Research in Spiritual Care and Palliative Care: A Global Perspective

Caring for the Human Spirit
Dr. Kathleen M. Foley
March 31, 2014

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Objectives

Participants will be able to

-describe the global issues which generate a need for spiritual care in palliative care

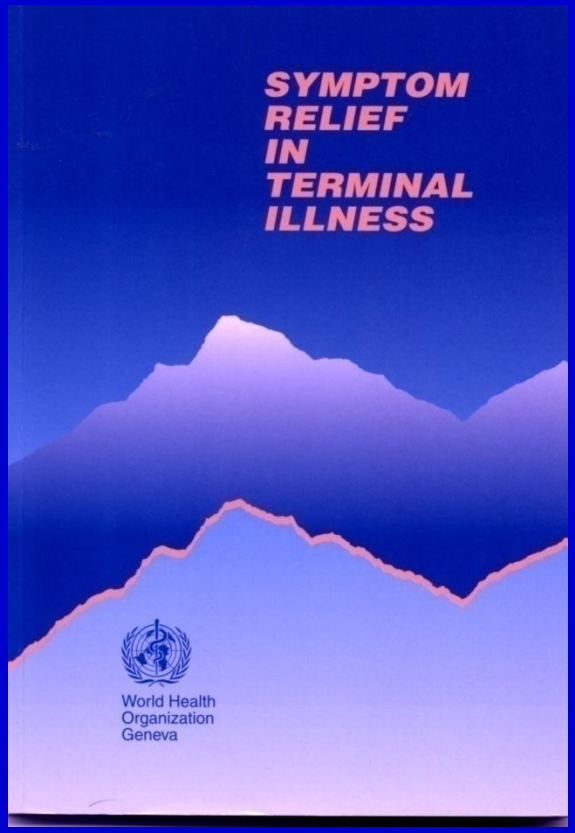
-discuss major challenges and opportunities for spiritual research globally

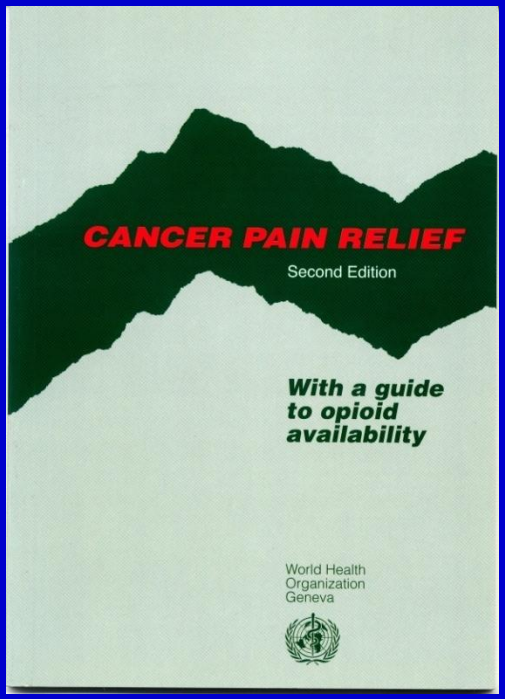
-identify research questions for work locally and globally

1986 WHO Definition of Palliative Care

- Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

WHO MONOGRAPHS





World Health Organization

Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes

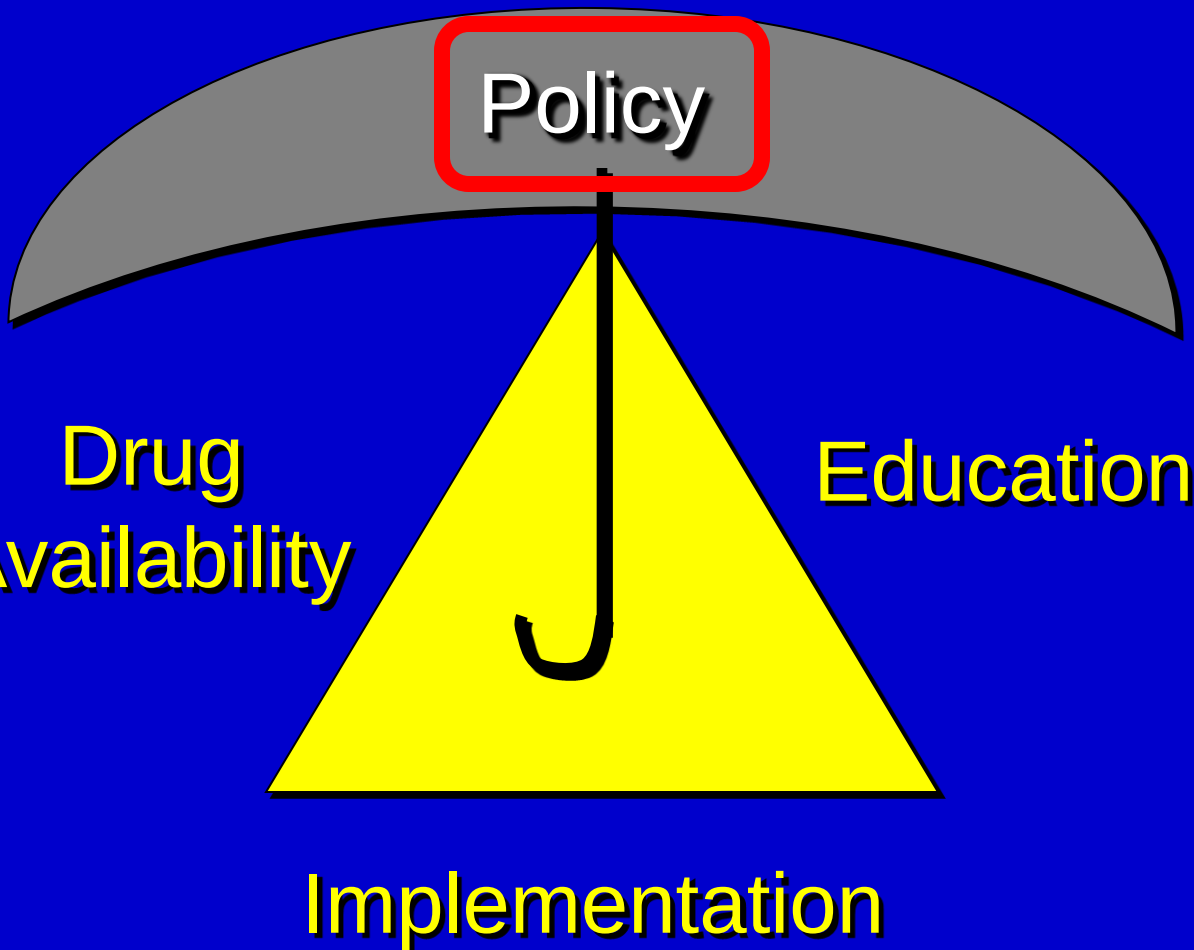
Palliative Care

World Health Organization

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"

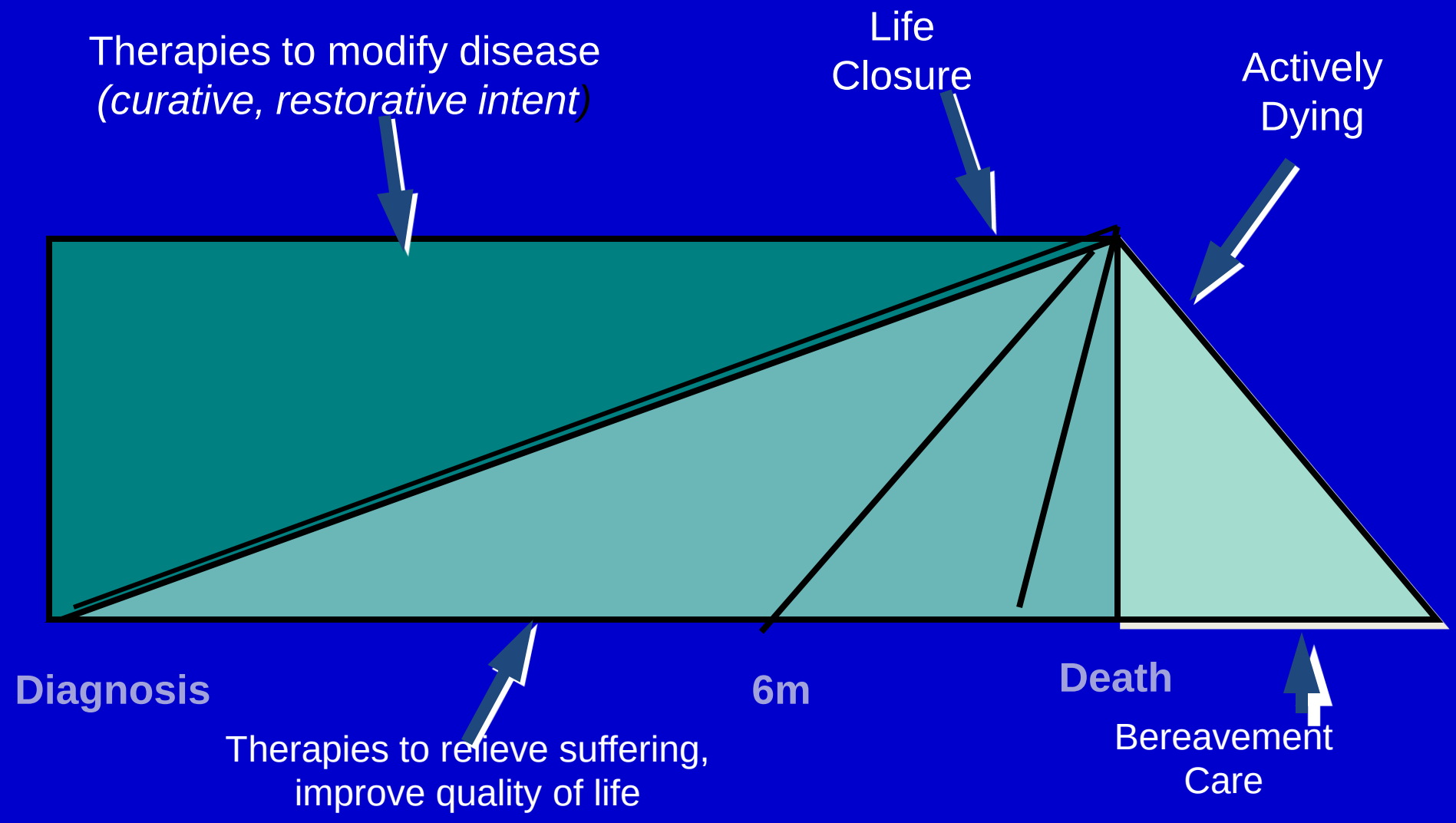
WHO Public Health Model



Context

Outcomes

The continuum of palliative care



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

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)

wpca
worldwide palliative care alliance

World Health Organization

Global Atlas of Palliative Care at the end of life

Spirituality and the United Nations

"Unless there is spiritual renaissance, the world will know no peace."

Dag Hammarskjold

Spirituality and the United Nations

"We pray, therefore, we are."

"At the heart, we are dealing with universal values."

"To be merciful, to be tolerant, to love thy neighbor, there is no mystery here. Such values are deeply ingrained in the human spirit itself. It is little wonder that the same values animate the Charter of the United Nations, and lie at the root of our search for world peace."

Kofi Annan

Spirituality and the United Nations

"This says to us that our world is geographically one. Now, we are faced with making it spiritually one. Through our scientific genius we have made of the world a neighborhood; now through moral and spiritual genius, we must make it a brotherhood."

Dr. Martin Luther King

UN NGO Committee on Spirituality, Values and Global Concerns

Evolving Vision Statement

The NGO Committee on Spirituality, Values, and Global Concerns (NY) envisions a global culture of peace based on justice, solidarity, inclusiveness, shared responsibility, harmony, cooperation, compassion, love, wisdom, goodwill and reverence for the sacredness of all life through active peaceful engagement.

Infused with a foundation of spirituality and values which are universal in nature, transcending the boundaries of religion, ethnicity, gender and geography, the Committee is resolved to help bring about a culture in which we, the peoples of the world, can address together our common global concerns in a positive, holistic and transforming way and live together in peace with one another, thus realizing the core objectives and universal principles stated in the United Nations Charter and the Universal Declaration of Human Rights.

Special Article

Palliative Care as an International Human Right

Frank Brennan, MBBS, FRACP, FAChPM, LLB
Calvary Hospital, Sydney, New South Wales, Australia

Abstract

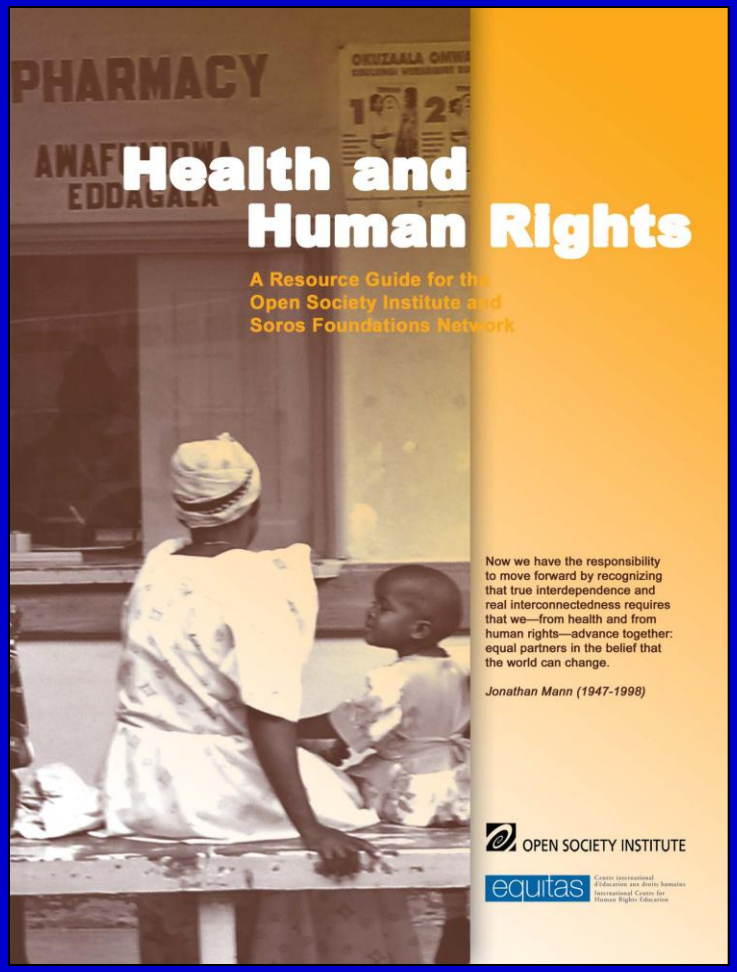
There are major disparities in the provision of palliative care around the world. In recent years, a statement of advocacy and objective has been repeatedly articulated that the provision of palliative care is a human right. This article examines the foundation for this assertion in the context of international human rights law. The strengths and weaknesses of this assertion are examined. The nature of both the right and, correlatively, the obligation on individual governments is discussed. J Pain Symptom Manage 2007;33:494–499.

Key Words

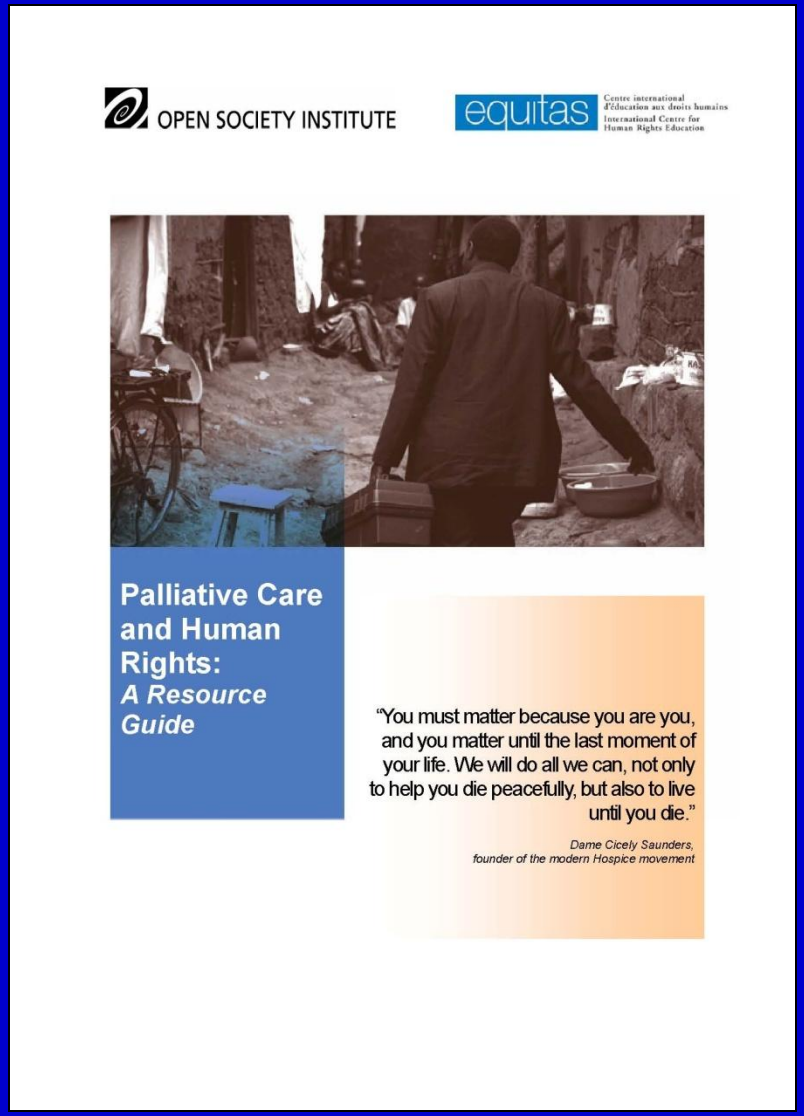
Palliative care, human rights, health

New Global Initiatives in Palliative Care

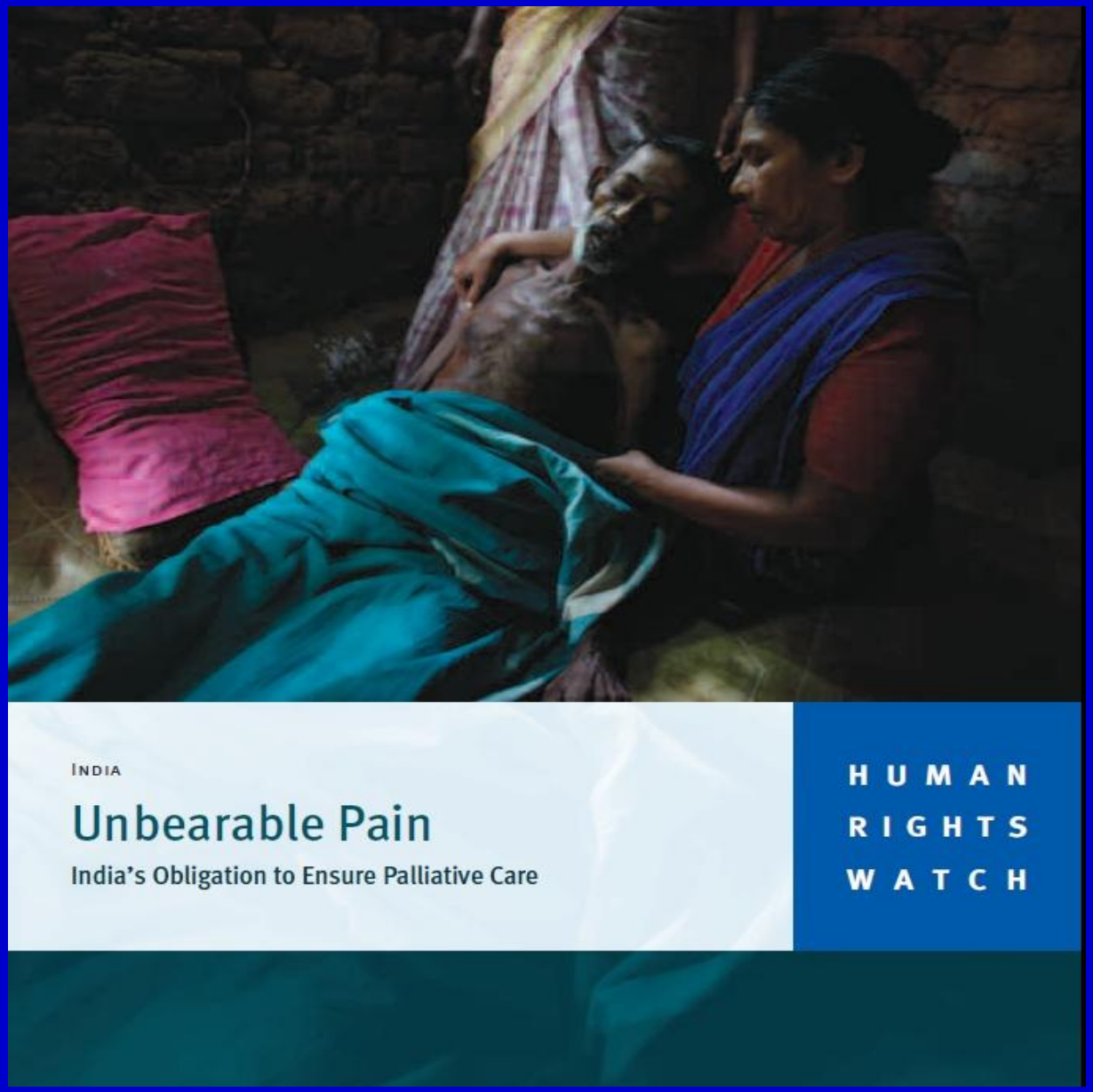
- IASP Montreal Declaration on pain relief as a fundamental human right
- A World Medical Association Declaration on access to pain relief
- Human Rights Watch reports on access to pain relief and palliative care
  - -India, Kenya, Ukraine, Senegal



www.equalpartners.info



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



World Health Organization Resolution 2014

134th session EB134.R7

Agenda item 9.4 23 January 2014

Strengthening of palliative care as a component of integrated treatment within the continuum of care

WHO resolution on access to palliative care

Talha Khan Burki

Lancet Oncology. Vol 15;2014.

On Jan 23, WHO's Executive Board introduced a resolution urging member states to integrate palliative care services into their health-care systems. They described provision of such care as an “ethical responsibility”, and added that, when needed, palliative care is “fundamental” to improve quality of life, wellbeing, comfort, and human dignity. In May, the resolution will be presented to the World Health Assembly, but ratification should be a formality.

Palliative care: a peaceful, humane global campaign is needed

The Lancet, March, 2014

- In today's *Lancet*, a tripartite Series revisits the oft-quoted militaristic challenge initiated by US President Richard Nixon's National Cancer Act of Dec 23, 1971. Although it might be tempting to compare the outcome of Nixon's projected war on cancer to that of the political cold war that was being pursued relentlessly at the time—tense, inconclusive, and enormously costly—Douglas Hanahan's paper reminds us of some of the successful sorties that have been made against cancer in the intervening four decades. Notable victories have been achieved against some diseases, such as testicular cancer and childhood acute lymphoblastic leukemia; oncologists have arguably led the way in medicine by devising targeted therapeutic agents and developing biomarkers to guide diagnosis and treatment; and cancer screening and vaccination programs have been deployed at vast scale in high-income countries.

Developing a Consensus on Spiritual Dimensions in Healthcare

- 2004- National Consensus Project developed 8 required domains of care including spiritual, religious, and existential issues
- 2009 -Improving Quality Spiritual Care as a Domain of Palliative Care developed a consensus definition of spirituality ,literature based categories of spiritual care and recommendations for improving spiritual care in palliative settings

Developing a Consensus on Spiritual Dimensions in Healthcare

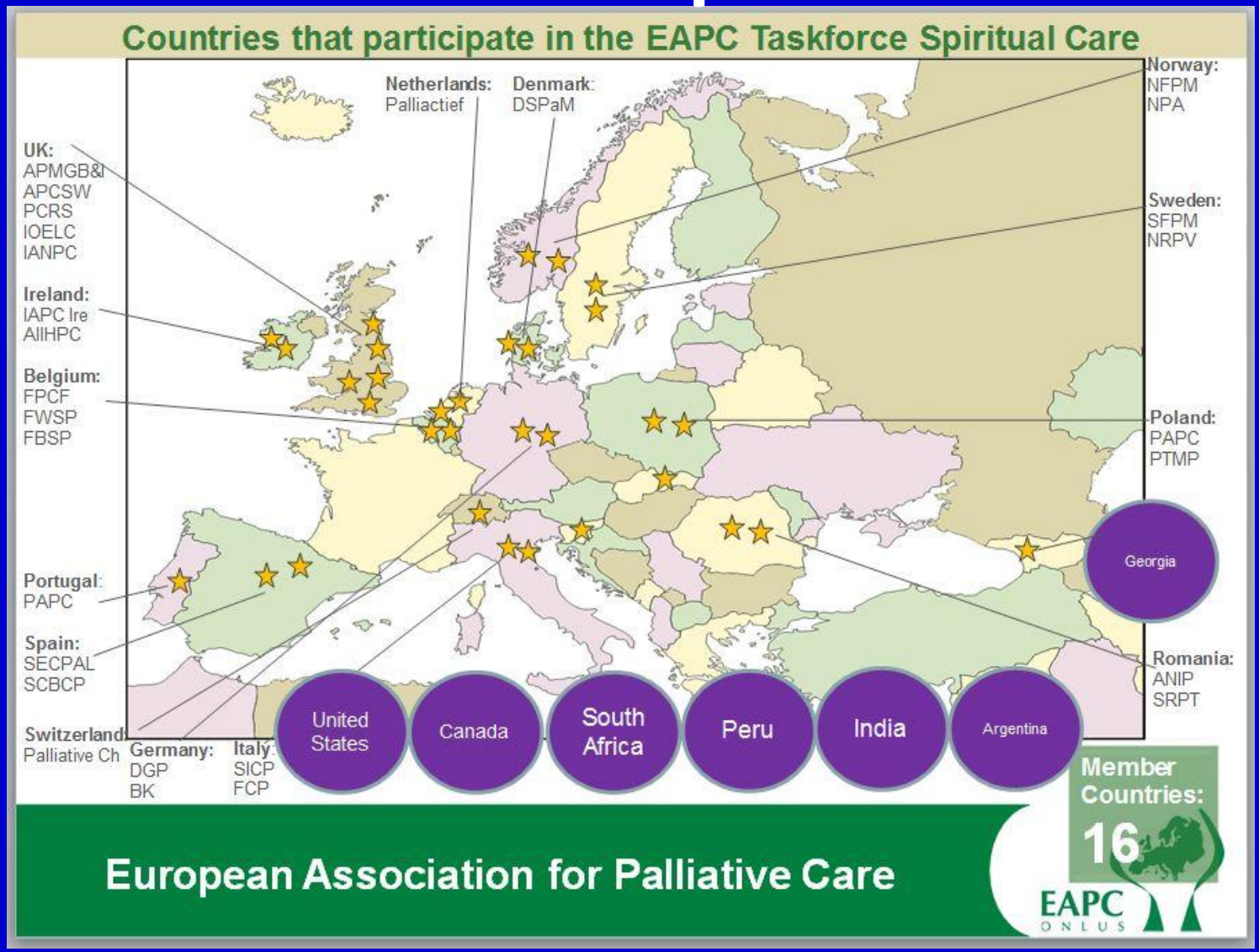
- 2012 - National Consensus Conference on Creating Compassionate Systems of Care developed strategies in research, education and clinical practice and recommendations for incorporation into healthcare settings
- 2013 -Improving the Spiritual Dimensions of Whole Person Care engaged 41 international leaders to develop an international definition, proposed standards and a strategy for developing a global consensus .

Puchalski C, Ferrell B. A Consensus Conference Convened , February, 2009

TABLE 1. NATIONAL CONSENSUS PROJECT GUIDELINES[21] AND NATIONAL QUALITY PREFERRED PRACTICES FOR SPIRITUAL DOMAIN[22]

National Consensus Project Guidelines spiritual domain	*National Quality Forum preferred practices*
Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied. *Criteria:* • The interdisciplinary team includes professionals with skill in assessment of and response to the spiritual and existential issues common to both pediatric and adult patients with life-threatening illnesses and conditions, and their families. These professionals should have education and appropriate training in pastoral care and the spiritual issues evoked by patients and families faced with life-threatening illness. • The regular assessment of spiritual and existential concerns is documented. This includes, but is not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, and life completion tasks. • Whenever possible a standardized instrument should be used to assess and identify religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family. • Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences should occur with regularity and be documented. Spiritual/existential care needs, goals, and concerns are addressed and documented, and support is offered for issues of life completion in a manner consistent with the individual's and family's cultural and religious values. • Pastoral care and other palliative care professionals facilitate contacts with spiritual/religious communities, groups or individuals, as desired by the patient and/or family. Of primary importance is that patients have access to clergy in their own religious traditions. • Professional and institutional use of religious/spiritual symbols is sensitive to cultural and religious diversity. • The patient and family are encouraged to display their own religious/spiritual or cultural symbols. • The palliative care service facilitates religious or spiritual rituals or practices as desired by patient and family, especially at the time of death. • Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made when appropriate.	**DOMAIN 5.** **SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE** **PREFERRED PRACTICE 20** Develop and document a plan based on assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan. **PREFERRED PRACTICE 21** Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient's own clergy relationships. **PREFERRED PRACTICE 22** Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care. **PREFERRED PRACTICE 23** Specialized palliative and hospice spiritual care professional should build partnerships with community clergy and provide education and counseling related to end-of-life care.

Countries that participate in the EAPC Taskforce on Spiritual Care



EAPC CREATED

- A European network of researchers in SCPC
- Consensus conference in Geneva, 2013
- Research presentations developed
- Methodologies and countries reports in progress and in press

EAPC Taskforce on Spiritual Care & Palliative Care

- Completed a survey of palliative care practitioners and research priorities for spiritual care research
- 971 people from 87 countries participated

EAPC TASK FORCE DEFINITION

- *Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.*

EAPC DEFINITION

The Spiritual Field is Multidimensional:

Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).

Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).

Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).

Netherland's Implementing Spiritual Care at the End of Life

Case Example Liget, C, Eur J Pall Care 2012

- Developed guidelines for spiritual care
- Promoted education of healthcare professionals
- Chaplains educated in palliative care
- Multidisciplinary groups developed
- Healthcare insurance company pays for chaplains providing home- based spiritual care

Case Example-Germany

International Society for Health & Spirituality:

- developed a program to understand spirituality and spiritual care among health care professionals in German speaking countries

What are the Research Questions?

Chochinov H, et al. J Pall Med. 2005

- How do we define spirituality?
- How do we understand the constructs of spiritual well being
- transcendence
- hope
- meaning,
- dignity

How Do We Frame These Issues?

Chochinov H, et al. J Palliat Med. 2005

- Faith- based perspectives
- Secular perspectives
- Differing professional viewpoints
- Diverse cultural settings

How do we correlate these constructs with variables and outcomes such as

Chochinov H, et al. J Palliat Med. 2005

- Quality of life
- Pain control
- Coping with loss
- Acceptance

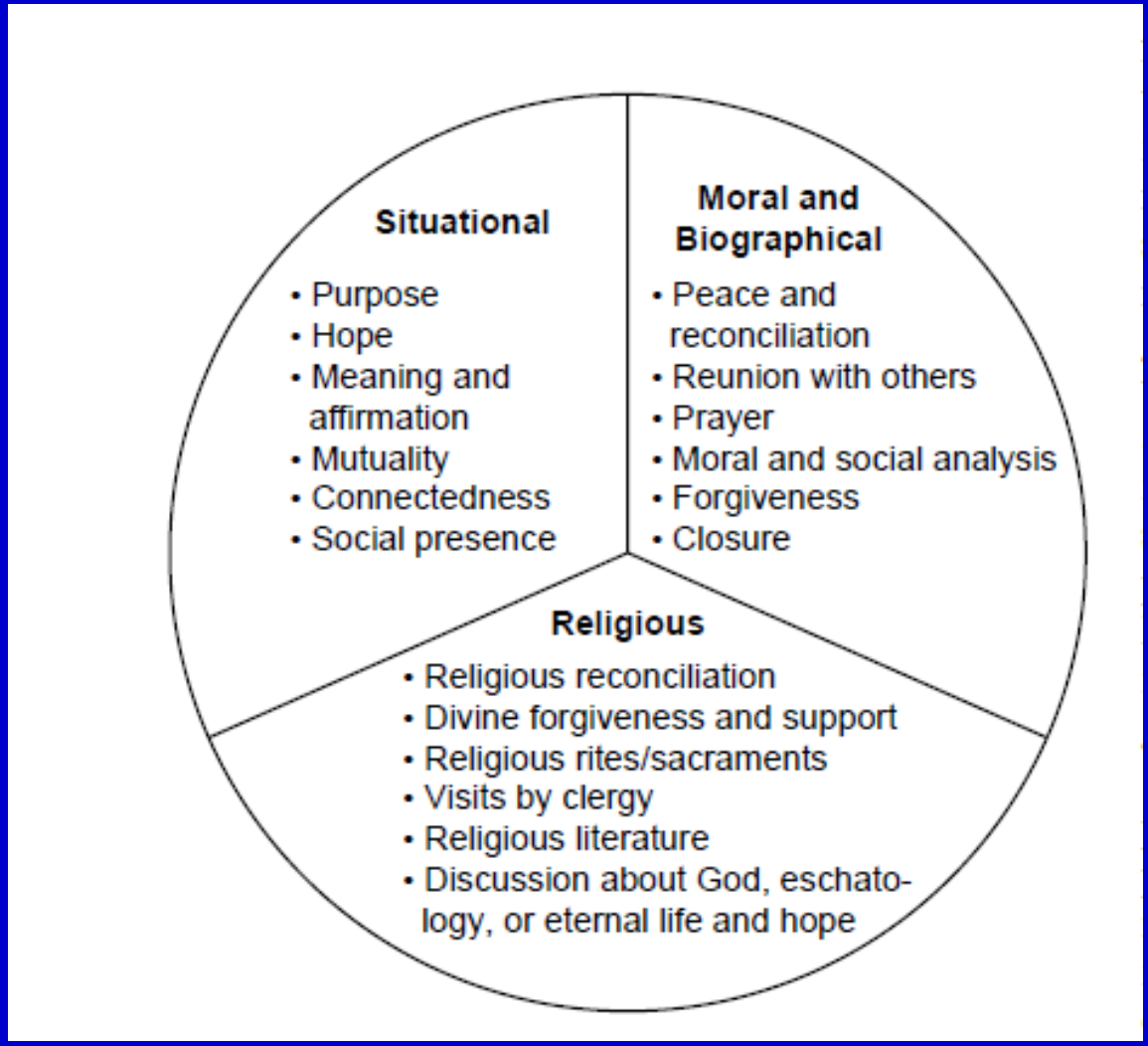
Spirituality and palliative care: A model of needs

Kellnehear A. J Palliat Med. 2000

'Good spiritual care' may mean a similar recognition of interdisciplinarity, understanding that the meaning of wellness in this particular context is dependent on the successful ability of all of us to transcend the ordinariness of everyday life, and to gather meanings in the unseen worlds of the spirit.

Dimensions of Spiritual Need

Kellnehear A. J Palliat Med. 2000



UK End of Life Care Strategy University of Hull, Staffordshire, & Camden

Systematic review of literature 2000-2010

-248 resources

-17 different countries

UK 41% US 55%

UK End of Life Strategies
Five Overarching Themes

1. Disciplinary and professional contexts:
   Nursing 25%, Chaplaincy 14%,
   Social Work 10%
2. Concepts and Definition:
   Spirituality and its relationship to health outcomes

UK End of Life Strategies
Five Overarching Themes

3. Spiritual Assessment:

   Numerous tools to assess spiritual clusters

4. Spiritual Interventions:

   Models poorly developed

5. Education and Training:

   Except for Chaplaincy limited

Opportunities to Advance Spirituality in Healthcare

- Spiritual concerns are a component of the WHO definition of palliative care and included in the proposed WHO resolution
- Increasing international consensus on a definition of spirituality and specific recommendations
- Growing research agenda and peer- reviewed literature
- Closely aligned to a human rights approach with a focus on human dignity

Challenges to Advance Spirituality in Healthcare

- Palliative care is a new field of medicine with a small workforce
- Prevalent concerns that spirituality is not the domain of healthcare providers
- Increasing secularism that disparages spirituality discourse
- Limited philanthropic support for a balanced discussion