THE WAY TO INTEGRATION: PALLIATIVE CARE IN EUROPE

Presenter: Prof Dr Philip J Larkin PhD RN, Ireland
President, European Association for Palliative Care

Overview of the presentation

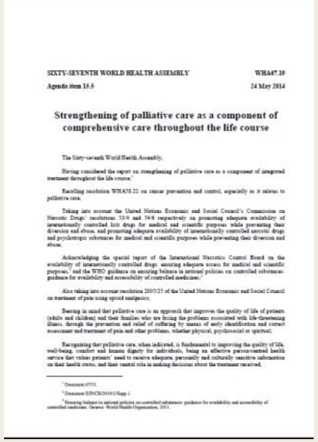
- Contextual issues in European Palliative Care
- Why is integration important for Europe
- What opportunities and challenges are expected in an integrated approach to palliative care?
- The wisdom of our Elders

Palliative care- changing focus

Palliative Care as a Public Health issue

Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor



SIXTY-SEVENTH WORLD HEALTH ASSEMBLY WHA67.19

Agenda item 15.5 24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;[1]

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,[2] and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;[3]

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

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[1] Document A67/31.

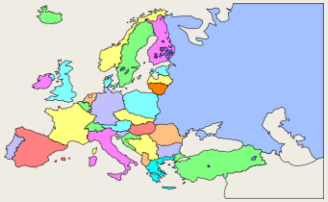
[2] Document E/INCB/2010/1/Supp.1.

[3] Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization, 2011.

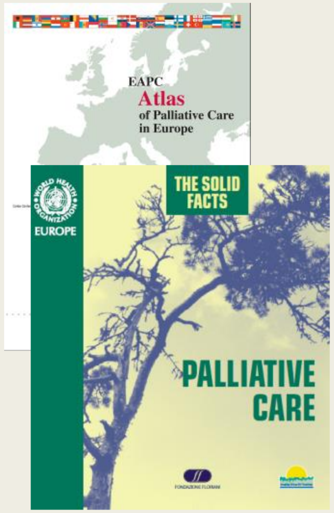
WHO COLLABORATING CENTRE PUBLIC HEALTH PALLIATIVE CARE PROGRAMMES

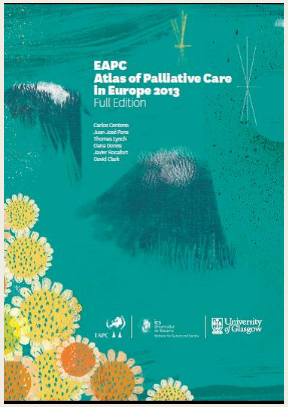
‘*Strengthening of palliative care as a component of comprehensive care throughout the life course*’(WHA 67.19 2014) - serious concern about inequality between different groups and their access to, experience of, and outcomes from palliative care.

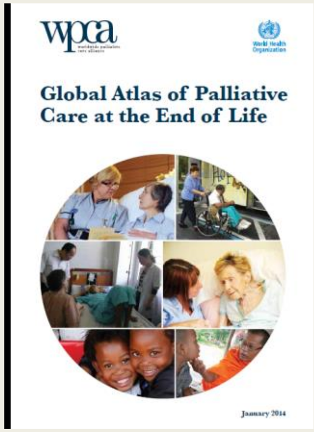
Developments in European Palliative Care

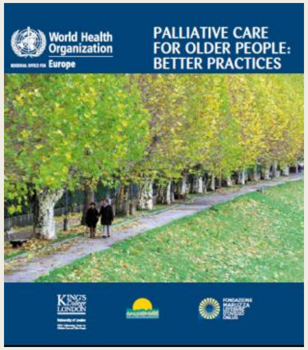


- WHO Euro Region
- ‘Palliative Care: the solid facts’
- Better palliative care for older people’
- ‘Better palliative care for older people: better practices









Why Palliative Care is important for Europe

Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste & Stephen Connor

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Epidemiology

75% of European citizens who die would benefit from a palliative care intervention

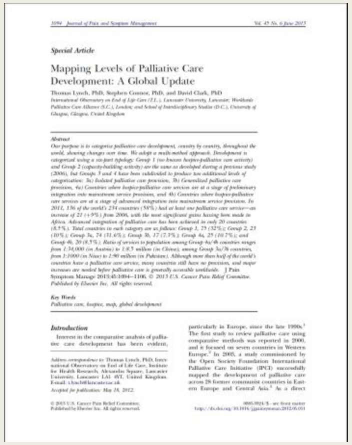
Most are elderly people with multi morbid disease

Significant impact on the health and social system:

- - 20-25% of patients visiting a GP have palliative care needs
- - 35-45% of hospital beds are being used by people with palliative care needs
- - 50-70% of people in nursing homes need palliative care

- People in need of palliative care are the cause of 70% of costs in the last 6 months of life, mostly due to inappropriate hospital admissions

Paper 1 (Lynch *et al*., 2013)



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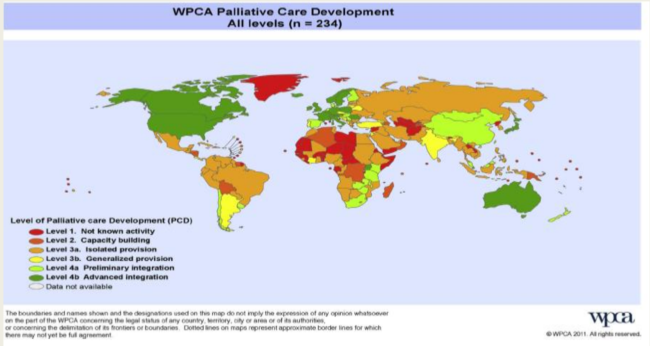
Special Article

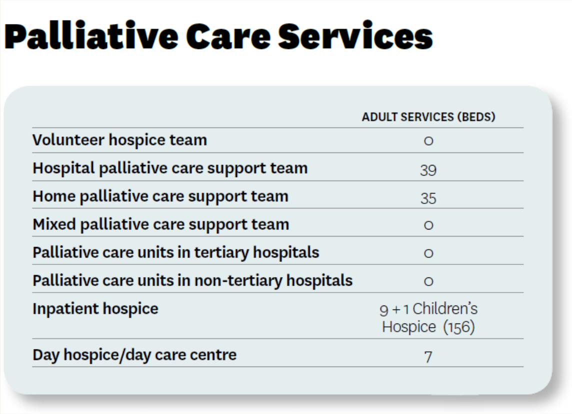
Mapping Levels of Palliative Care Development: A Global Update

Thomas Lynch, PhD, Stephen Connor, PhD, and David Clark, PhD

- 58% of 243 countries have a palliative care service (26% increase on 2006)
- Only 20 countries internationally have advanced integration
- Many countries still have no palliative access at all.



Ireland

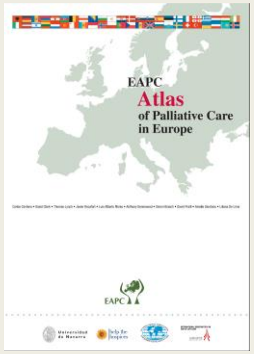


Palliative Care Services

	ADULT SERVICES (BEDS)
Volunteer hospice team	0
Hospital palliative care support team	39
Home palliative care support team	35
Mixed palliative care support team	0
Palliative care units in tertiary hospitals	0
Palliative care units in non-tertiary hospitals	0
Inpatient hospice	9 + 1 Children's Hospice (156)
Day hospice/day care centre	7

SOCIO-ECONOMIC DATA

Population 2012	4579498
Density 2012	65.2
Surface	70273
Gross Domestic Product per capita 2011	36145
Physicians per 1000 inhab.	3.173
Health expenditure per capita, PPP, 2010	3704
Health expenditure, total (% of Gross), 2010	9.2
Human Development Index 2012	0.916
Human Development Index Ranking Position 2012	7



EAPC
Atlas
of Palliative Care
in Europe

Paper 2 Kane et al., (2015)

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Original Article

The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Nonmalignant Conditions

Pauline M. Kane, MB BCh, BAO, LRCP&SI, MSc, Barbara A. Daveson, BMus (Mus Thy), DipHSM, PhD, Karen Ryan, MB BCh, BAO, BMedSc, FRCPI, Regina McQuillan, MB BCh, BAO, FRCPI, Irene J. Higginson, BMedSci, BMBS, PhD, FMedSci, FRCP, FFPHM, and Fliss E.M. Murtagh, FRCP, MRCGP, PhD, on behalf of BuildCARE

Department of Palliative Care, Policy & Rehabilitation (P.M.K., B.A.D., I.J.H., F.E.M.M.), King's College London, Cicely Saunders Institute, London, United Kingdom; and St. Francis Hospice and Mater Misericordiae University Hospital (K.R.), and St. Francis Hospice and Beaumont Hospital (R.M.), Dublin, Ireland

Abstract

Context. Over the history of palliative care provision in Ireland, services have predominantly provided care to those with cancer. Previous estimates of palliative care need focused primarily on specialist palliative care and included only a limited number of nonmalignant diseases.

Objectives. The primary aim of this study was to estimate the potential population with generalist and/or specialist palliative care needs in Ireland using routine mortality data inclusive of nonmalignant conditions. The secondary aim was to consider the quality of Irish data available for this population-based estimate.

Methods. Irish routine mortality data (2007–2011) were analyzed for malignant and nonmalignant conditions recognized as potentially requiring palliative care input, using specific International Statistical Classification of Diseases and Related Health Problems-10th Revision codes. The method developed by Murtagh et al. was used to give a population-based palliative care needs estimate, encompassing generalist and specialist palliative care need.

Results. During the period 2007–2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from noncancer conditions. The majority of deaths, 81% (91,914), were among those ≥65 years. There was a 13.9% (901) increase in deaths of those ≥85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%).

Conclusion. Future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease and associated palliative care need. New models of palliative care may be required to address this. J Pain Symptom Manage 2015;49:726–733. © *2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, terminal care, end-of-life care, needs assessment, public health, chronic illness, Ireland

Introduction

In Ireland in 2011, one in 10 (11%) of the population were aged 65 years or older. This number is projected to double to 22% by 2041,[1] as the proportion of those aged 65 years or older is increasing in Ireland at the fastest rate in the European Union.[2] It is internationally recognized that the prevalence of advanced chronic conditions increases with older age. Consistent

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0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2014.09.011

What is the future potential generalist and specialist population need?

The rise of health and social 'commodification' of care.

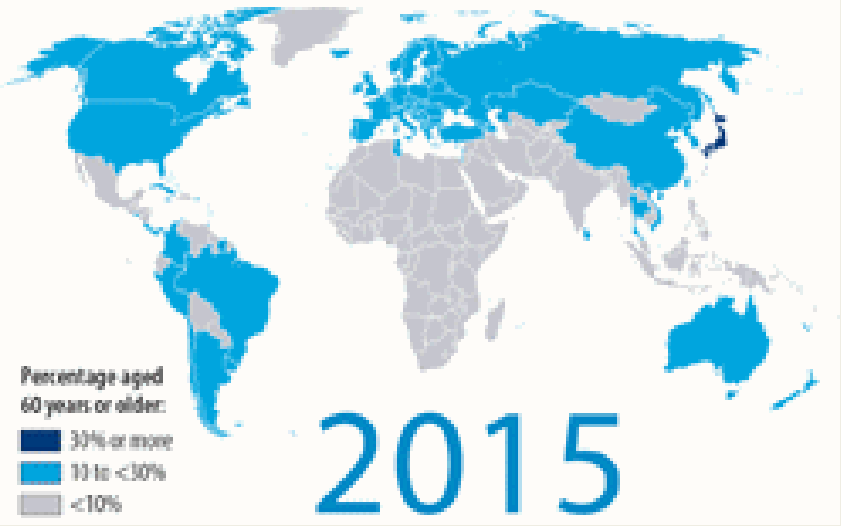
Palliative care cancer focused

80% of all deaths (141,807) had associated palliative care needs

81 % ≥ 65 (13% ≥ 85)

Increase in deaths from dementia and neurodegenerative disease (and cancer).

Elder care – an international health challenge

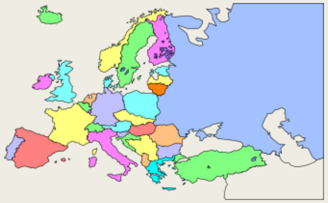


600 million older persons worldwide

Doubled by 2025

2 billion by 2050

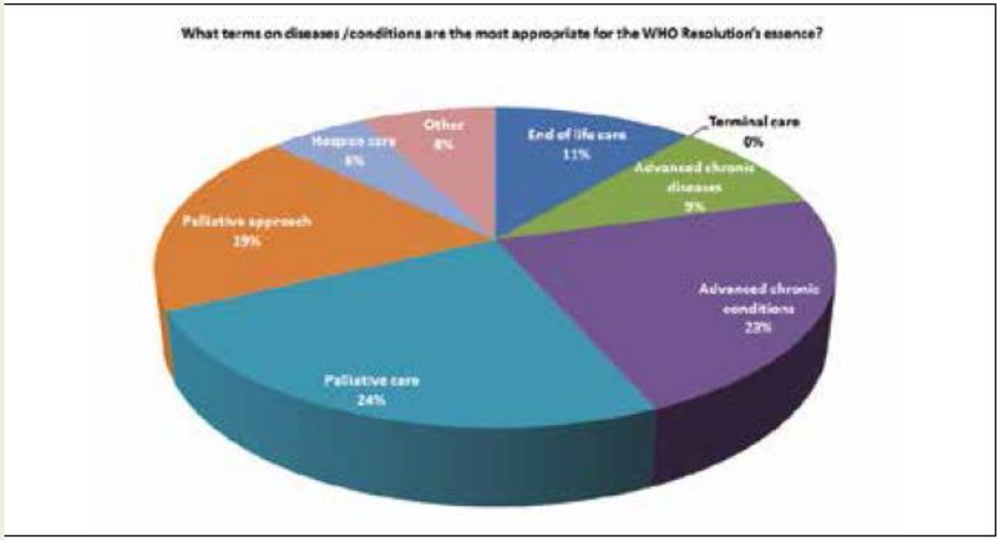
Strengths and Weaknesses - a European lens



- Strengths
- Palliative care reduces hospital admissions, costs and the inadequate use of emergency services, promoting a primary care agenda.
- Promotes a more responsive, comprehensive and judicious delivery of care to those in need in their place of need.
- Weaknesses
- Failure of the system to see the value of early integration of palliative care.
- Confusion in the language which describes what palliative care is and is not.

Palliative Care – what is in a name?

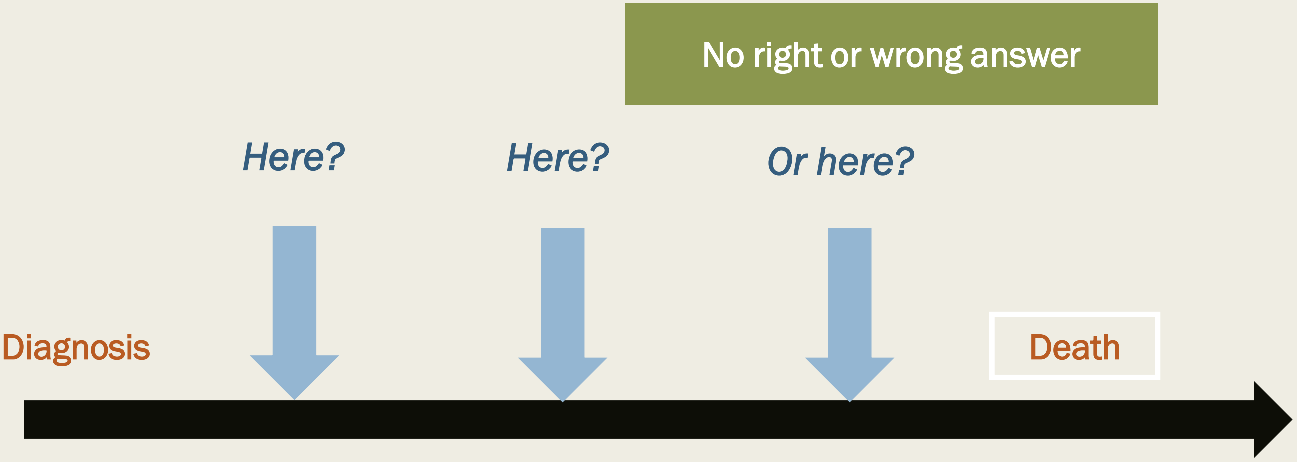
Figure 1. Proposals of conceptual definitions: Responses of the TAG



- Confusion over language to describe palliative care
- Supportive care seems to fit well in the healthcare context
- Terminal care largely avoided
- Descriptors are culturally determined
- We still need clarity over who we are and what we do.

Why integration is important?

When should PC be initiated?



No right or wrong answer

Here?

Here?

Or here?

Diagnosis

Death

….. But important to actively think about it

Ongoing treatment and palliative care not necessarily contradictory

What does an integrative approach really mean?

Change from	Change to
Terminal disease	Advanced progressive disease
Short life prognosis (weeks or months)	Life-limiting
Curative versus palliative	Shared and combined care together
Disease OR palliation	Disease AND palliation
Prognosis as referral point	Complexity as referral point
Patient and family as care recipient	Patient and family as care planner
Specialist service alone	Service across all settings

InsupC : integrated palliative care

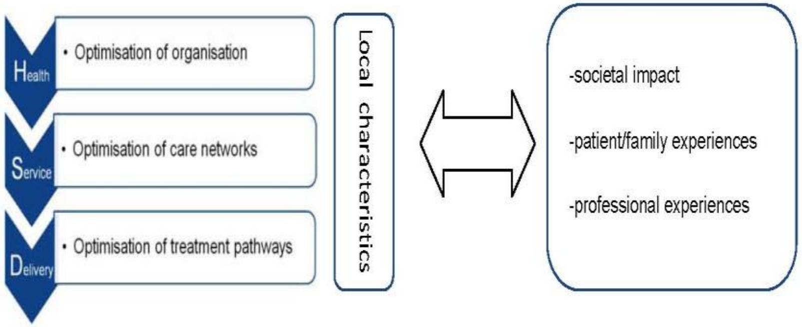


Figure 2: Identification of best practices in integrated palliative care delivery

- Optimisation of organisation
- Optimisation of care networks
- Optimisation of treatment pathways

Local characteristics

-societal impact

-patient/family experiences

-professional experiences

Integrated palliative care

Jeroen Hasselaar

Sheila Payne

(editors)

A definition of integrated care

Integrated palliative care

Integrated
palliative
care

Jeroen Hasselaar

Sheila Payne

(editors)

“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers (paid and unpaid)”

Siouta N, Van Beek K, van der Erden ME. *et al*; (2016). Integrated Palliative Care in Europe: a qualitative systematic review of empirically tested models in cancer and chronic disease. BMC Palliative Care, 15:56.

Why this is important?

STUDY PROTOCOL

Open Access

Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe: protocol for an international, multicenter, prospective, mixed method study

ORIGINAL ARTICLE

How well is palliative care integrated into cancer care? A MASCC, ESMO, and EAPC Project

Sees the value in a matrix of involved persons

See the person as an ‘ actor’ - that is, can influence the decisions made for and by them

Understands the bonds that tie people at critical times in their lives - *communitas*

Considers the wider political and social dimensions that impact on living and dying

Integrated model of palliative care

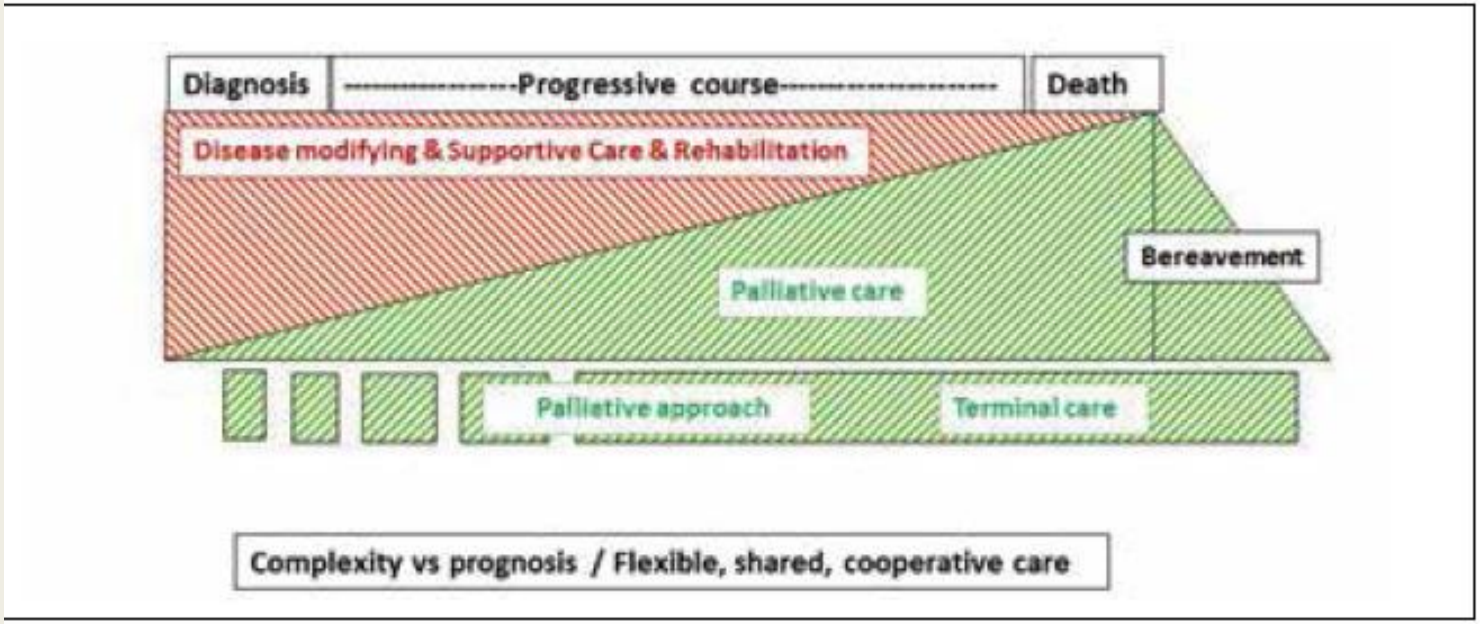


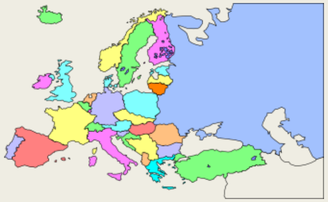
Figure 3. Integrated model of palliative care along disease evolution

Key messages for integrated palliative care

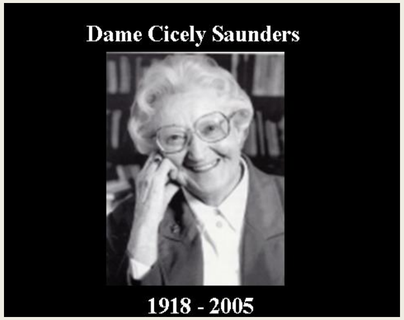
- One of the most important messages for the transformation of our health care systems
- Changing hearts and minds
- Value the equality and respect of all persons
- Integrated palliative care speaks to reality of living and dying in society
- IPC underpinned by the elements of collaboration, cohesion and compassion
- One small step....

Challenges and opportunities

A new vision to alleviate suffering



- How one woman's vision changed the world….
- A movement, underpinned by a spiritual discernment
- A practice which evoked a global movement



The care of dying people as a human right

- Suffering cannot be treated unless recognized
- Having the courage to ask
- Having the strength to wait

Are human rights enough?

The Meaning, Limitations and Possibilities of Making Palliative Care a Public Health Priority by Declaring it a Human Right

Timothy W. Kirk, City University of New York

There is a growing movement to increase access to palliative care by declaring it a human right. Calls for such a right—in the form of articles in the healthcare literature and pleas to the United Nations and World Health Organization—rarely define crucial concepts involved in such a declaration, in particular 'palliative care' and 'human right'. This paper explores how such concepts might be more fully developed, the difficulties in using a human rights approach to promote palliative care, and the relevance of such an enterprise to public health ethics.

Introduction

Background and Definitions

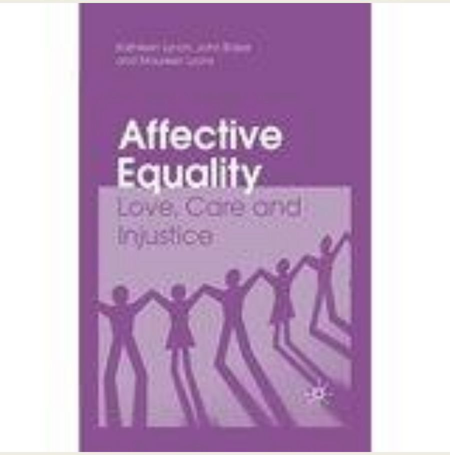
'Palliative Care'

- A palliative care discourse of human rights may ignore wider socio-political issues in healthcare.
- Overt focus on the individual rather than the collective.
- Who is ultimately responsible to deliver on a human right?

Equity and equality

- *' ..it is unethical, unjust and unacceptable to promote or condone a global system which in effect offers disease-modifying therapy to the rich and palliative care to the poor' (Selwyn, p.513).*
  - Selwyn PA. Palliative Care and Social Justice. *JPSM* 2008, 36 (5): 513-515

Dimensions of effective equality



- Respect and recognition – acceptance of diversity
- Resources – understanding the impact of poverty
- Love, care and solidarity – public attention/private matters
- Power relations – Protection against inhumanity

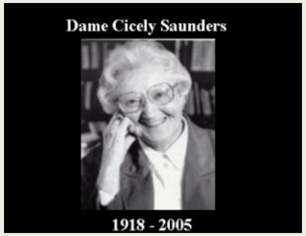
WORKFORCE DEVELOPMENT: A CHALLENGE FOR THE FUTURE OF PALLIATIVE CARE IN EUROPE?

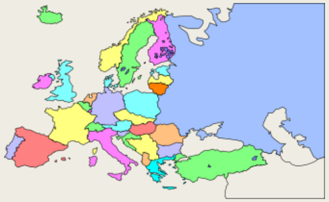
The ‘brain drain’

1726 nurses

725 doctors

10,000 applications since 2010 for Certificate of Current Professional Status



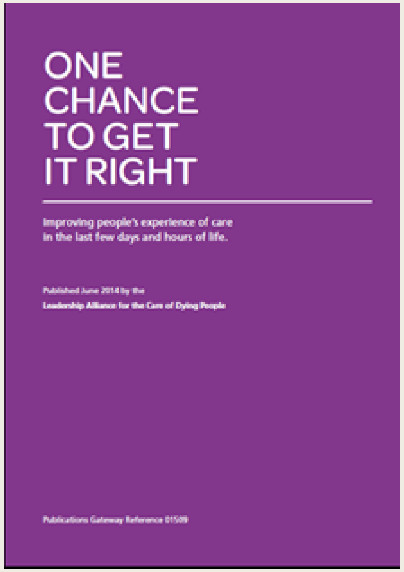


Key messages for Europe

Key messages

- The context and practice of palliative care is changing
- Palliative care continues to work in partnership with others
- Dying is an important part of the work we do – but it is not all we do
- Patient outcomes improve when collaboration is the primary driver of care.

40 million people need palliative care worldwide
2.1 million children need palliative care worldwide



ONE
CHANCE
TO GET
IT RIGHT

Improving people's experience of care
in the last few days and hours of life.

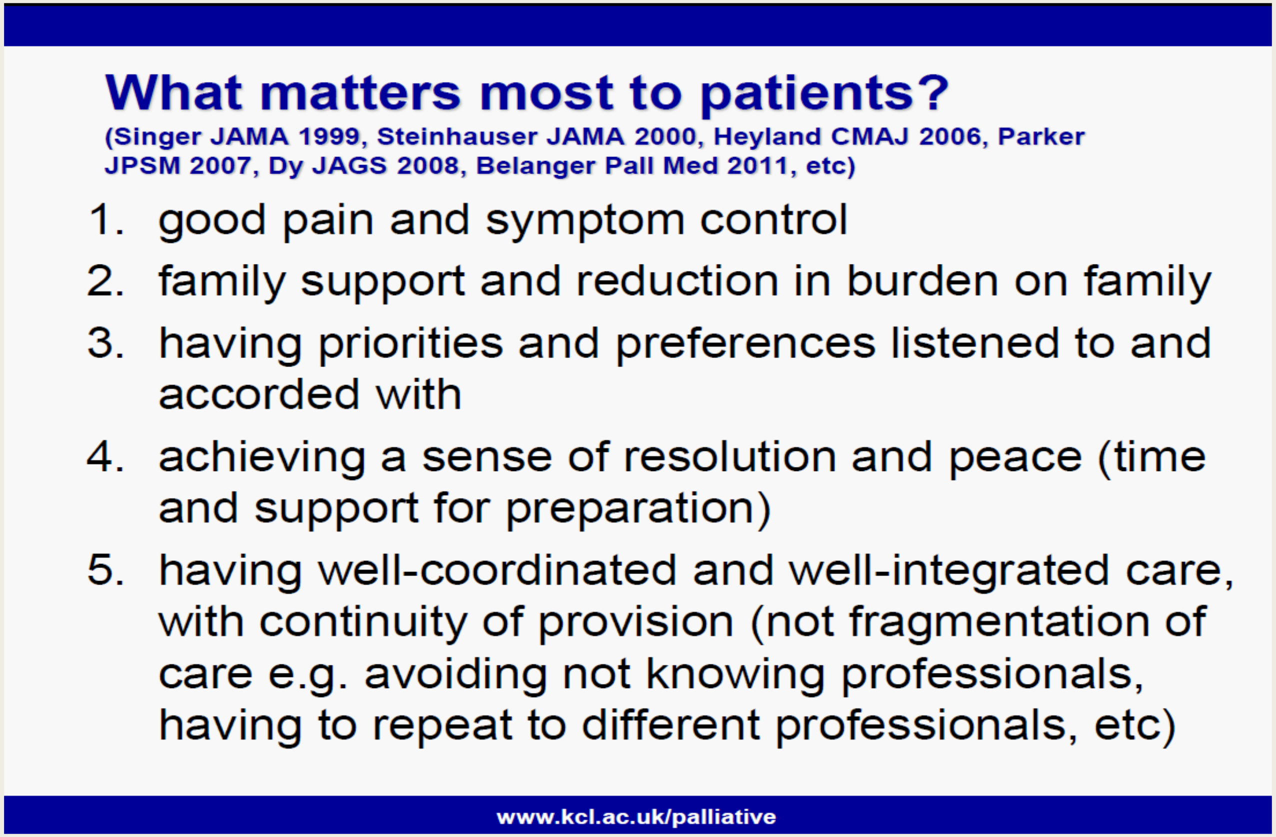
Published June 2014 by the
Leadership Alliance for the Care of Dying People

Publications Gateway Reference 01509

> *'we have only one chance to get end-of-life care right for an individual and at present this chance is sadly being missed on too many occasions'*

Clare Henry, CE, National Council for Palliative Care, UK

What patients need most from palliative care



What matters most to patients?

(Singer JAMA 1999, Steinhauser JAMA 2000, Heyland CMAJ 2006, Parker JPSM 2007, Dy JAGS 2008, Belanger Pall Med 2011, etc)

1. good pain and symptom control
2. family support and reduction in burden on family
3. having priorities and preferences listened to and accorded with
4. achieving a sense of resolution and peace (time and support for preparation)
5. having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)

www.kcl.ac.uk/palliative

A final thought

‘*Ar scáth a chéile a Mhairimíd*’
We live in the shadow of each other

Thank You