

Providing Palliative Care in Resource Limited Settings: Model Initiatives Challenging Innovation and Creativity

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**Critical Conversations in Palliative Care and at the End of Life
September 19, 2014**

Examples of Canadian Expertise at the Congress

- Palliative care discharge planning to remote communities
- The needs of First Nation caregivers
- Telemedicine: closing the distance
- Canadian Virtual Hospice

OSF International Palliative Care Initiative: Open Society Foundations

International Palliative Care Initiative

- The overall goal of this initiative is to serve as a catalyst to create palliative care as an essential aspect of health care policy and health care systems and to build capacity for palliative care services, education, and advocacy around the world.

International Palliative Care Initiative Goals

1. Integrate palliative care into national health care plans, policies, standards, and across delivery systems
2. Integrate palliative care into medical and nursing education
3. Increase public awareness

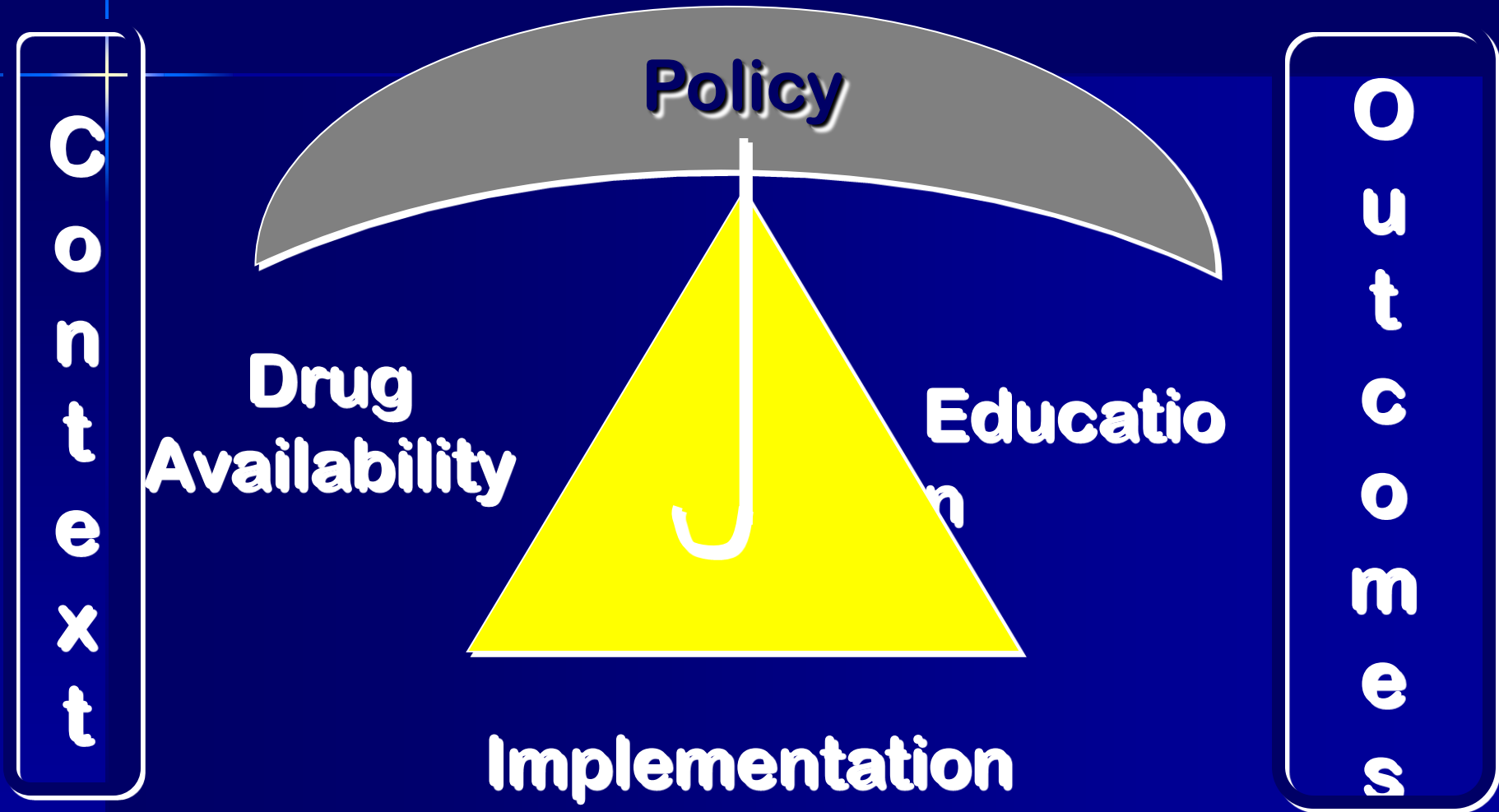
International Palliative Care Initiative Goals

4. **Ensure availability** of essential drugs for pain and symptom management for adults and children with life-limiting illnesses, especially opioid analgesics
5. **Increase funding** for palliative care
6. Serve as an **international resource** for palliative care development
7. **Convene** leaders to work collaboratively

IPCI History

- In 2000, began in Central and Eastern Europe and the Former Soviet Union
- In 2002, expanded to South Africa
- In 2005, expanded to West Africa, East Africa, Sub-Saharan Africa, South East Asia, and Vietnam
- In 2014 work in 13 countries and 5 regions

WHO Public Health Model



2002 WHO Definition of Palliative Care

"Palliative care is an approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes



Planning



World Health
Organization

Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes



Palliative Care



World Health
Organization

	Core	Expanded	Desirable
Palliative care	<ul style="list-style-type: none"> ● Provide pain relief and palliative care with emphasis on home-based care, following national minimum standards ● Balance legislative measures to ensure access to and availability of oral morphine, and other affordable palliative care essential medications included in the WHO's essential medicines list ● Develop reference centres that can provide in-service training to primary and community health caregivers 	<ul style="list-style-type: none"> ● Provide palliative care at all levels of care with emphasis on primary health care clinics and home-based care, following national protocols ● Ensure availability of essential medications in both rural and urban centres ● Develop reference centres that can provide undergraduate and postgraduate training ● Develop curricula in both nursing and medical schools to teach palliative care both at the undergraduate and graduate levels 	<ul style="list-style-type: none"> ● Reinforce the network of palliative care services integrated with cancer and other related services ● Provide support to the centres acting as national and international reference palliative care centres

**THE SOLID
FACTS**

PALLIATIVE CARE



FONDAZIONE FLORIANI





EUROPE

Better Palliative Care for Older People



ff
FONDAZIONE FLORIANI



Global Atlas of Palliative Care at the End of Life



Setting priorities

- Develop a thorough needs assessment
- Engage all the stakeholders
- Create integrated not parallel programs
- Address the special needs of children
- Use innovative communication and evaluation strategies
- Role of radio, Skype, telemedicine

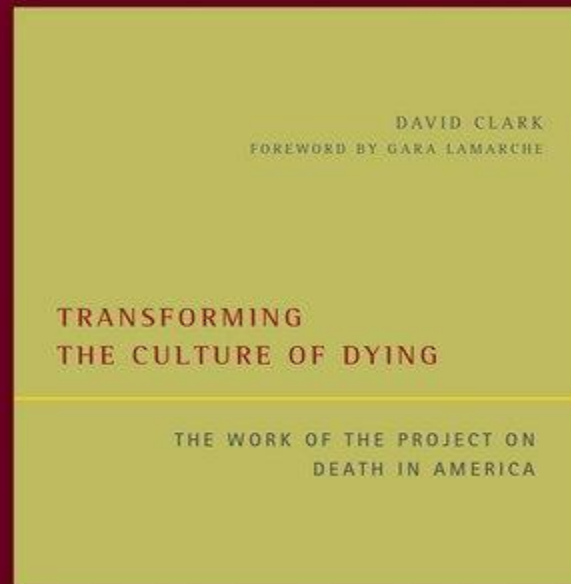
Setting priorities

- Be culturally competent
- Support community expertise
- Increase nursing certification for prescribing
- Ensure pharmacy availability 24/7
- Develop emergency kits and protocols for common end of life events

Setting Priorities

- Remember access to palliative care is their right!

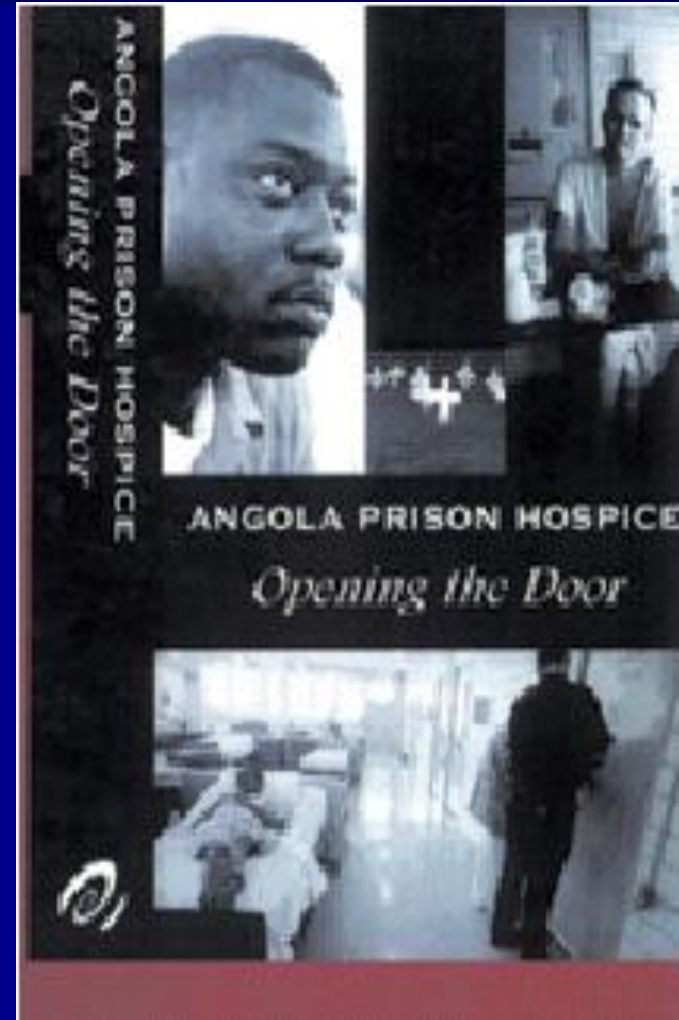
The Project on Death in America 1995-2003



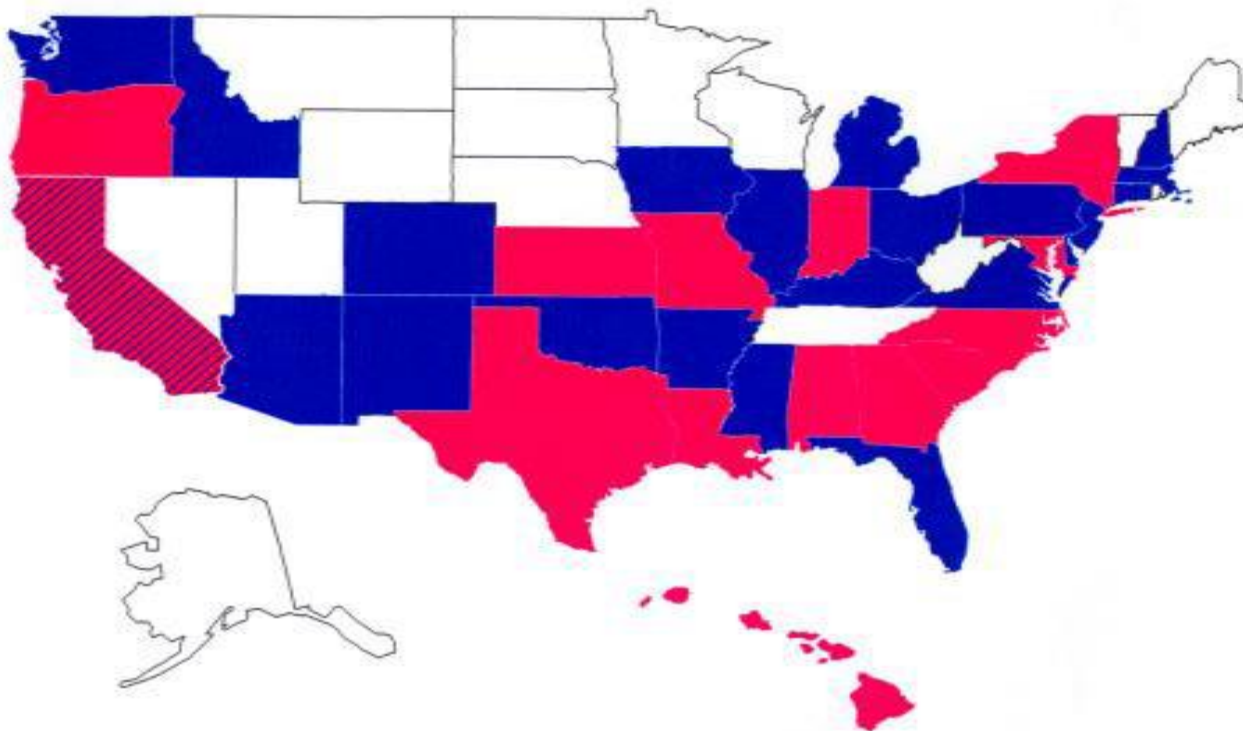
OXFORD

U.S. PRISON POPULATION

- 2,026,596 people imprisoned
- 3,000 die each year
- 5,108 men incarcerated
- 85% will die in Angola



End of Life Care in Corrections Nationwide



-  Operating Programs
-  Requested Technical Assistance
-  No Information



Volunteers of America®

Palliative Care Minority & Medically Under-Served Communities

- Access Gaps
- Knowledge Gaps
- Cultural Issues
- Political Issues

Palliative Care Issues for Minority Patients

■ Differences in patient perspectives

(McKinley ED et al. J Gen Int Med 1996;11:651-6)

- Black patients more likely to feel advanced directives will increase a sense of hopelessness & lead to decrease levels of care

■ Differences in physician perspectives

(Mebane et al. J Am Geriatr Soc 1999;47:579-91)

- Black physicians more likely to endorse aggressive life-sustaining treatment for their patients and themselves

Some “Facts”

- Underutilization of hospice and other palliative care services

(Facts and Figures on Hospice Care in America: The National Hospice and Palliative Care Organization)

- Underutilization of advance directives and other end-of-life tools

(McKinley ED et al. J Gen Int Med 1996;11:651-6)

- Prefer resource intensive care: aggressive interventions over withdrawing or withholding treatments

(Mebane et al. J Am Geriatr Soc 1999;47:579-91)

MSKCC-NGH Collaboration



Criteria for Evaluation of Outcomes

- **Process measures**
 - Improved access; measures of assessment; quality measures of care; "bottom-up" input
- **Patient-outcome measures**

Specific Curricula for Minority Populations

APPEAL Curriculum:

A Progressive Palliative Care Educational
Curriculum for the care of African-
Americans at Life's End

Palliative Care in the Pueblo of Zuni

Kitzes, JPM, 2004

- Collaborative effort
- Tribally operated home health agency
- Indian Health Service
- Academic Medical Center UNM

Palliative Care in the Pueblo of Zuni

Kitzes, JPM, 2004

Challenges:

- Rural setting
- Limited workforce
- Competing demands
- Need for coordination among distinct organizations
- Need to address dying in a culturally proficient manner

Helping Hands Program Bristol Bay, Alaska

RWJ Demonstration Project with medical anthropologist and development committee

- Home based, staffed by family and village members
- Drugs stored in locked box, durable medical equipment flown in
- Home deaths increased from 37% to 77%



End-of-Life Nursing Education Consortium

A Collaboration of

**CITY OF HOPE
NATIONAL MEDICAL
CENTER**

Los Angeles, CA

**Betty Ferrell,
Marcia Grant,
Rose Virani**

**AMERICAN
ASSOCIATION OF
COLLEGES OF NURSING**

Washington, DC

**Pam Malloy
Geraldine Bednash**

International ELNEC Efforts



- ELNEC's primary aim is to educate nurses to improve EOL care.
- Translated into 9 languages, web-based, train the trainer program.
- 17,000 nurses in US
- 20,000 nurses internationally

Some ELNEC MODULES

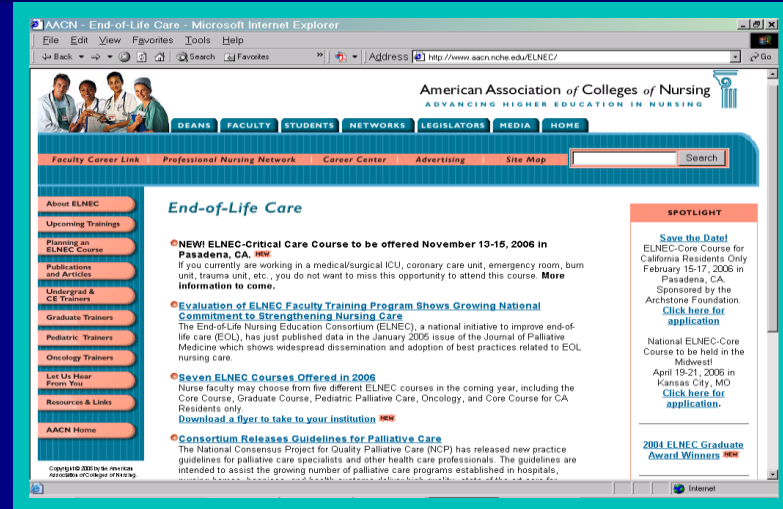
- Palliative Nursing Care
- Pain Management
- Symptom Management
- Ethical/Legal Issues
- Cultural Considerations in End-of-Life Care
- Communication
- Loss, Grief, Bereavement
- Achieving Quality Palliative Care
- Preparation for and Care at the Time of Death

ELNEC WEBSITE

■ The ELNEC project is described in detail at www.aacn.nche.edu/ELNEC.

ELNEC Trainers use the Website to locate colleagues with whom to consult and partner.

■ Multiple courses in pediatrics ,geriatrics, emergency medicine ,ICU



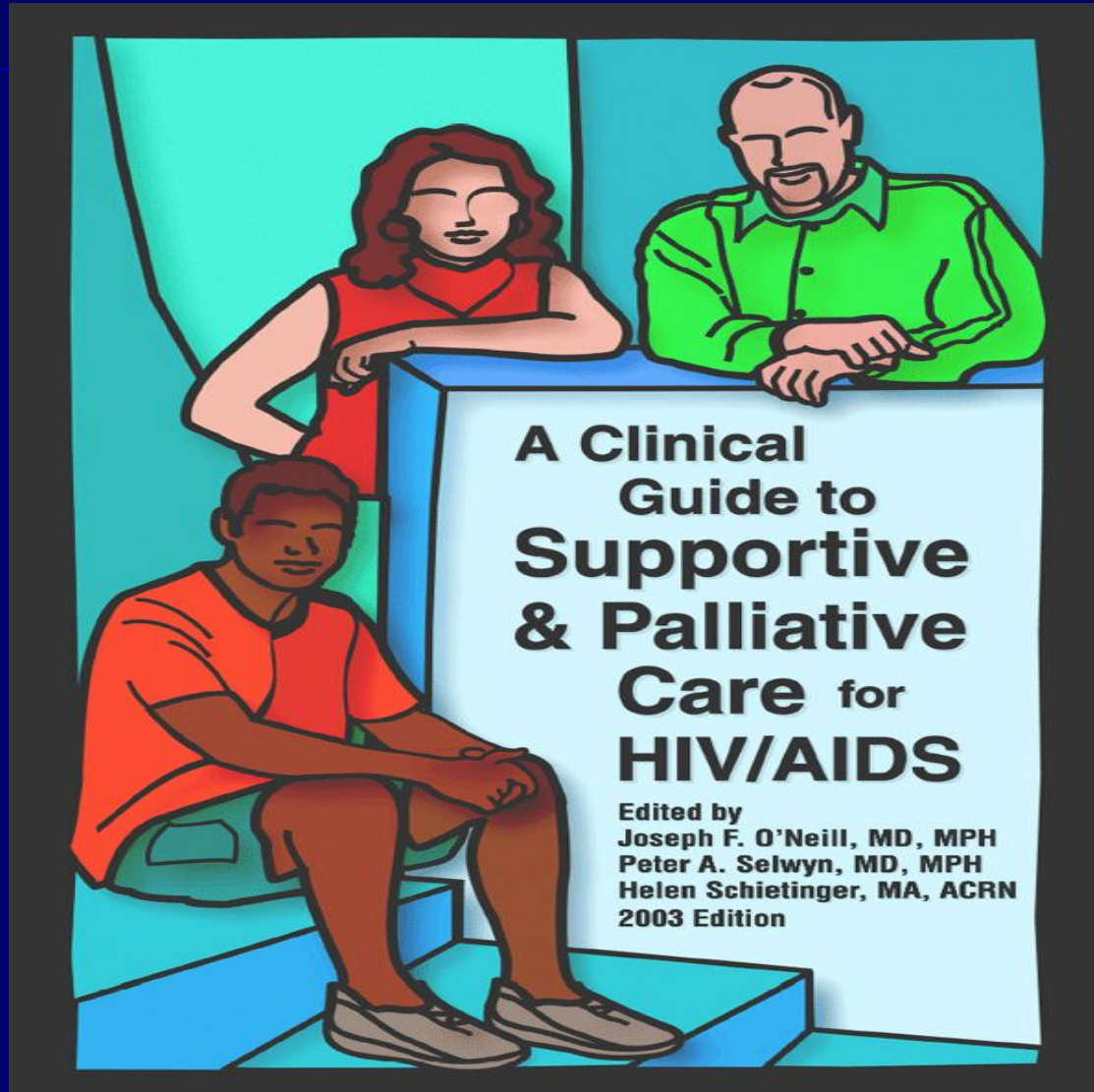
Palliative Care as a Public Health Issue

- affects all people
- need for better information on end-of-life care
- potential to prevent suffering
- potential to prevent disease

Palliative Care as a Prevention Model

- prevents needless suffering
- provides peer education
- provides patient centered care
- incorporates self-management programs

<http://hab.hrsa.gov/tools/palliative/>



A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa

2006 Edition

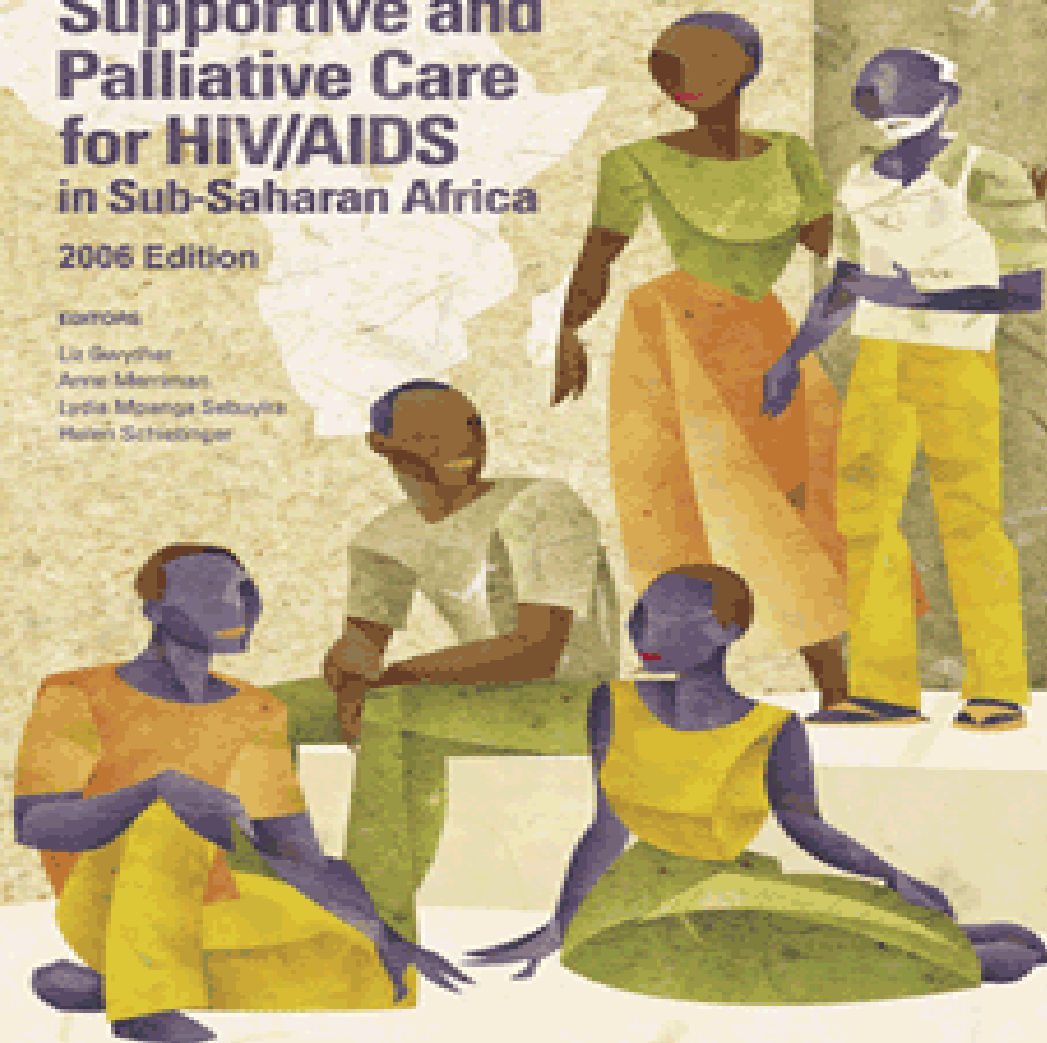
Editors

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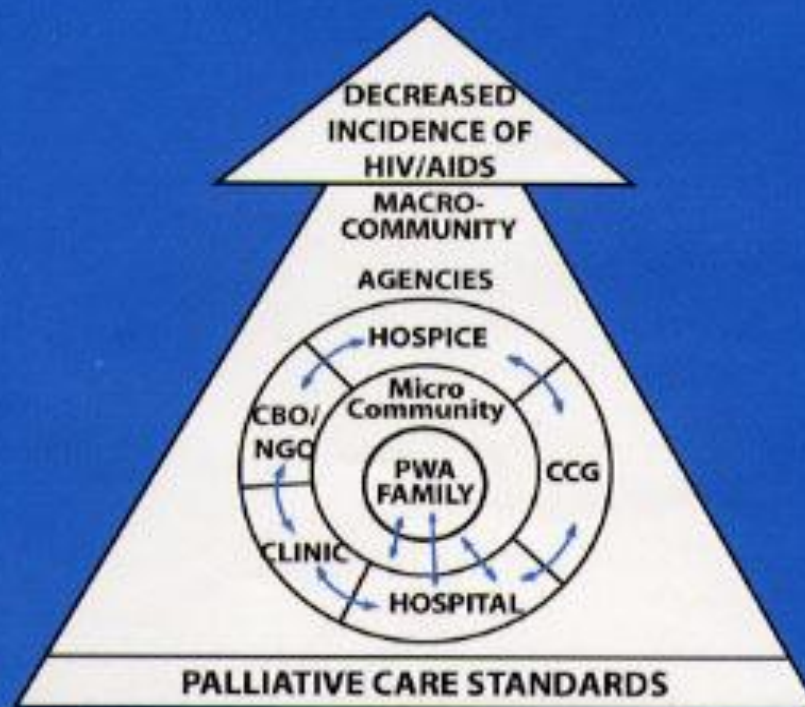
Lydia Mwangi Sebuyika

Helen Schiedinger



Model Initiatives in Palliative Care in South Africa

HPCA-SA developed integrated community
based home care models (ICBHBC)



HPCA of South Africa Mentorship Program

- Developed a robust education and training mentorship program to teach community-based home-based care programs palliative care and end of life care.
- Developed tool kits, training manuals
- Provided oversight and experiential training

Community and Home-Base Care

Strengths:

- Community and home-based care has existed forever
- Opportunity to ensure the continuum of palliative care
- Convenient for patients and families









Lessons learned in caring for the carers

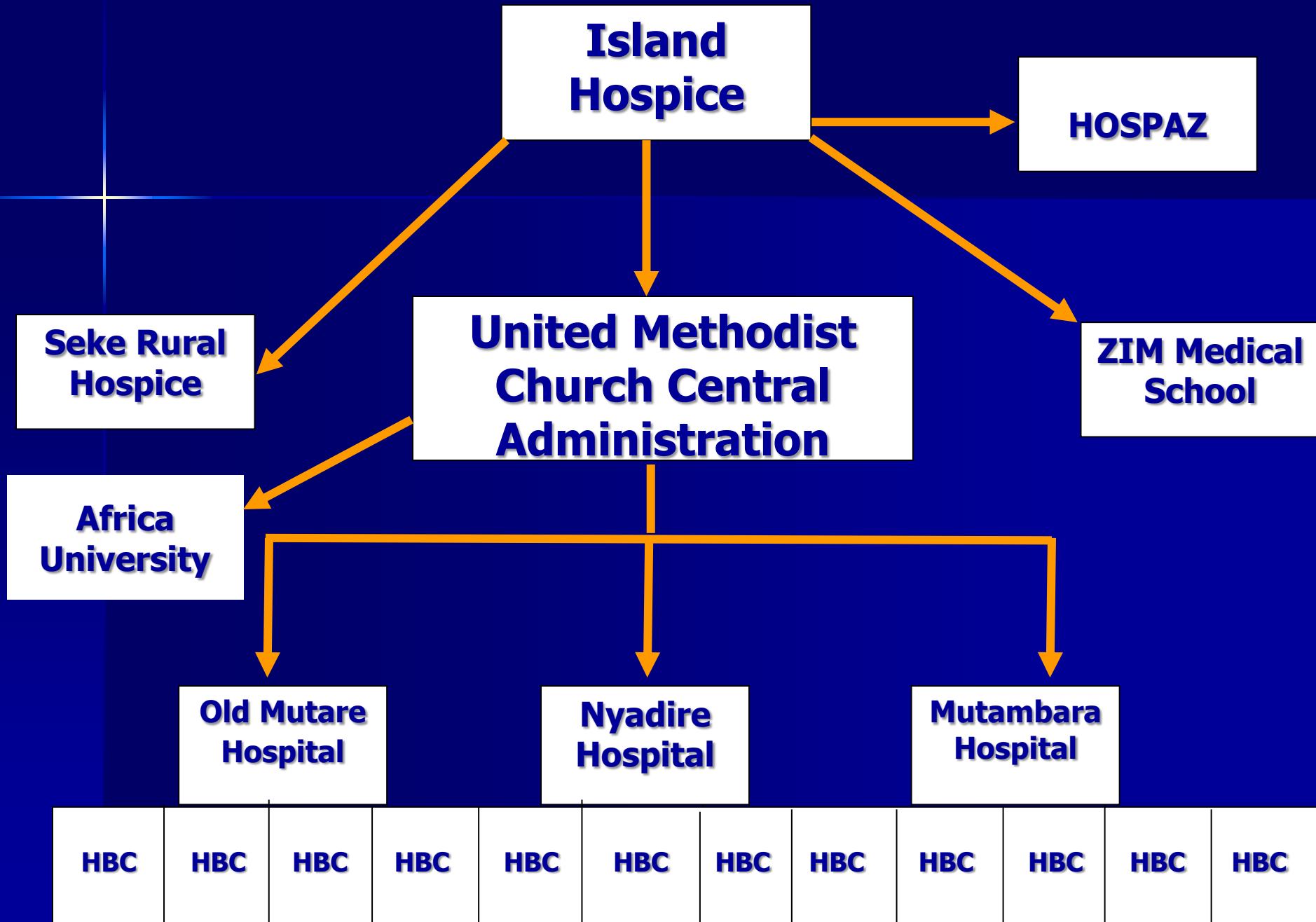
- Limited literacy in community workers and volunteers requiring pictorial educational format
- Develop innovative supports for workers like providing food, laundry access, bicycles or cars, tuition for childrens' schools, uniforms etc







ZIMBABWE





WHO Community Health Approach to Palliative Care for HIV and Cancer Patients in Africa

Model Initiative in Providing Palliative Care

- Uganda Ministry of Health included palliative care in its National Health Sector Strategic Plan
- Uganda developed and funded an essential drug program and changed restrictive laws to allow oral morphine in home-based settings

Uganda Case Example

- Strategic Health Plan of Uganda included palliative care as an essential service
 - added liquid morphine to the essential drug list
 - adopted new set of guidelines for handling morphine
 - authorized prescription by nurses(2009)
 - 79 nurses and clinical officers received training and 34/56 districts have drug

GAPRI | Global Access to Pain Relief Initiative



www.gapri.org



Global Access to Pain Relief Initiative (GAPRI)



Goal

Universal access to essential pain medicines by 2020

Objectives

1. Strengthen government leadership

by providing staff (fellows) and technical assistance directly to health ministries

2. Reduce cost and improve availability of medicines

by negotiating with suppliers and providing technical assistance to buyers

3. Improve clinical and regulatory policies and practice

by advocating on international, national, and facility levels

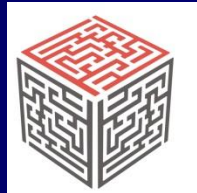
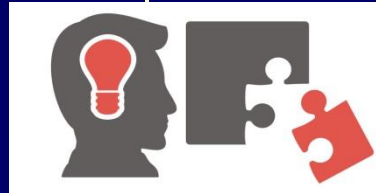
4. Improve skills and motivation of individual clinicians

by improving access to information and to other clinicians interested in pain treatment

Strategy

- Develop high-profile projects in countries with large unmet need; prompt change in neighboring countries and adoption by other organizations

The MORPHINE framework



Mindset | **O**rganize | **R**egulations | **P**rocurement | **H**healthworker | **I**nitiation | **N**ationalization | **E**mpowerment

Ensure that policy makers understand the issues and are prepared to take a lead role

Consult stakeholders to map process and barriers to access

Ensure that they are up-to-date or identify needed changes

Establish budget for drug purchase, storage, and distribution. Estimate quantities, identify suppliers, secure product registrations, develop tenders, place and pay for orders, and receive and distribute to regional medical stores

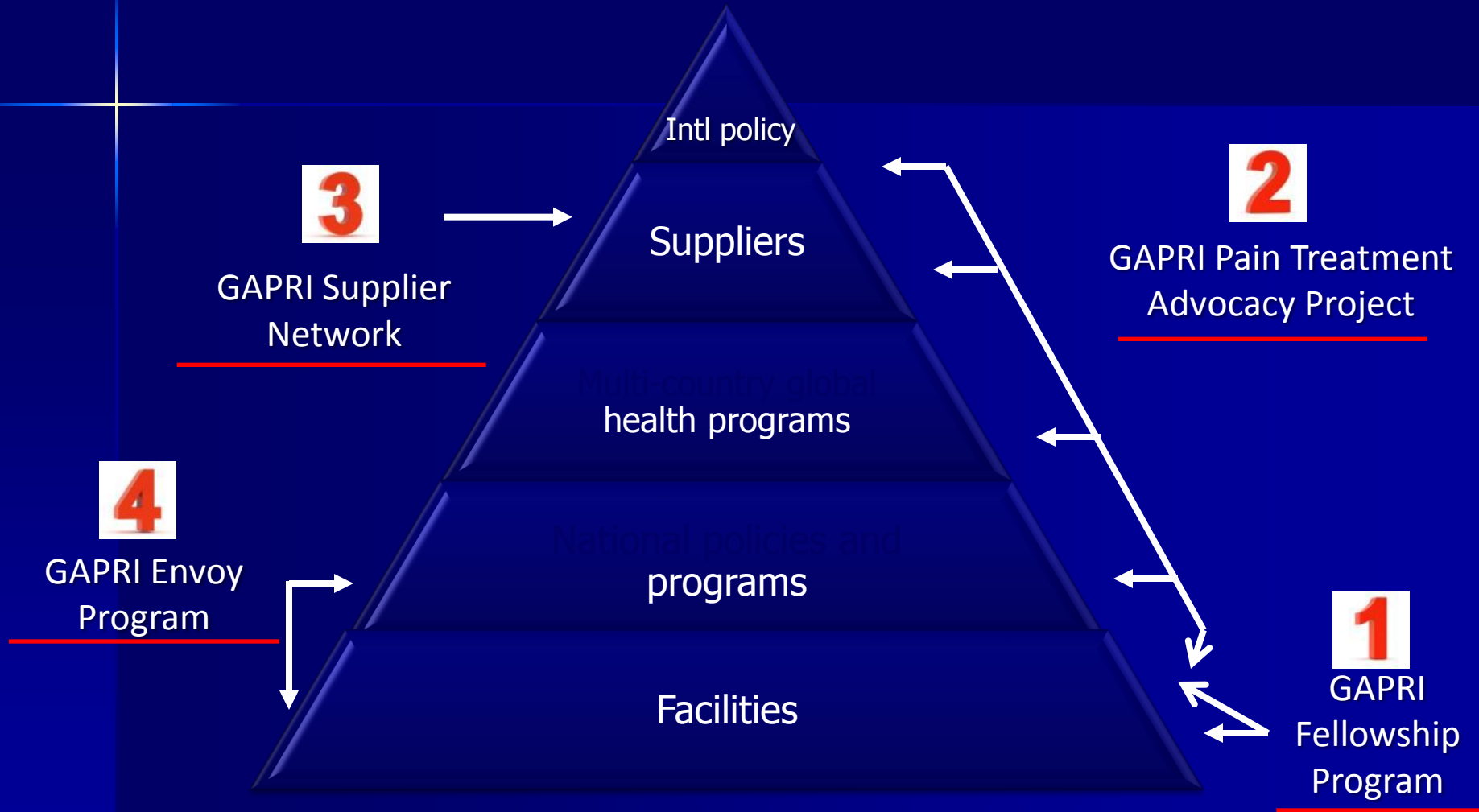
Organize awareness-raising activities, in-service training, and continuing medical education; develop reference materials and guidelines

Establish pain treatment by trained clinicians, usually at large clinical centers or specialized clinical units

Integrate into service delivery at regional and district hospitals and ensure adequate geographical coverage to make pain relief accessible to all who need it

Create a sustainable stakeholder base

UICC'S GAPRI Strategy



GAPRI Supply Project: Uganda

Population: 33
million

Deaths in pain:
68,000

Coverage: 7%

In 2010 GAPRI brokered a deal between government and an NGO to create a national morphine production program

- Government's cost of purchasing morphine has been reduced by 40%
- Increased stability of supply and expanded access
- Morphine is now free for all patients
- Finalized a donation of morphine powder that will generate 170,000 USD to upgrade production facility and ensure its sustainability

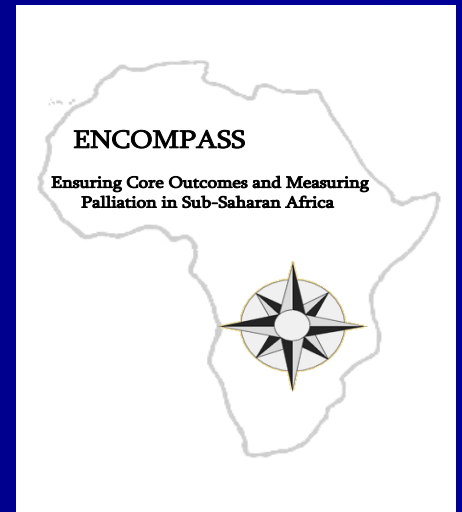


**Cicely Saunders
International**
Better care at the end of life

ENCOMPASS: summary programme findings



**Dr Richard Harding,
Senior Lecturer**



Cicely Saunders International/ ENCOMPASS Impact

- **Developing research careers in Africa**
 - First palliative care research nurses in Africa trained and active
 - New emerging research careers post-ENCOMPASS
 - MSc Scholarships
 - Further PhD funding on data collected
- **Significant increase in African data**
 - 1199 pts/families validation/14,000 clinical assessments in audit
 - Further analysis: MSAS data on 300 pts
 - Feasible, successful model of clinical audit for replication
- **Catalysing research in developing settings**
 - APCA African POS widely adopted used:
 - Across 12 sites in Kenya and Uganda in PEPFAR evaluation
 - At Mildmay International
 - In Tanzania and beyond
 - For training in public health clinics/ SA Govt sector
 - Exploration of replication in India and Vietnam
 - 'How-To' Manual on palliative care audit : simple and affordable
 - Methods paper: research in African palliative care (Harding et al JPSM 2008)
 - Paediatric POS being pursued

Improvement strategies designed and implemented

A. PAIN

- Improve pain assessment, drug availability and prescribing
- Refer to physiotherapy where appropriate
- Nurses to refer patients to a doctor within 2 days if pain score T1 has not improved by T2
- Advocate for syringe drivers

Improvement strategy cont'd

B. SYMPTOMS

- Nurses to refer patients to a doctor within 2 days if symptoms do not improve
- Ensure prescription of correct laxatives

c. WORRY

- All patients with psychosocial problems to be referred to social worker/ counsellor as appropriate
- Family worry hypothesized to improve as patient worry & symptoms improve

Campaign to Assess Availability of Essential Drugs

Kenya “Stock out campaign” used cell phones and specially designed app

- Families went to local pharmacy
- Reported their availability
- Media attention to lack of essential medications

Your Responsibilities as a patient are:

- To comply with the prescribed treatment or rehabilitation procedures.
- To enquire about the related costs of treatment and/or rehabilitation and to arrange for payment.
- To take care of health records in your possession.
- To take care of your health.
- To care for and protect the environment.
- To respect the rights of other patients and health providers.
- To utilise the health care system properly and not abuse it.
- To know your local health services and what they offer.
- To provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purpose.
- To engage in healthy lifestyles for example; always eating a balanced diet; living a life free of excessive alcohol, not smoking, not engaging in unprotected sex.
- To complete dosage as instructed at the health care facility
- To advise the health care providers on your wishes with regard to your death.

Palliative Care as a human right is about access to quality palliative care, access to pain relief, dignity, non-discrimination and equality.



OPEN SOCIETY INSTITUTE
& Soros Foundations Network

For more information please contact us at;
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P.O. Box 20854-00202, Nairobi Kenya
Tel: +254 (20) 2729302
Cell: +254 (0) 722 507219
Email: info@kehnpca.org
Website: www.kehnpca.org



Kenya Hospices and Palliative Care Association

KNOW YOUR PALLIATIVE CARE RIGHTS

"You may have at one time in your life had an awful experience at the health care facility be it from delay in health care service, an undignified treatment or denial of the same but had no idea what you can do as a patient. If you now know your Rights, you are empowered to claim.

Be empowered; know your rights"

Vietnam Case Example

- 2005- rapid assessment analysis of need for palliative care published
- 2006- MOH issued detailed guidelines to practitioners in palliative care and pain management
- 2008- government approved new guidelines on opioid prescribing and a package of training courses

Kerala Model of Palliative Care

- Community mobilization model
- Owned by the local community
- Community volunteers: help identify need and run palliative care units
- Visit patients at home and support them at the clinic do administrative work raise funds, advocate with the government

Kerala Model of Palliative Care

- Supported volunteer doctors and nurses
- Supplied food to dying families
- Helped support children to attend school of poor patients
- Transport pts to medical facilities
- Income-generating activities

INCTR sponsored & funded physician education at Pain and Palliative Centre, Calicut, Kerala, India



- 7 physicians, 2 administrators and 20 nurses attended intensive courses in 2003 & 2004

Factors contributing to Success of the NRHM Kerala Model

- Public awareness and media support
- High level policy recognition
- NHRM innovative palliative care project
- Decentralized system of governance in Kerala

Improving clinical and regulatory policies and practice: India



Population: 1.2 billion
Deaths in pain 709,000
Coverage: 6%

Working with partners in India to implement the **Pain-Free Hospital Initiative**

A one-year hospital-wide quality improvement initiative in 3 cancer centers

- Motivate clinicians to evaluate and treat pain
- Equip clinicians with the skills and tools to effectively treat pain
- Measure the impact of the program
- Communicate the impact of the program

Policy Initiative Examples

- Romanian Experience
 - Drug Policy Project—PPSG worked with Romanian palliative care leaders and government officials to review and revise laws and regulations governing opioid usage.

Old and New Policy in Romania

35-year-old policies

- No independent prescribing authority beyond 3-day period
- Opioid analgesics limited by patient diagnosis (3)
- Limit of 60 mg per day of morphine
- 10-day prescription possible, but with very complex authorization process (expires in 90 days).
- Burdensome for physicians and patient family

New policies

- Prescribing authority granted for 30-day period
(for physicians with specific specialties or who have received training)
- Not limited by patient diagnosis
- No limit of daily dose
- Less burdensome for physicians and patient family

WHO Workshop, Budapest 2002



Progress in Europe

1.	<u>France:</u>	7 days	28 days
2.	<u>Italy:</u>	8 days	1 month; Rx simpl.
3.	<u>Germany:</u>	1 day	no limit
4.	<u>Poland:</u>	100 mg	4.0 grams
5.	<u>Romania:</u>	3 days	30 days

Progress in Colombia

Prescription amount from 10 days to 30 days of medication,
15 December 2005

Working to improve distribution of morphine supply from
warehouses in Bogota to rural areas.

Success in ensuring at least one pharmacy in each district
stocks opioids 24 /7.

Actively engaging with Government authorities to address
opioid access.

Colombian Senate passed new palliative care law in 2014



MORPHINE SYRUP 10mg/ml

_____ Mixture (s) to be taken 4 hrly

Time: 6a.m, 10a.m, 2p.m, 6p.m, 10p.m

Name _____

Date _____

Keep all medicines out of children's reach

MORPHINE SYRUP 10mg/ml

_____ Mixture (s) to be taken 4 hrly

Time: 6a.m, 10a.m, 2p.m, 6p.m, 10p.m

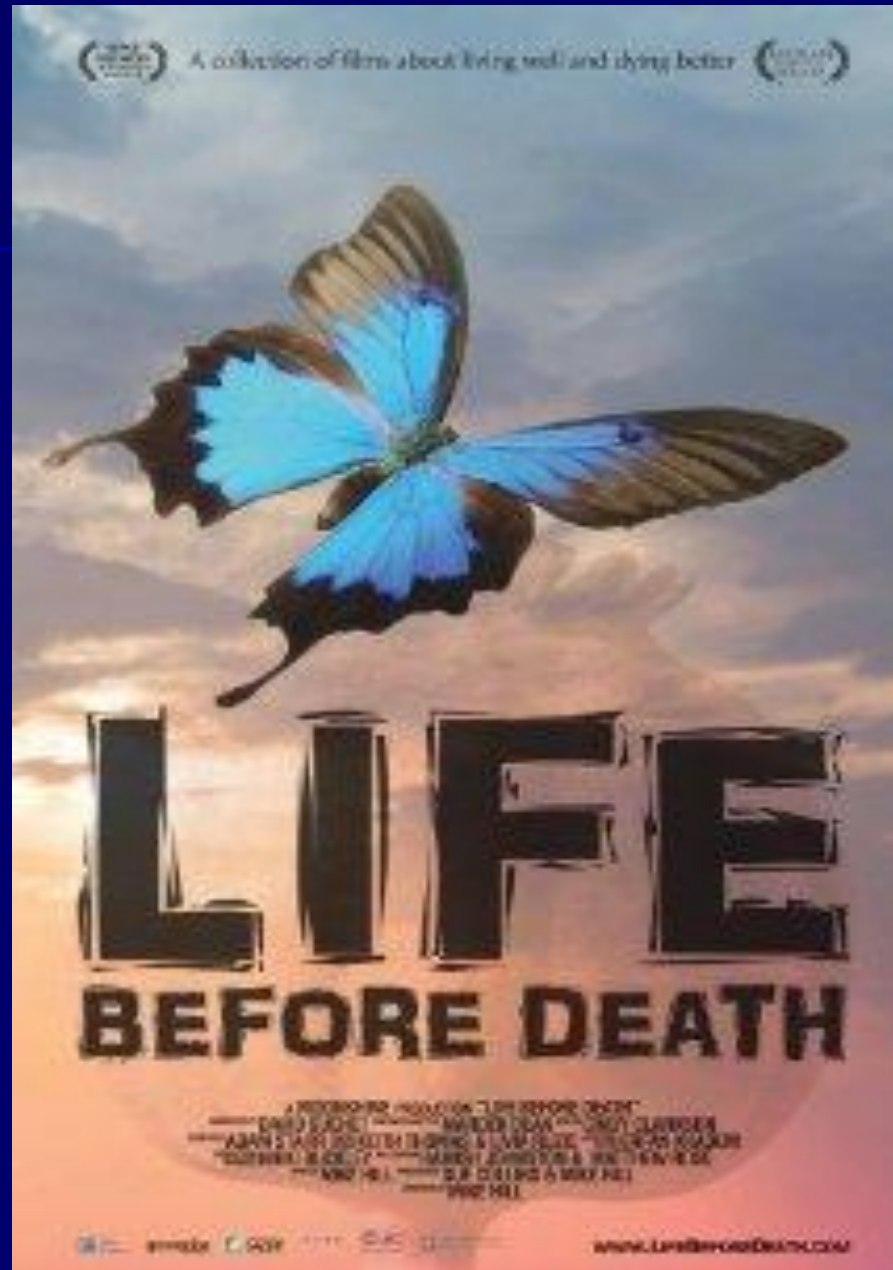
Name _____

3/5/2003

Keep all medicines out of children's reach



<http://www.lifebeforedeath.com/movie/index.shtml>





The Struggle for Access to Essential Medicines in East and Southern Africa



Voices of consumers on affordability and availability



INTENSITY

MILD
MODERATE
SEVERE
OVERWHELMING
1 - 2 Weeks
2 - 6 Weeks
6 - 12 Weeks
> 12 Weeks
CONSTANT
INTERMITTENT
SLEEP
MOBILITY

DURATION

PERIODICITY

EFFECT

EFFECTS OF PRESENT MEDICATION: NO DIFFERENCE
PARTIAL CONTROL
COMPLETE CONTROL

OTHER TREATMENT: NERVE BLOCK
RADIOTHERAPY
OTHER

EFFECT

NO DIFFERENCE
PARTIAL CONTROL
COMPLETE CONTROL

RELATIVE VIEWS

OTHER INFORMATION:

POSSIBLE CAUSES

NIGHT



EVENING



AFTERNOON



MORNING



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PURPOSE

Pain

MEDICINE

Morphine

2030382
2030878
orthospice.org
7 294

VICE

MEDICATION

