

A Right to Palliative Care: A Critical Component of Healthy Ageing

Open-ended Working Group on Ageing

Panel 3: Social security and the right to health

Kathleen M. Foley M.D.

Open Society Foundations

August 13, 2013



World Health
Organization



World Health Day 2012
- Ageing and health -

Toolkit for event organizers

GOOD HEALTH ADDS LIFE TO YEARS

World Health Day 2012

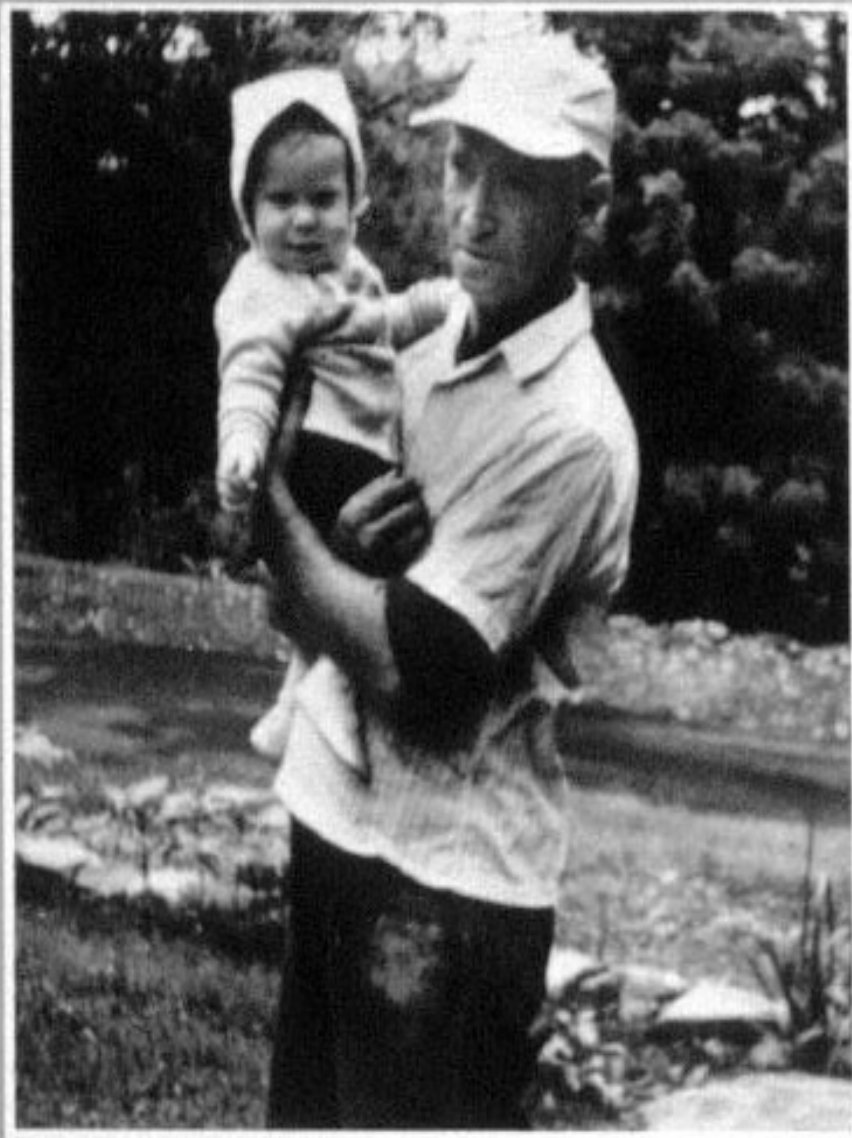
Taking Action on Ageing and Health

- Promote good health and healthy behaviors to prevent or delay the development of chronic disease.
- Minimize the consequences of chronic disease through early detection and quality care
 - Early detection
 - Chronic care
 - Long-term care
 - Palliative care

World Health Day 2012

Taking Action on Aging and Health

- Create physical and social environments that foster the health and participation of older people.
- Reinventing aging-changing social attitudes to encourage the participation of older people.



Frank Tugend and his grandson, Dan Jury, 1954.



Dan Jury and his grandfather, Frank Tugend, 1974.

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"



EUROPE

**THE SOLID
FACTS**

PALLIATIVE CARE



FONDAZIONE FLOIANI





World Health
Organization

REGIONAL OFFICE FOR
Europe

PALLIATIVE CARE FOR OLDER PEOPLE: BETTER PRACTICES



KING'S
College
LONDON

University of London
We Celebrate Care for
Older People



FONDAZIONE
MARUZZA
LEFEBVRE
D'OVIDIO
ONLUS

Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes



Palliative Care



World Health
Organization

EURAG



EUROPEAN FEDERATION OF OLDER PERSONS

**Making
PALLIATIVE CARE
a Priority Topic on the
European Health Agenda**

**and
Recommendations for the Development of
Palliative Care in Europe**



Palliative care for older people in the European Union

Brussels 2012



In association with



New Global Initiative in Pain and Palliative Care

- UN General Assembly Meeting on Non-Communicable Diseases 2011:

Calls for the integration of pain and palliative care into health care services

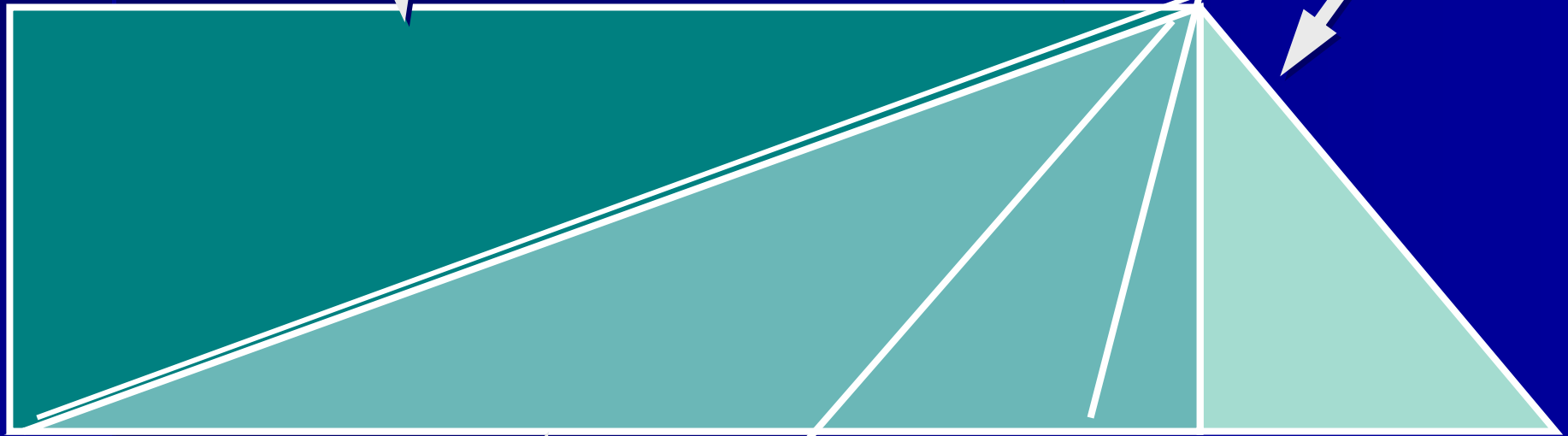
Includes palliative care indicators

The continuum of palliative care

Therapies to modify disease
(curative, restorative intent)

Life
Closure

Actively
Dying



Diagnosis

6m

Death

Therapies to relieve suffering,
improve quality of life

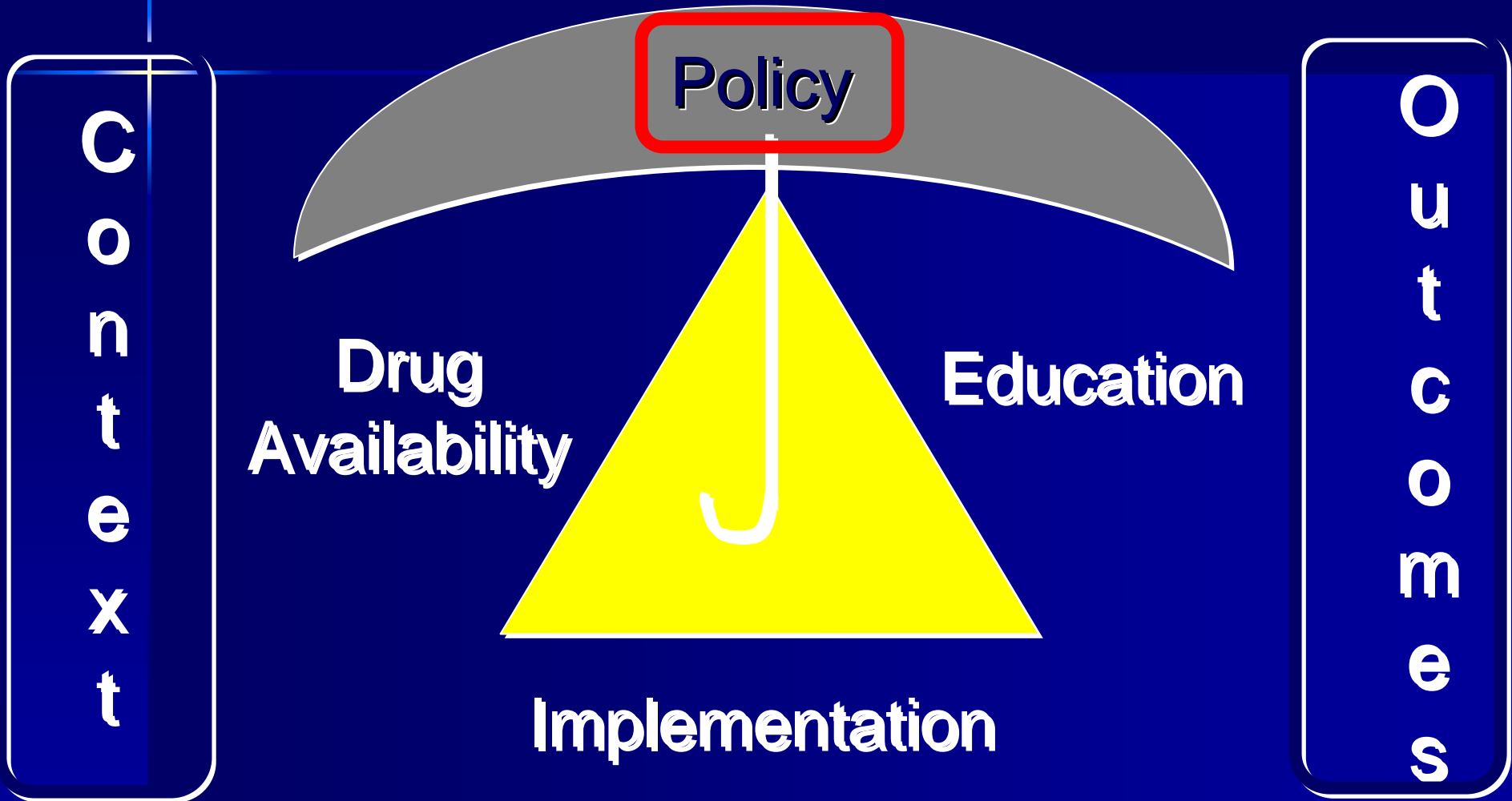
Bereavement
Care

WHO Three-Step Analgesic Ladder



Source: World Health Organization, 1990.

WHO Public Health Model



WHO Public Health Model

Policy

- Palliative care part of national health plan, policies, related regulations
 - Funding / service delivery models support palliative care delivery
 - Essential medicines
- (Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
 - Importation quota
 - Cost
 - Prescribing
 - Distribution
 - Dispensing
 - Administration
- (Pharmacists, drug regulators, law enforcement agents)



Implementation

- Opinion leaders
 - Trained manpower
 - Strategic & business plans – resources, infrastructure
 - Standards, guidelines measures
- (Community & clinical leaders, administrators)

Education

- Media & public advocacy
 - Curricula, courses – professionals, trainees
 - Expert training
 - Family caregiver training & support
- (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Palliative Care: A World View

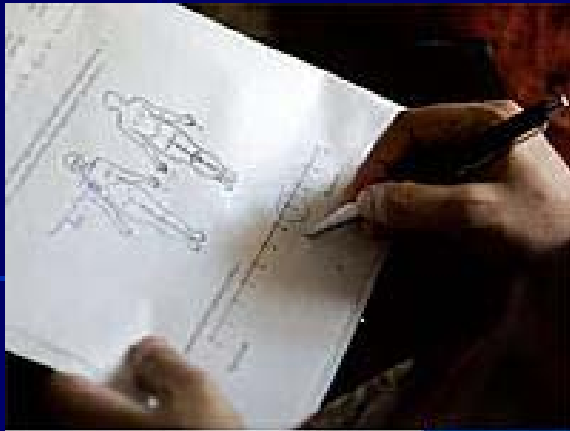
- Palliative Care is a public health issue
- Palliative Care is human rights issue
- Pain relief is a fundamental human right

Palliative care rights include:

- Pain relief
- Symptom control for other physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Communication for shared decision- making
- Access to legal services
- Care by trained palliative care professionals

Palliative Care: World View

- Palliative Care improves the quality of Life of patients and families
- Palliative Care is cost effective
- Palliative Care is a health system strengthening approach



“Please , do not make us suffer anymore.....”

“Please, do not make us suffer any more...”

Access to Pain Treatment as a Human Right

HUMAN
RIGHTS
WATCH

Access to Pain Treatment as a Human Right

In this 47-page report Human Rights Watch said that countries could significantly improve access to pain medications by addressing the causes of their poor availability. These often include the failure to put in place functioning supply and distribution systems; absence of government policies to ensure their availability; insufficient instruction for healthcare workers; excessively strict drug-control regulations; and fear of legal sanctions among healthcare workers.

<http://www.hrw.org/en/reports/2009/03/02/please-do-not-make-us-suffer-any-more>

Pain Prevalence in Older People

- Pain is the most frequent symptom in older people reported by 73% in community dwelling older people
- Chronic pain affects:
 - 50% of older people in the community
 - 80% of nursing home patients
 - 67% of hospitalized elderly



The problem of unrelieved pain

Globally,
7.3 million
people die of cancer or HIV
each year in moderate or
severe pain

More than
2.9 million
die without pain relief

99.9%
of these deaths are in low and
middle-income countries

There is a great disparity in access to pain relief

Low and middle-income countries

70% of cancer deaths

99% of HIV deaths

just **7%** of medicinal opioids



US, Canada, UK, Australia

11% of cancer deaths

<1% of HIV deaths

67% of medicinal opioids

Global Atlas of Palliative Care at the End of Life



The need - a global perspective

- 57 million deaths
- >1 million deaths/week
 - >800,000 unrelieved pain
- ~25 million need palliative care
- Families (at least 2 each)



Availability of Palliative Care Globally

- ±16,000 services
- ±3 million patients
- 6-9 million family
- 8-12% of need met



Legal rights to palliative care

- ▣ The Universal Declaration of Human Rights states :
“Everyone has the right to a standard of living adequate for the health of himself and of his family...”

- ▣ In 2000 the Committee overseeing the ICESCR issued a General Comment on the right to health stating ‘core obligations’ of signatory nations:
 - Access to health facilities, services on non-discriminatory basis, to provide essential drugs (WHO), adopt and implement national health strategy

International Covenant on Economic, Social and Cultural Rights (ICESCR)

The best and most complete statement of the right to health is in

Article 12:

- ***“the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”***

Thematic study on the realization of the right to health of older persons Anand Grover

“The right to health clearly proscribes discrimination in respect of age, including within palliative health care services. States are obliged to respect the right to health by refraining from denying or limiting equal access for all persons to palliative care services.

Human Rights Council Realization on the Right To Health of Older Persons 2011

- High Commissioner for Human Rights,
Navi Pillay:

“Health lies at the heart of all human rights issues when we age.”

“Adequate access to palliative care is essential to ensure that these people (older persons) can live, and ultimately die, with dignity.”

United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health

Dr. Paul Hunt, Special Rapporteur, strongly supports palliative care as a human rights issue.

At the UN Human Rights Council in March, 2008, he said: “Many other human rights issues need urgent attention such as palliative care.”

He urged that on October 11, World Hospice and Palliative Care Day that this issue would receive its proper attention.

International Covenant on Civil and Political Rights (ICCPR)

- *“No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.”*

Report of Special Rapporteur Mendez On Torture and Cruel, Inhuman or Degrading Treatment or Punishment, 2012

- Highlighted denial of pain treatment as a key instance of abuse in health care settings

“When the failure of States to take positive steps ,or refrain from interfering with health-care services condemns patients to unnecessary suffering from pain, states not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment”

“Failure of government to take reasonable measures to ensure accessibility of pain treatment.... Raises questions whether they have adequately discharged their obligation to take measures to protect people under their jurisdiction from degrading treatment.”

Manfred Nowak, UN Special Rapporteur on Torture and other Cruel, Inhumane, and Degrading Treatment and Punishment. Report “Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Right, including the Right to Development. January 14, 2009

Palliative Care and Standards on the Rights Of Older People: Obligations of Governments

- ❑ The creation and implementation of palliative care policies.
- ❑ Equity of access to palliative care services, without discrimination for adults and children.
- ❑ Availability and affordability of essential palliative care medications, including opioids.
- ❑ The provision of palliative care at all levels of care to adults and children.
- ❑ Access to support for open communication on care options, choice of place of death and supported decision-making
- ❑ Access to legal services to complete wills, and protect property inheritance and guardianship rights
- ❑ The integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals

A Convention on the Rights of Older Persons Would:

- Highlight the critical need for palliative care
- Define specific state obligations that would be legally binding
- Assure systematic monitoring
- Improve the quality of care for older persons

<http://www.hrw.org/sites/default/files/reports/health1009webwcover.pdf>



INDIA

Unbearable Pain

India's Obligation to Ensure Palliative Care

HUMAN
RIGHTS
WATCH

Patient in South India presenting at a palliative care clinic



Patient after a dose of morphine sitting up and enjoying tea



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

Ⓜ A collection of films about living well and dying better Ⓜ



**LIFE
BEFORE DEATH**

A PRODUCTION PRESENTING LIFE BEFORE DEATH
LIFE BEFORE DEATH: A COLLECTION OF FILMS ABOUT LIVING WELL AND DYING BETTER
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