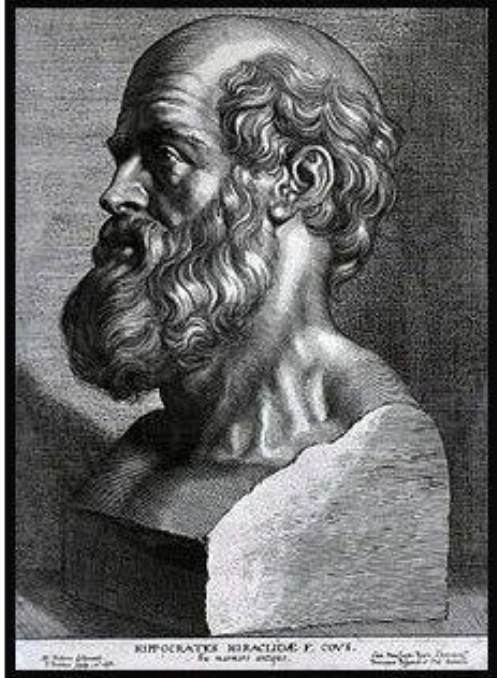

It's far more important to know what person the disease has than what disease the person has.

(Hippocrates)

Country of "Thousand hills"

Population[1]	**12.3 million** **84% rural**
Per capita GDP[2]	**$ 772,968** **($125 in 1994)**
GNI per capita	**$ 780** **($160 in 1994)**
Human Development Index[3]	**0.524 (158th)**
Physician: Patient Ratio[2]	**1 : 20,000**

1. NISR 2017
2. World Bank 2017
3. UNDP 2017

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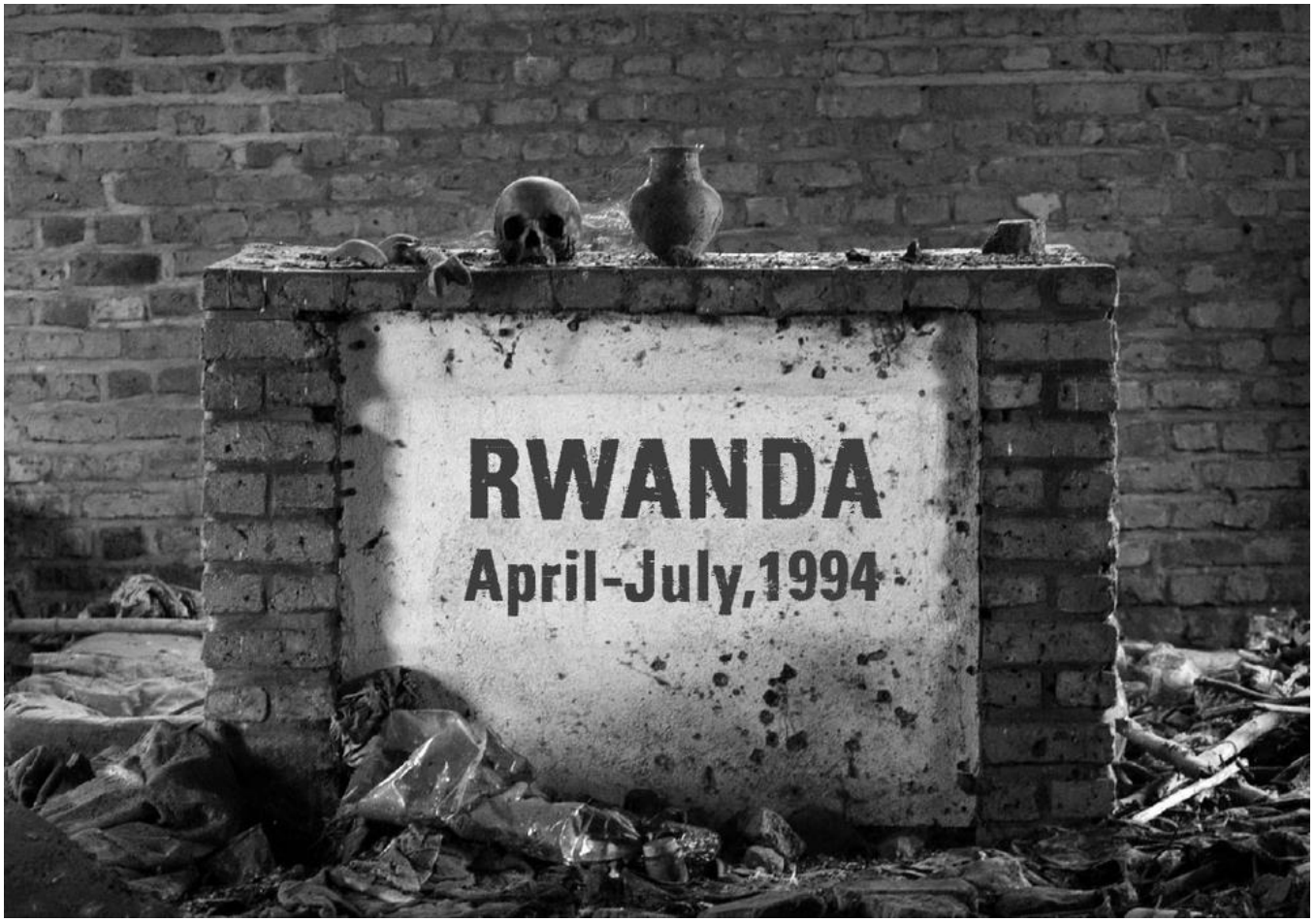
“Humanity itself seemed lost…”



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

1 Million people killed during 100 days

”Resilience” in Rwandan Society

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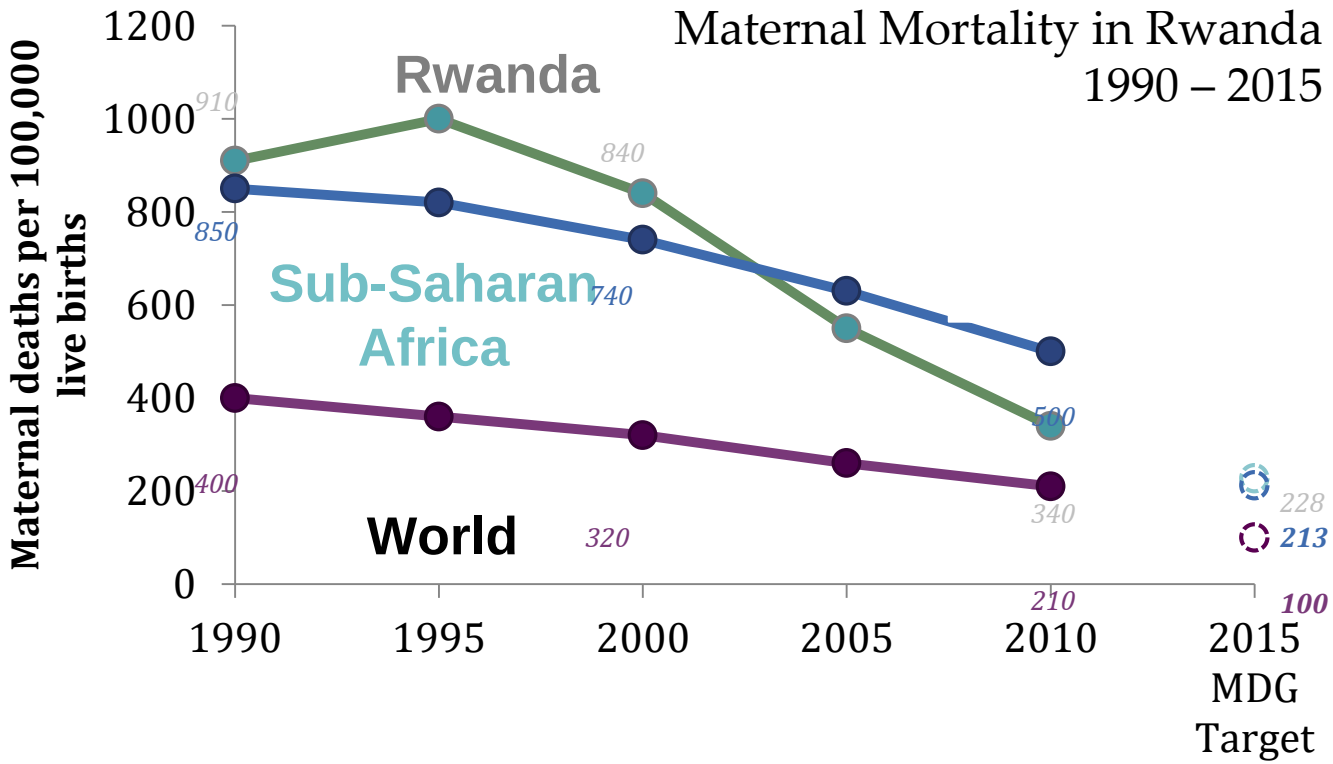
"…Rose up from ushers…"

Improvements in Health Indicators



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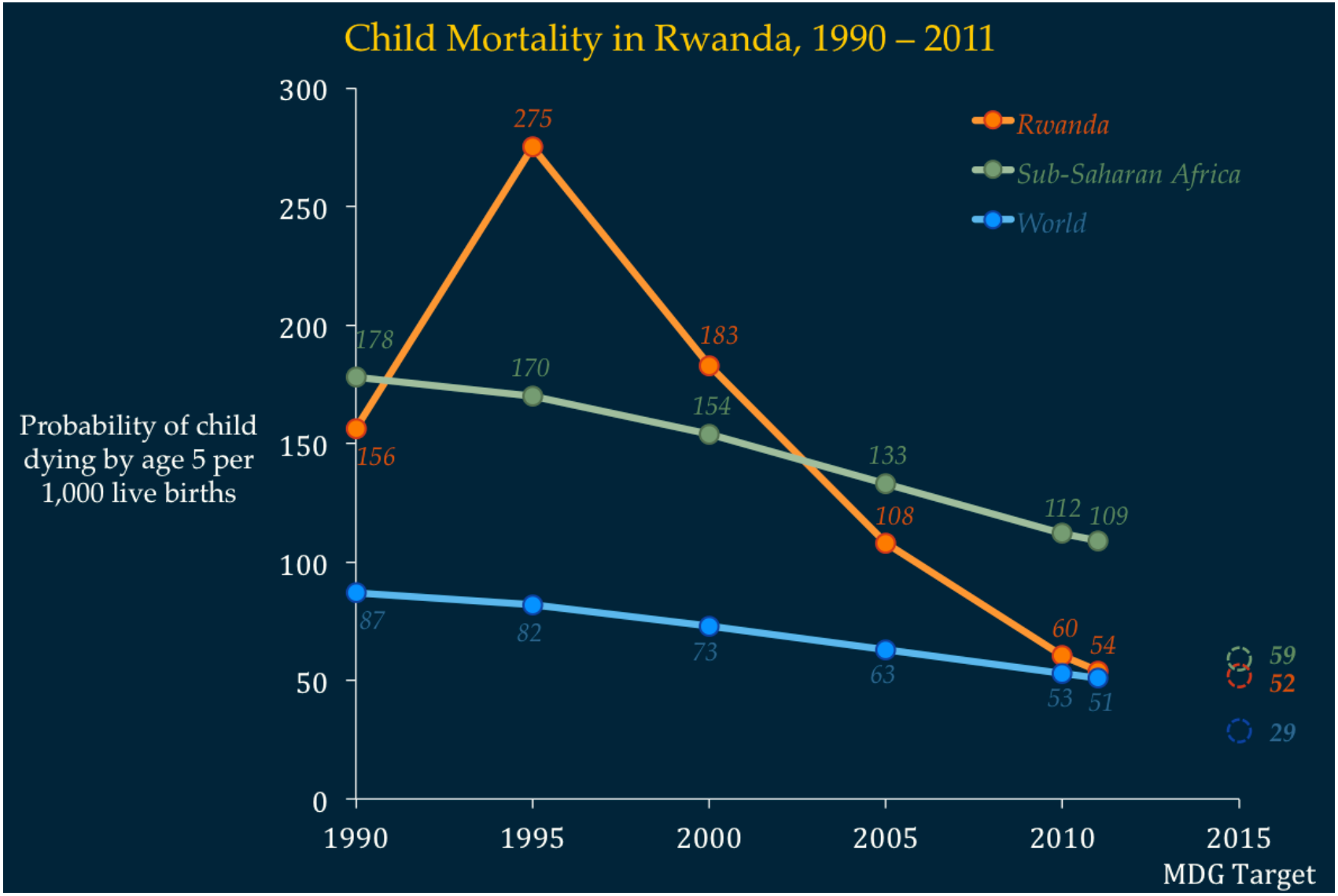
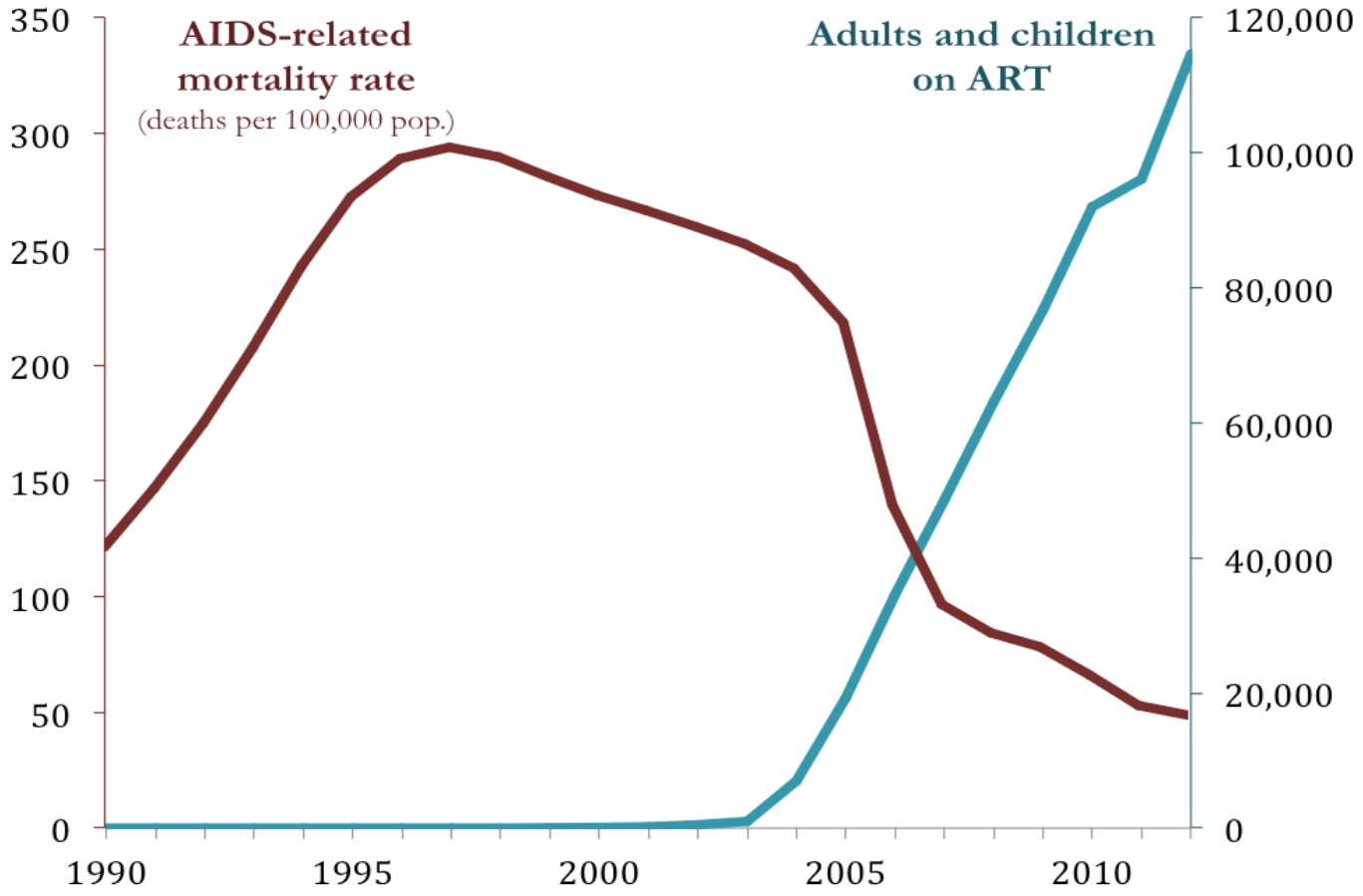
Farmer P et al. (2013). "Reduced Premature Mortality in Rwanda: Lessons from Success." British Medical Journal 346(f65): 20-22.



Farmer P et al. (2013). “Reduced Premature Mortality in Rwanda: Lessons from Success.” British Medical Journal 346(f65): 20-22.!

The HIV Epidemic in Rwanda, 1990—2012



Binagwaho A, Farmer PE, Karema C, et al. Rwanda 20 Years On: Investing in Life. The Lancet. [e-pub ahead of print].
DataBank: World Development Indicators and Global Development Finance. Washington, D.C.: World Bank, 2013. (www.databank.worldbank.org/)
UNAIDS. AIDSInfo Database. Geneva: UNAIDS, 2013. (www.unaids.org/en/dataanalysis/datatools/aidsinfo).

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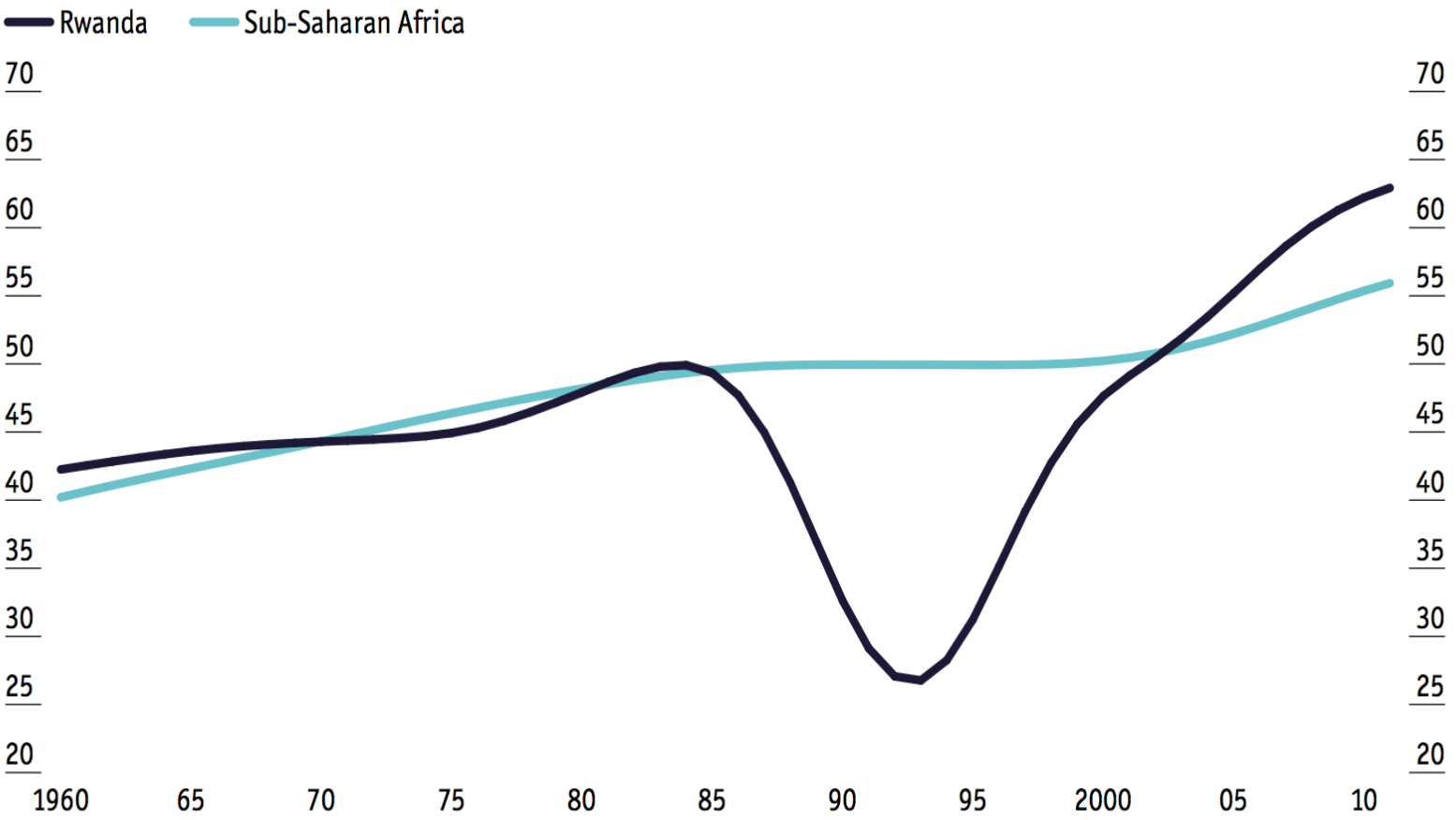
Upward bound

Life expectancy in Rwanda and sub-Saharan Africa

(% respondents)



Source: World Bank.

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

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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

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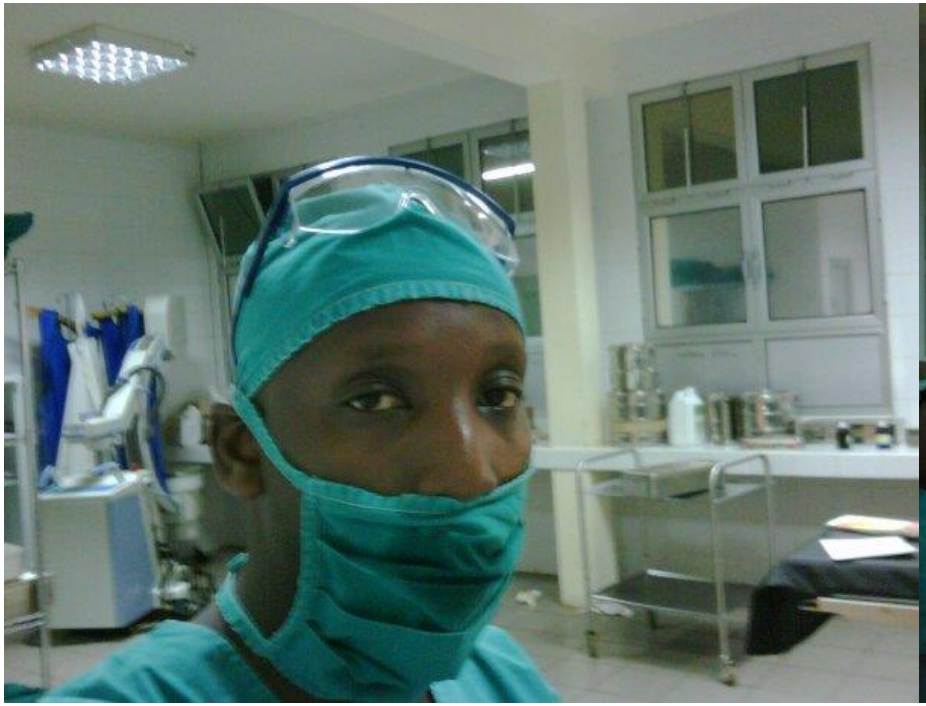
From surgery dream to palliative care passion



2. “How to reach the unreachable…”

A. "Policy"

Rwanda one year on, what has changed since the launch of a stand-alone palliative care policy?

October 23, 2012
Policy

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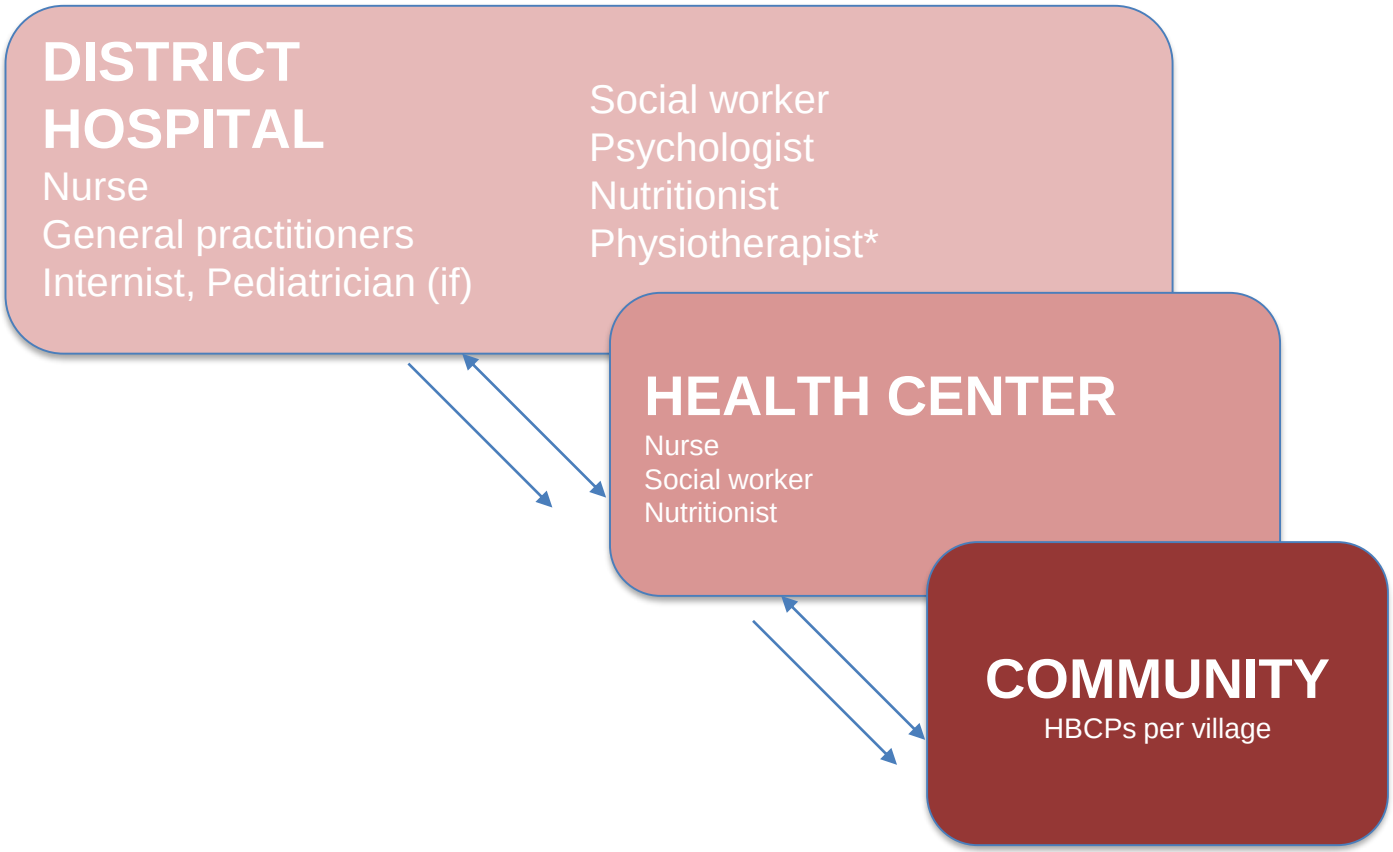
B. "Integration=Equity "



C. "Community=Social Justice"

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SOCIETY

Rwanda To Hire 1000 Palliative Caregivers

By Oswald Niyonzima February 08, 2018 at 6:50 pm

0

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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**.

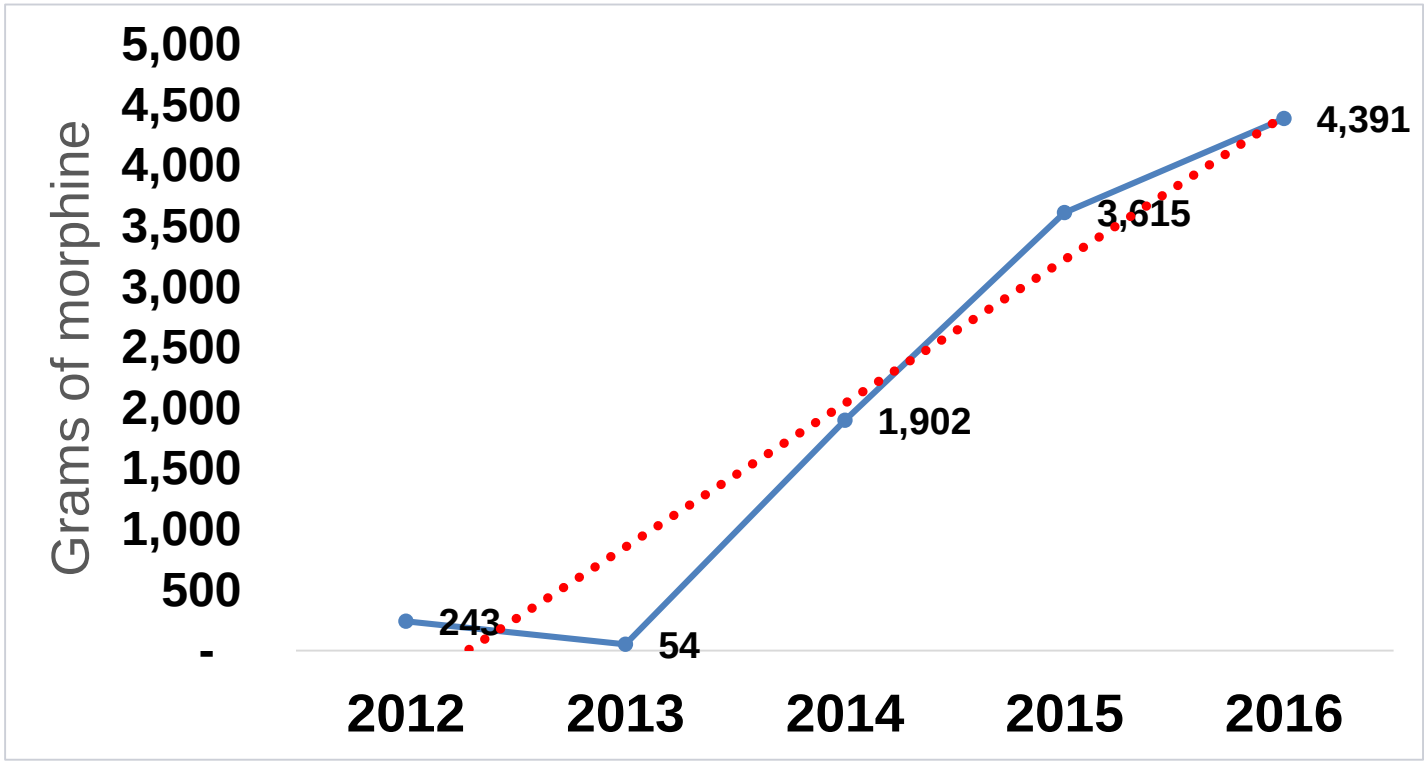
- **Oral morphine is free of charge**

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.

Morphine consumption trend 2012 – 2016 (mg)



MPPD/RBC data 2012 - 2016

E. "...Local is Global..."

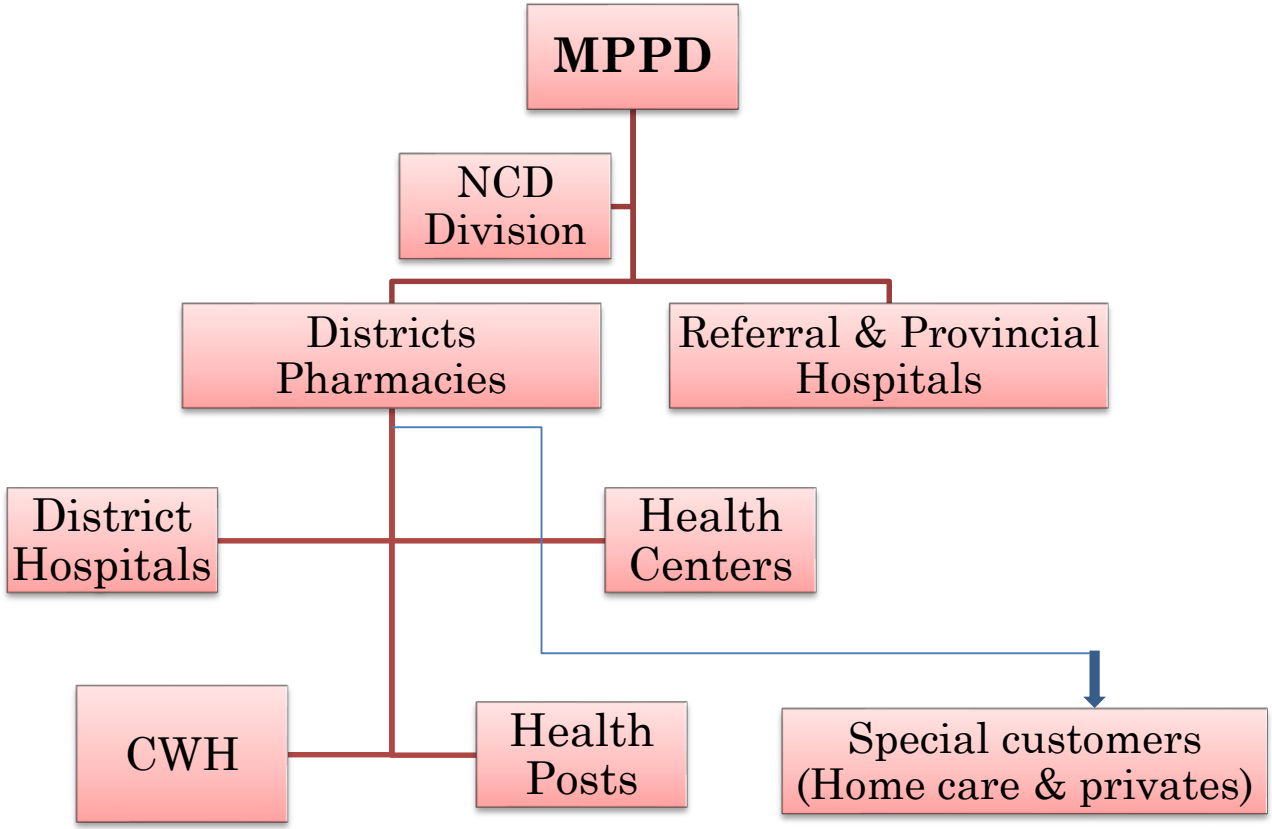
AP

Rwanda avoids US-style opioids crisis by making own morphine

Top Stories Topics Video Liste

By CARA ANNA and CLAIRE GALOFARO
December 25, 2019

F. "…Supply Chain, supply of hope…"



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G. "Task shifting"

Official Gazette n° 15 0f 09/04/2012

ITEGEKO N°03/2012 RYO KUWA 15/02/2012 RIGENA IMIKORESHEREZE Y'IBIYOBYABWENGE N'URUSOBE RW'IMITI IKORESHWA NKA BYO MU RWANDA

LAW N°03/2012 OF 15/02/2012 GOVERNING NARCOTIC DRUGS, PSYCHOTROPIC SUBSTANCES AND PRECURSORS IN RWANDA

LOI N° 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 ikoreshwa nka byo ntibishobora kugira uwo byemererwa bitari mu rwego rwo kugenerwa imiti kandi bikozwe n'aba bakurikira:

1° umuganga ubifitiye uruhushya;

2° umuganga w'amenyo ubifitiye uruhushya mu rwego rwo gukora umwuga wo kuvura amenyo;

3° umuvuzi w'amatungo ubifitiye uruhushya;

4° umubyaza cyangwa umuforomo ufite impamyabumenyi kandi ufite uruhushya rwo kubikoresha mu murimo we kandi mu rwego rwemejwe na Minisitiri ufite ubuzima mu nshingano ze.

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.

Official Gazette n° 15 0f 09/04/2012

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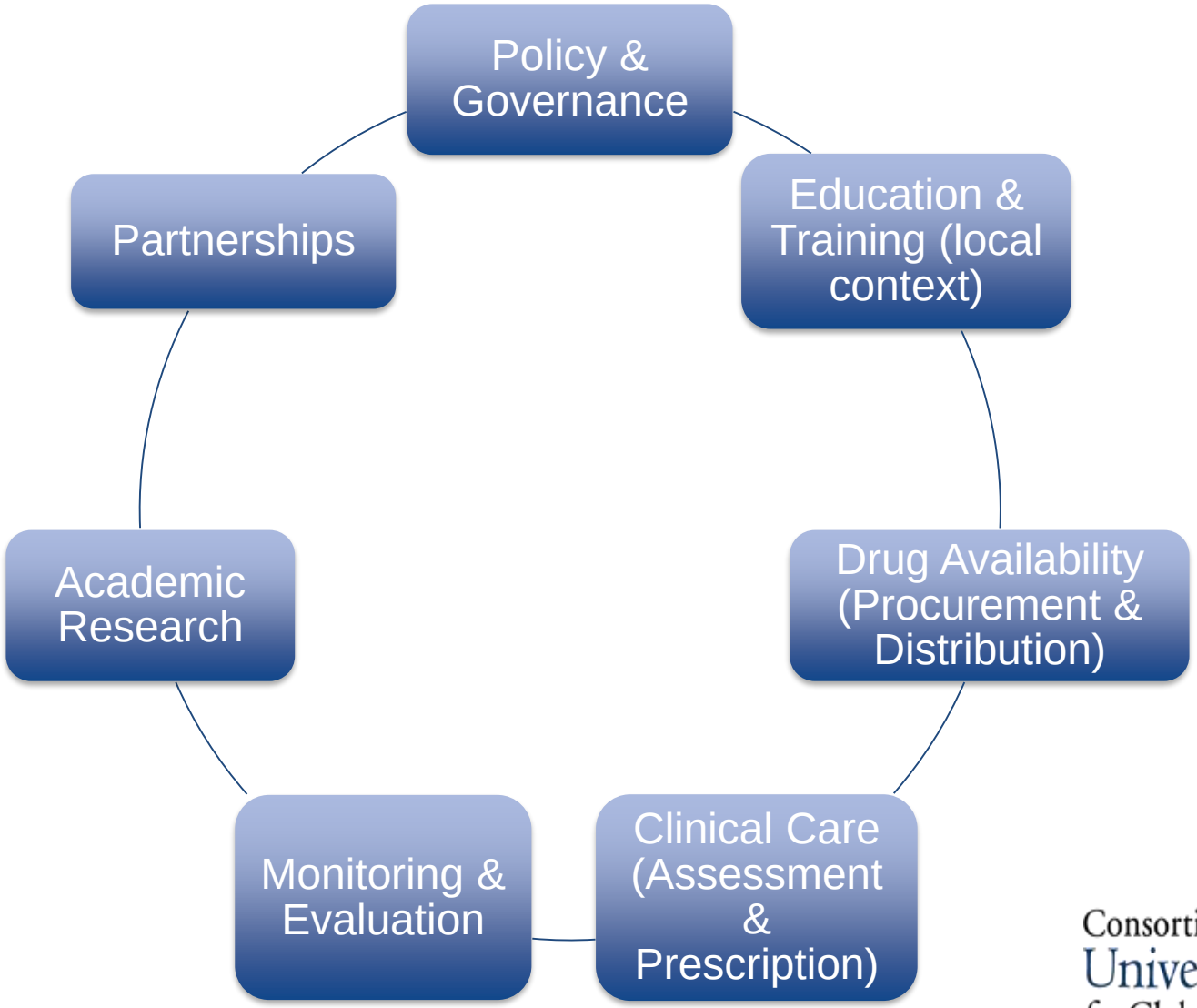
H. "Comprehensive model of care"



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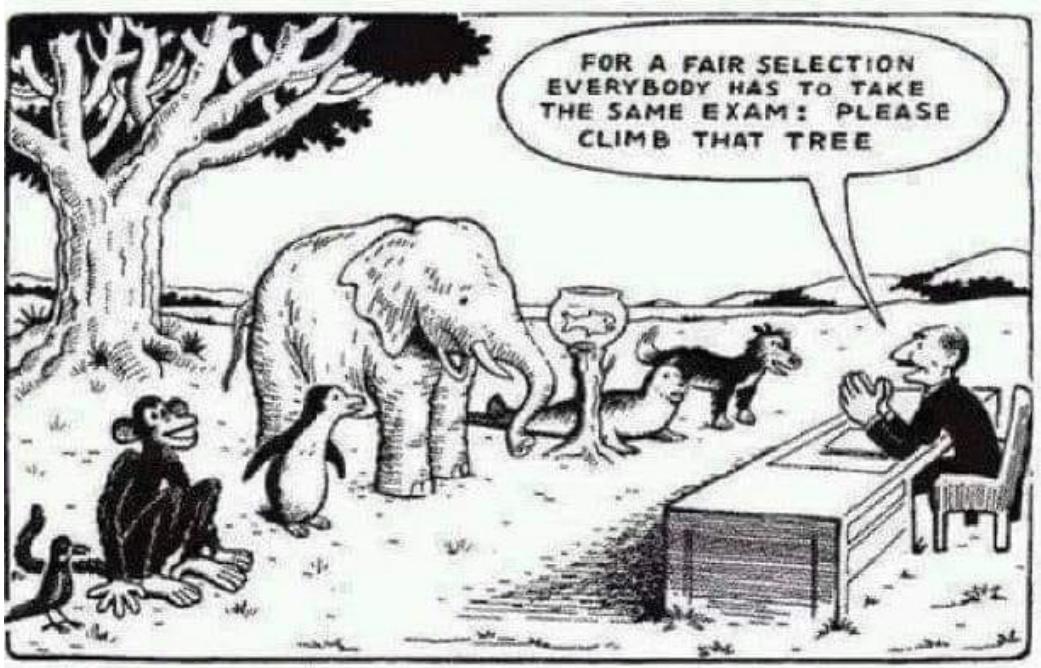
3. "Culture Matters"

Current models for advanced care planning and end-of-life care decision-making have grown out of the Euro-American clinical and cultural experience.



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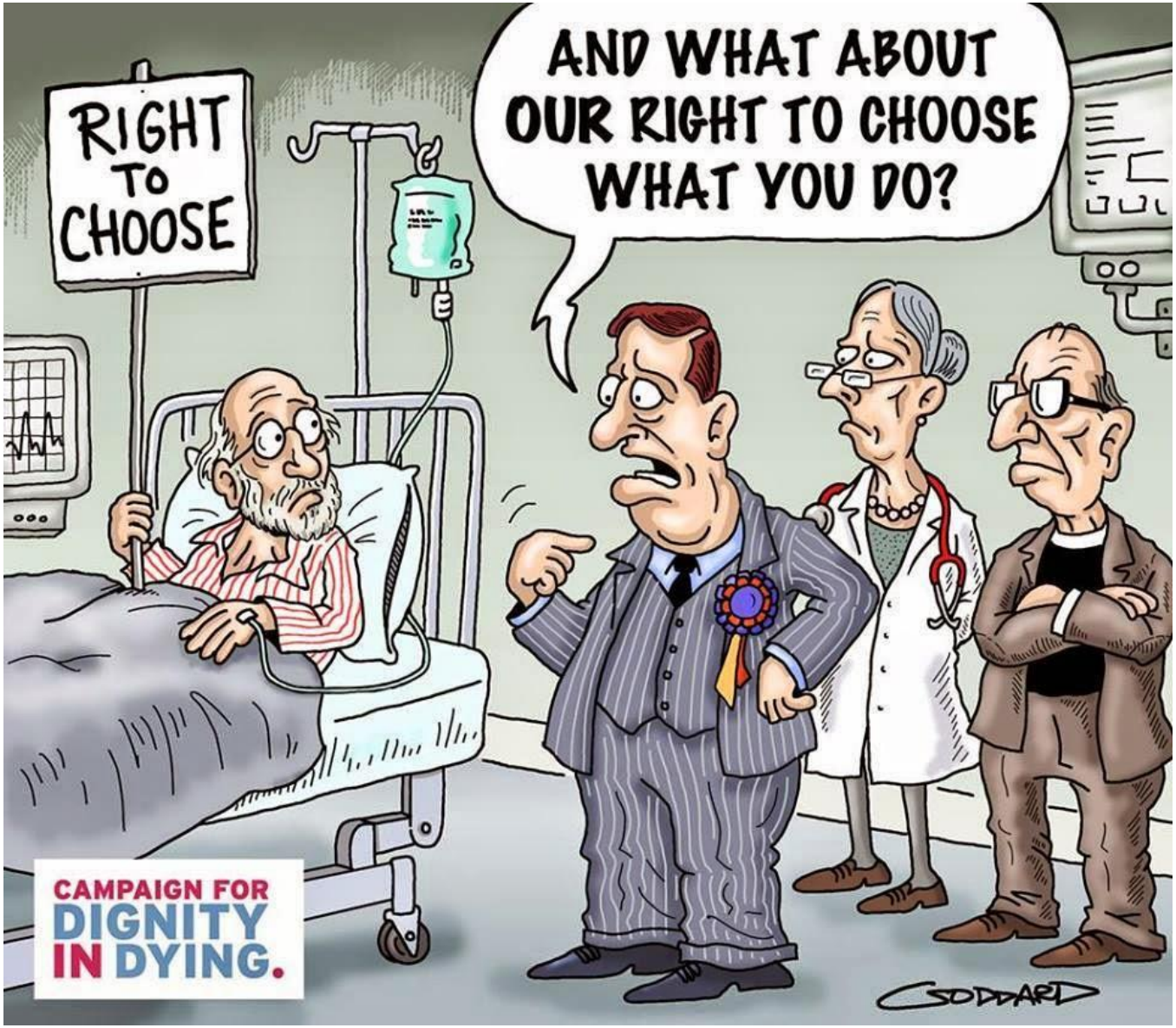
“Education doesn’t necessarily mean duplication but rather adaptation” (Christian Ntizimira)



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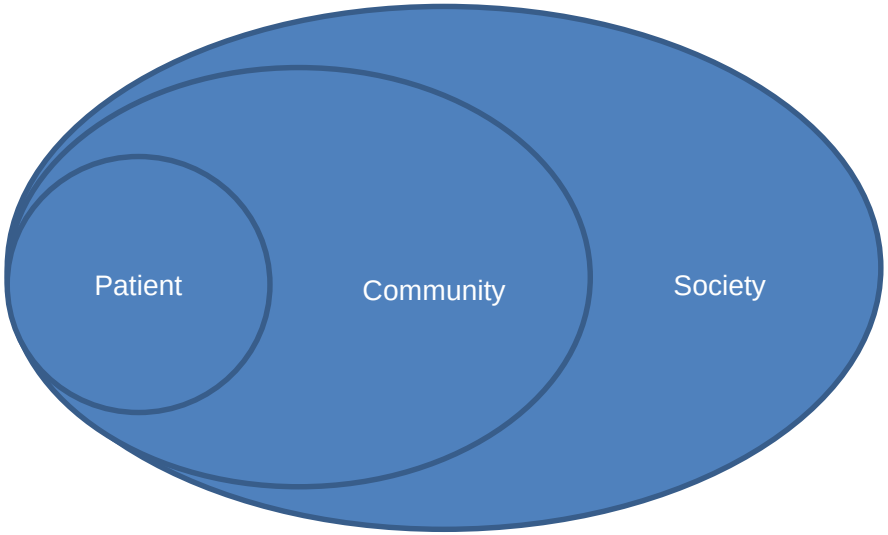
"Rwandan Social Context"

"When you are well, you belong to yourself but when you are sick, you belong to your family"

(Christian Ntizimira)

Patient autonomy

AND



Community responsibility

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"Role of family members…crucial"

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"…African philosophy…"

"Ubuntu philosophy" (understanding resources beyond funding)

"**People are people through other people**"

We define as "a Soul"

- Humanness
- Caring
- Sharing
- Respect
- Compassion

"**When people are everything, money is nothing**" (patient' quote)

Culture matters

	Western culture	African culture
Personhood	Individualism Autonomy Privacy	Familial self Extended Family
Family values	Nuclear family, Equality	Extended family, respect for elders
Disease and illness	Caused by specific agent	Imbalance between person, ancestral world, circumstances

	Western culture	African culture
Pain	Concept of total pain	Stoicism important
Death	Funeral private family event, community support	Funeral a major social event
Bereavement	Community support, bvt counselling	Extended family support

“The way people die can reflect how the society lives”

(Ntizimira C)

The Death of Socrates (Jean-Louis David, 1787)

"Naked but ashamed…" (Christian Ntizimira)

Conclusion

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*

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Thank you

Murakoze

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Questions?

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