



Rising to the Challenge: Palliative Care Across Boundaries

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A sense of direction?



Overview



WHAT DO WE MEAN BY
'BOUNDARIES' FOR
PALLIATIVE CARE ?



WHY DO WE NEED TO
WORK ACROSS
BOUNDARIES?



WHAT ARE THE
CHALLENGES AND
OPPORTUNITIES?



WHAT ARE THE KEY
LESSONS THAT CAN BE
SHARED?

What do we mean by boundaries for palliative care?

Dictionary Definition

- A boundary a line that marks the edges of an area of land and separates it from other area

What types of boundaries exist for palliative care?

Clinician–
patient/carer/community
boundaries

- Value of therapeutic relationship
- Risks and value
- **Public Health Palliative Care**

Practice Boundaries
Specialist~Generalist

- Specialist palliative care and General Practice

Specialist~Specialist

- Specialist palliative care and specialists for chronic diseases – eg Heart Failure

Settings of Care

- Hospital; community; nursing home , hospice

Interdisciplinary boundaries
within palliative care

- Types of Roles- nurse; physician, social worker; psychologist; chaplain; allied health professional; caregiver
- **Future workforce**



Why do we need to work across boundaries? Global need for palliative care

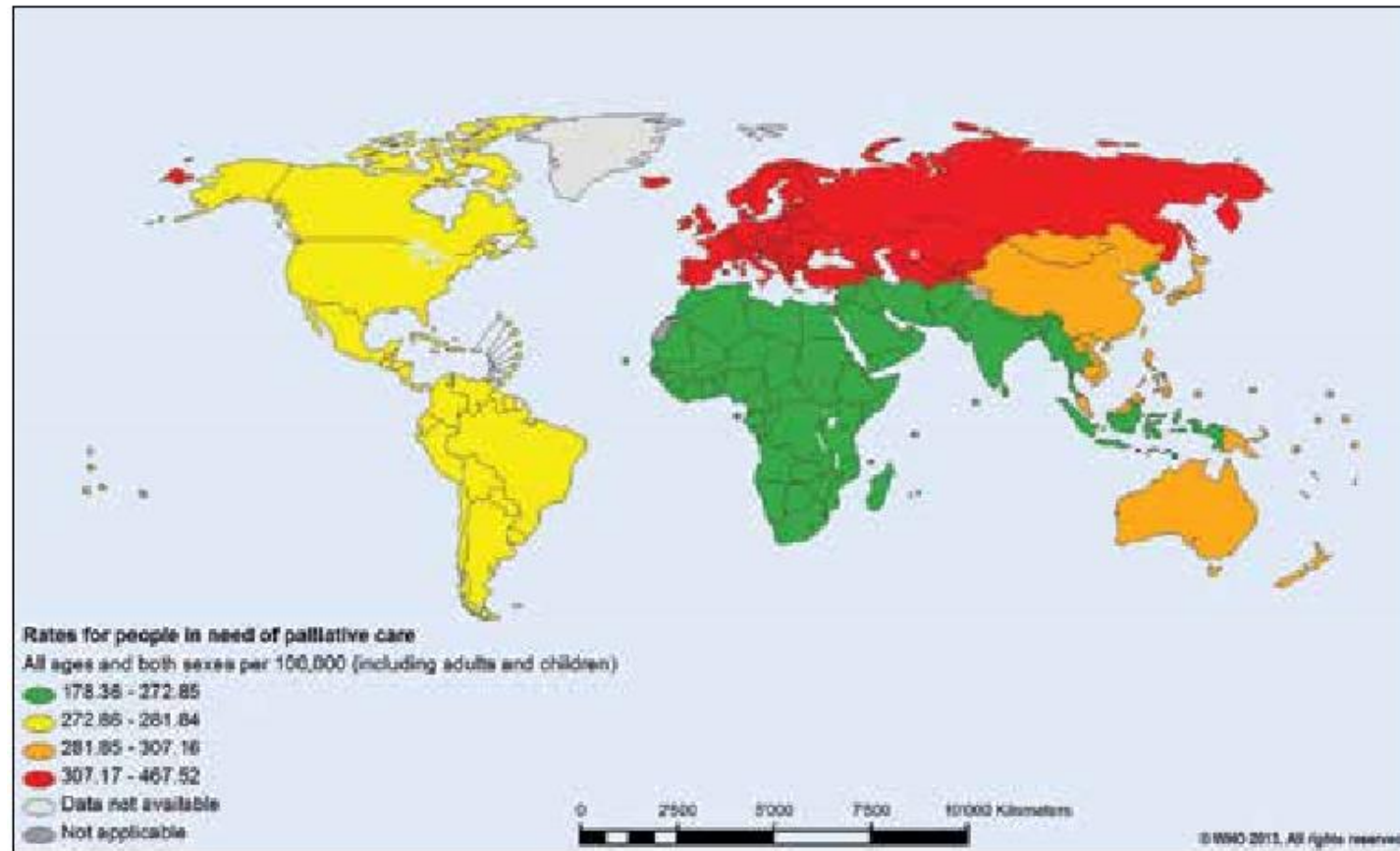


Figure: Global distribution by WHO regions of rates for people in need of palliative care at the end of life

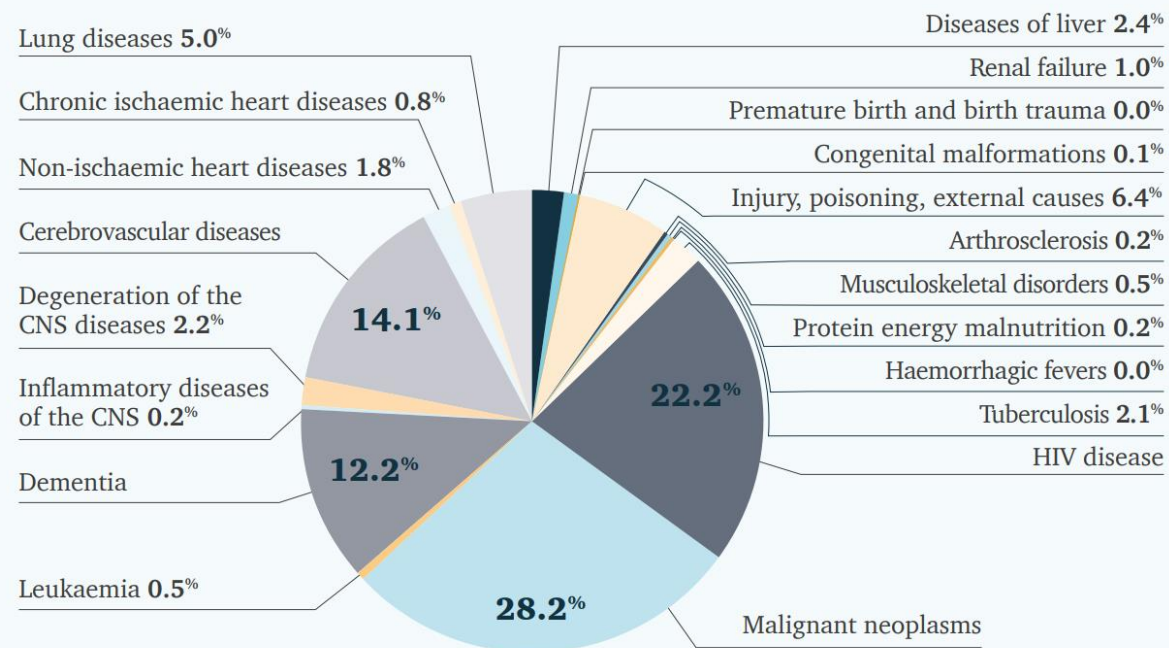
Global Burden

Palliative Care is ‘disease blind’ and needs led.....

Global burden for serious health related suffering double by 2060

- By 2060 estimated 48 million people each year will die with serious health-related suffering
- Increase most rapidly among older people (183% increase in those aged 70+ 2016–2060)

Figure 5
Worldwide need for palliative care for adults by disease groups (20+ years 2017)



“Immediate global action to integrate palliative care into health systems is an ethical and economic imperative”

Sleeman et al 2019

N = 52,883,093 adults

Global Mandate



- WHA Resolution 67.19
 - In 2014, the first ever global resolution on palliative care, called upon WHO and Member States to improve access to palliative care as a core component of health systems
 - Implications for health care system:
 - Palliative care needs to be included in the continuous plan of care provided alongside potential curative treatments
 - All should have access to essential safe affordable and effective palliative care services



Global rankings for palliative Care –we all love a ranking!

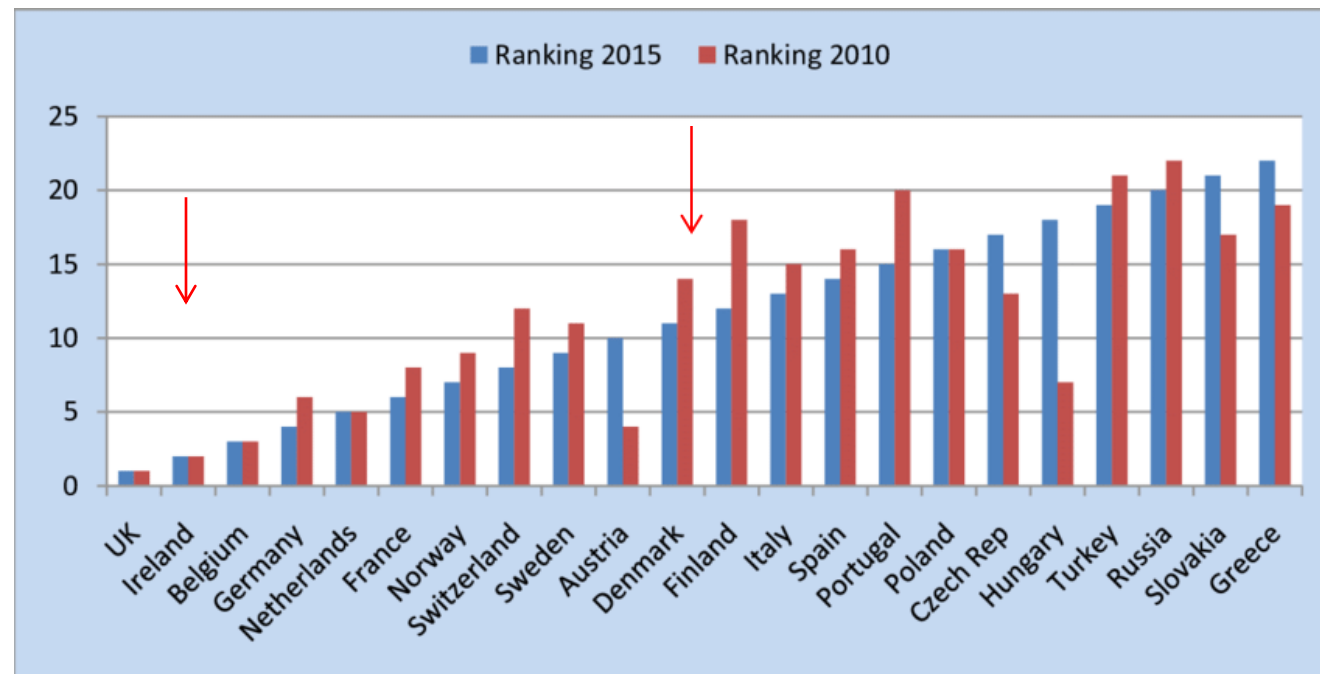
The Economist Intelligence Unit

The 2015 Quality of Death Index Ranking palliative care across the world

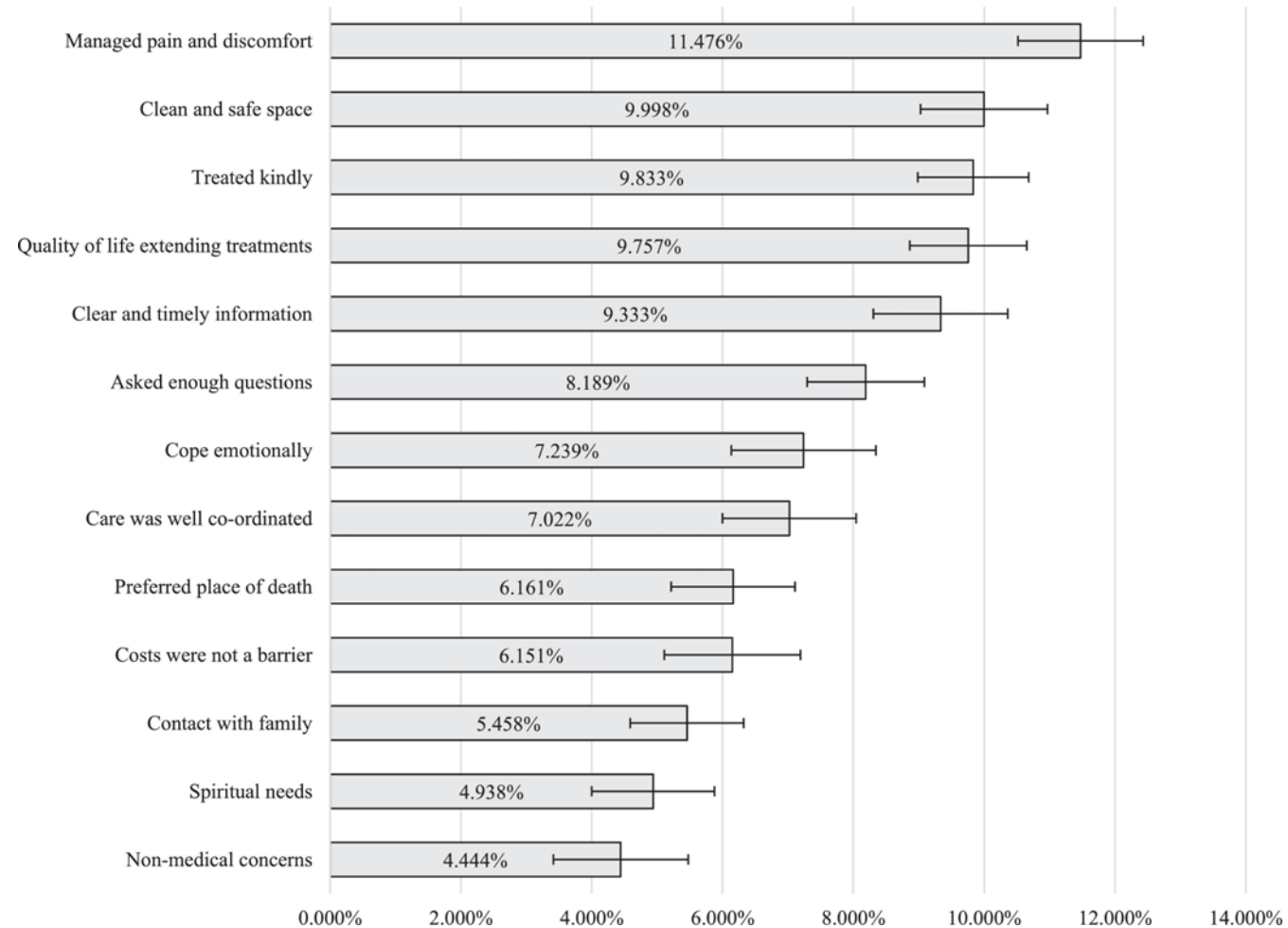
A report by The Economist Intelligence Unit



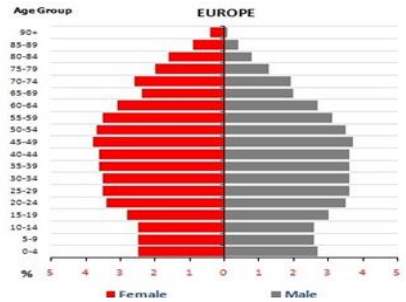
Commissioned by
 LIEN
foundation



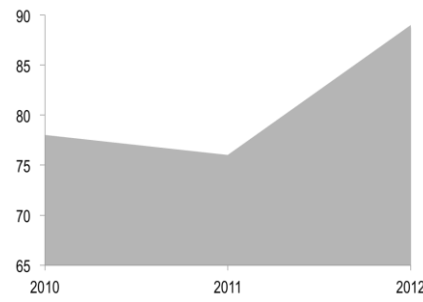
What matters most to patients and families at end of life? Quality of Death and Dying Index 2021



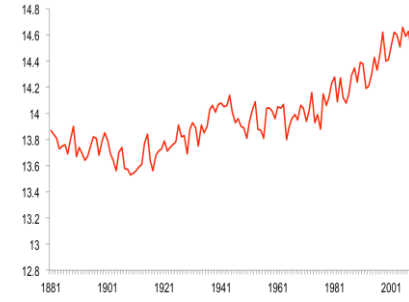
The changing global context: challenges and opportunities



Ageing



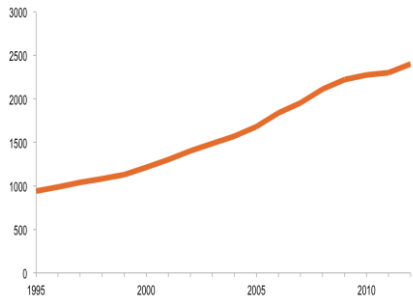
Innovation



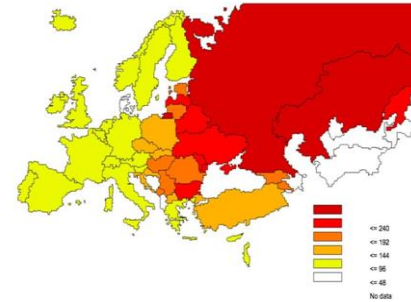
Climate change



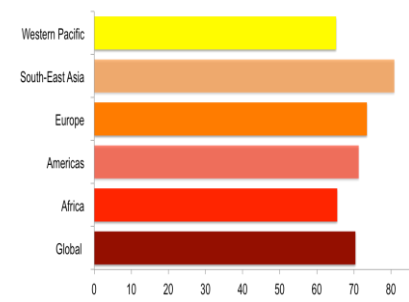
Globalization



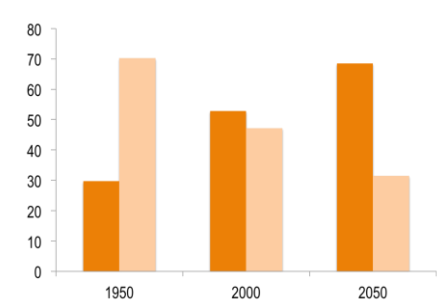
Rising costs



NCDs



Citizen voice

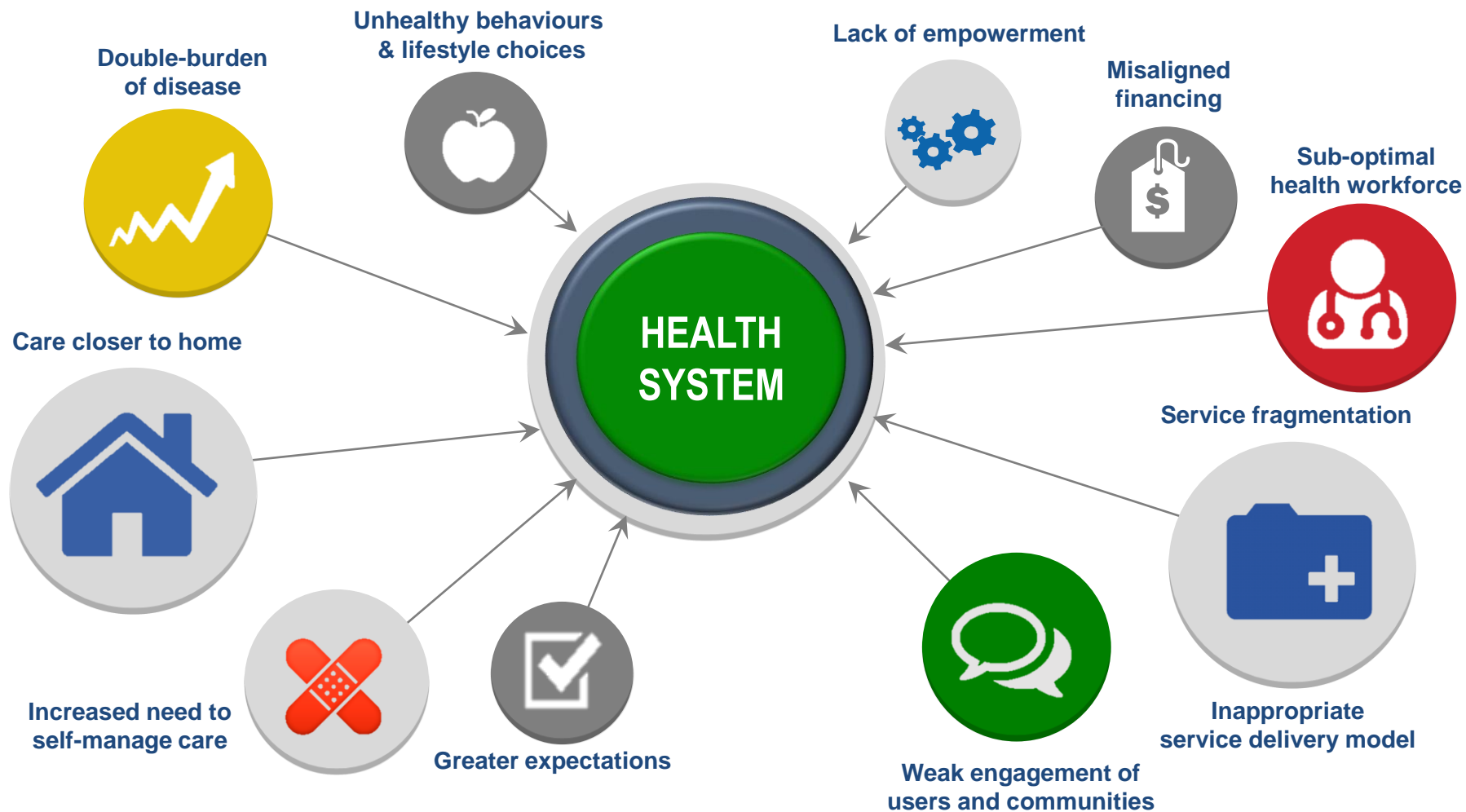


Urbanization

Health System Challenges

EMERGING DEMANDS

SYSTEM CONSTRAINTS



What are some of the challenges facing palliative care today?



- Cultural and social barriers
- Inequity of access –diagnosis; cause of death; ethnicity; gender and structured vulnerability
- Deficit focused –ie what is wrong rather than what matters most
- Poor team decision-making regarding plan of care
- Lack of continuity and coordination of care
- Inadequate symptom management – especially non-physical symptoms
- Poor communication with patients and families
- Research that is reductive rather than reflects complexity of human experience
- Lack of palliative care training and education

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Volume XX, Number XX, 2017
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2017.0039

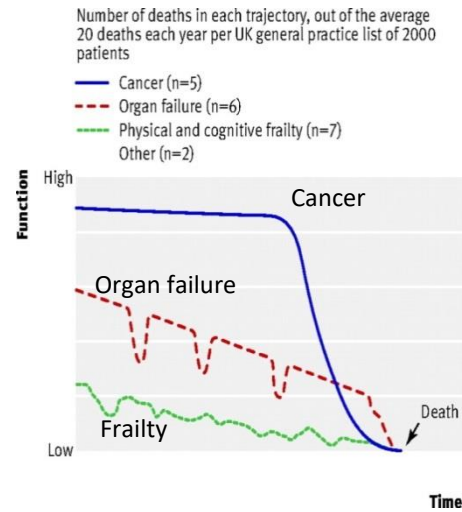
type: research-article
Original Article

The Palliative Care Challenge:
Analysis of Barriers and Opportunities
to Integrate Palliative Care in Europe
in the View of National Associations

Carlos Centeno,^{1,2} Eduardo Garralda,^{1,2} José Miguel Carrasco,^{1,2}
Marlieke den Herder-van der Eerden,³ Melissa Aldridge,⁴
David Stevenson,⁵ Diane E. Meier,⁶ and Jeroen Hasselaar^{3,*}

Changing face of palliative care

All Illnesses



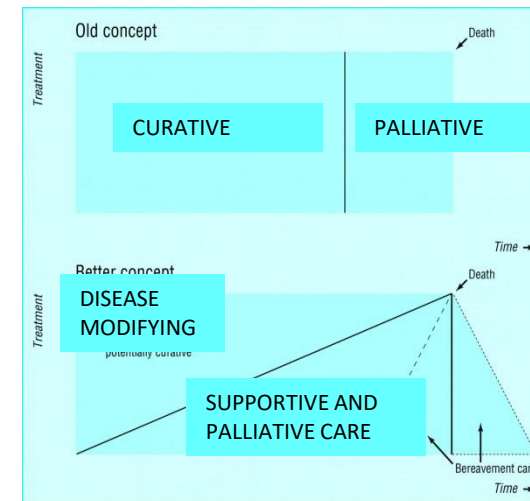
All Dimensions



All Settings



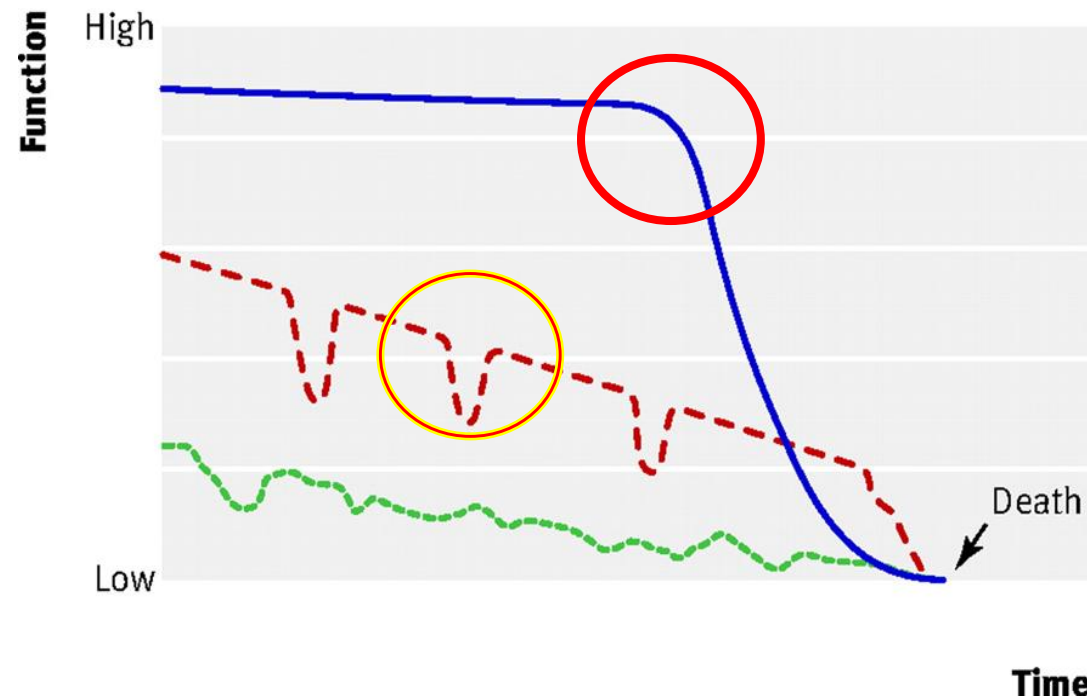
All Times



Palliative Care & Chronic Illness

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

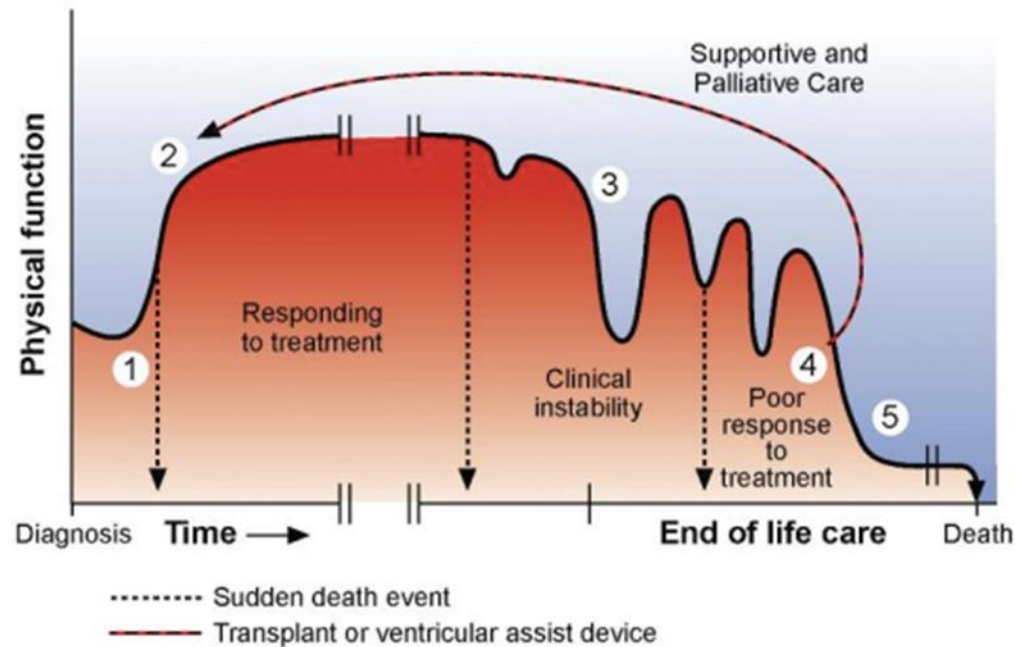
- Cancer (n=5)
- - - Organ failure (n=6)
- · - Physical and cognitive frailty (n=7)
- Other (n=2)



J Lynn, MD Rand Corp, Covinsky et al. JAGS 2003; Lynn & Adamson RAND 2003, Morrison & Meier N Engl J Med 2002.

All Illnesses –eg heart failure

Figure 1. The typical course of heart failure



Modified from Goodlin SJ¹⁰, Copyright JACC (2009), with permission from Elsevier.

While PC is a treatment which, in principle, can be delivered by all health care professionals, SPC is provided by multi-professional team who have undergone specialist training in PC

What the literature states...

- There is an inequity in patients with Heart failure receiving SPC intervention compared to patients with Cancer (Siouta et al 2017)
- Confusion pertaining to palliative care and end of life care (Singh et al 2019)
- Integrative literature review: Lack of knowledge of HCP is a barrier to patients with HF receiving SPC (Schallmo et al 2018)
- Heart Failure is associated with a high symptom burden that have a negative impact on quality of life (Stockdill et al 2019)
- Patients with HF are 1.5 times more likely to die in acute care setting, attend ED and be hospitalised than patients with cancer,(Lastrucci et al 2018)



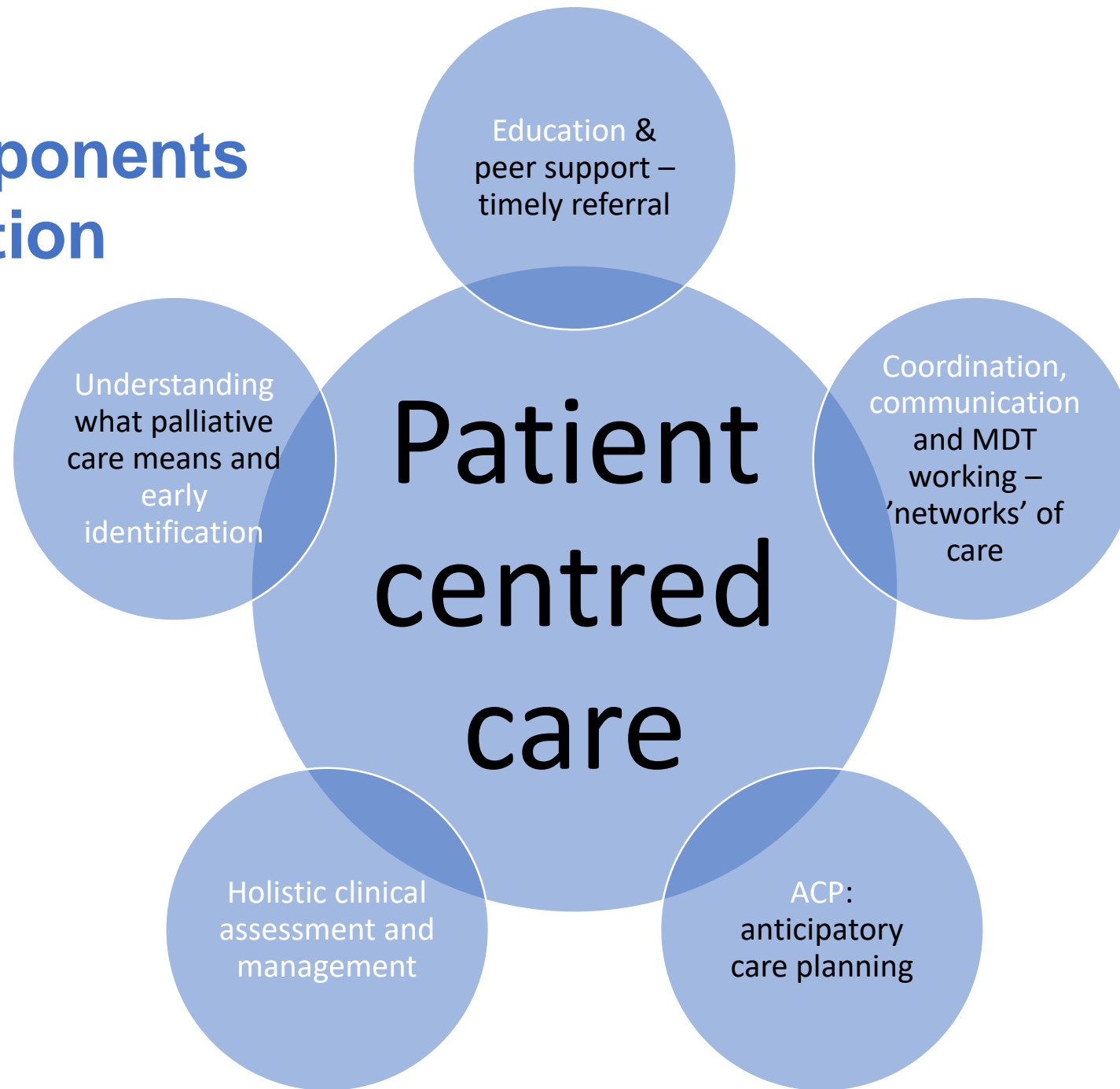
Which patients with heart failure should receive specialist palliative care?

Ross T. Campbell¹, Mark C. Petrie^{1,2}, Colette E. Jackson³, Pardeep S. Jhund¹, Ann Wright¹, Roy S. Gardner^{1,2}, Piotr Sonecki³, Andrea Pozzi⁴, Paula McSkimming⁵, Alex McConnachie⁵, Fiona Finlay³, Patricia Davidson⁶, Martin A. Denvir⁷, Miriam J. Johnson⁸, Karen J. Hogg⁹, and John J.V. McMurray^{1*}

¹BHF Cardiovascular Research Centre, University of Glasgow, Glasgow, UK; ²SNAHFS, Golden Jubilee National Hospital, Scotland, UK; ³Queen Elizabeth University Hospital, Scotland, UK; ⁴Hospital Papa Giovanni XXIII, Bergamo, Italy; ⁵Robertson Centre for Biostatistics, University of Glasgow, Glasgow, UK; ⁶Johns Hopkins University, Baltimore, MD, USA; ⁷Edinburgh University, Edinburgh, UK; ⁸Hull York Medical School, University of Hull, Hull, UK; and ⁹Glasgow Royal Infirmary, Glasgow, UK

Received 24 January 2018; revised 16 April 2018; accepted 21 May 2018; online publish-ahead-of-print 28 June 2018

Core components of Integration



Don't forget the carers!



Review Article

Carers' needs in advanced heart failure: A systematic narrative review

Leanne C Doherty^{1,2}, Donna Fitzsimons¹⁻³ and
Sonja J McIlfatrick^{1,2}

European Journal of Cardiovascular Nursing
2016, Vol. 15(4) 203-212
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The Journal of Cardiovascular Nursing, 34(1):11-19, JAN 2019
DOI: 10.1097/JCN.0000000000000516, PMID: 30157055
Issn Print: 0889-4655
Publication Date: 2019/01/01



Print

Inadequate Communication Exacerbates the Support Needs of Current and Bereaved Caregivers in Advanced Heart Failure and Impedes Shared Decision-making

Donna Fitzsimons;Leanne Doherty;Mary Murphy;Lana Dixon;Patrick Donnelly;Kenneth McDonald;Sonja McIlfatrick;

'The importance of planning for the future': Burden and unmet needs of caregivers' in advanced heart failure: A mixed methods study

Sonja McIlfatrick, Leanne C Doherty, Mary Murphy, Lana Dixon, Patrick Donnelly, Kenneth McDonald, Donna Fitzsimons

Show less ^

First Published December 13, 2017 | Research Article |

<https://doi.org/10.1177/0269216317743958>

All Dimensions challenge

- Physical
- Psychological
- Social
- Spiritual

McIlfatrick et al. *BMC Palliative Care* (2019) 18:57
<https://doi.org/10.1186/s12904-019-0436-3>

BMC Palliative Care

RESEARCH ARTICLE

Open Access

Examining constipation assessment and management of patients with advanced cancer receiving specialist palliative care: a multi-site retrospective case note review of clinical practice



Sonja McIlfatrick^{1*}, Deborah H. L. Muldrew¹, Esther Beck¹, Emma Carduff², Mike Clarke³, Anne Finucane⁴, Lisa Graham-Wisener³, Phil Larkin⁵, Noleen K. McCorry³, Paul Slater¹ and Felicity Hasson¹

RESEARCH ARTICLE

Open Access

Evaluation of the impact of telementoring using ECHO© technology on healthcare professionals' knowledge and self-efficacy in assessing and managing pain for people with advanced dementia nearing the end of life



Bannin De Witt Jansen¹, Kevin Brazil², Peter Passmore³, Hilary Buchanan⁴, Doreen Maxwell⁵, Sonja J. McIlfatrick^{6,7}, Sharon M. Morgan⁸, Max Watson⁹ and Carole Parsons^{1*}

Personhood on the clinical radar?

- A- Attitude
- B –Behaviour
- **C- Compassion**
- D –Dialogue
- Question: *“What should I know about you as a person to help me to take the best care of you that I can?”*

ANALYSIS

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them

The late Anatole Broyard, essayist and former editor of the *New York Times Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer. “To the typical physician,” he wrote, “my illness is a routine incident in his rounds while for me it’s the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.”¹

Broyard’s words underscore the costs and hazards of becoming a patient. The word “patient” comes from the Latin *patiens*, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is no small matter and can exact considerable costs.² These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem incompatible with life itself. When patients experience a radical unsettling of their conventional sense of self and a disintegration of personhood,³ suffering knows few bounds. To feel sick is one thing, but to feel that who we are is being threatened or undermined—that we are no longer the person we once were—can cause despair affecting body, mind, and soul. How do healthcare providers influence the experience of patienthood, and what happens when this frame of reference dominates how they view people seeking their care?

Dignity and patienthood

Answering these questions begins with an examination of the relationship between patienthood and notions of dignity. Although the literature on dignity is sparse, it shows that “how patients perceive themselves to be seen” is a powerful mediator of their dignity.⁴ In a study of patients with end stage cancer, perceptions of dignity were most strongly associated with “feeling a burden to others” and “sense of being treated with respect.”⁵ As such, the more that healthcare providers are able to affirm the patient’s value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient’s sense of dignity will be upheld. This finding, and the intimate connection between care provider’s affirmation and

EDITORIAL, p 167

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Accepted: 15 May 2007

patient’s self perception, underscores the basis of dignity conserving care.⁶

Yet, many healthcare providers are reticent to claim this particular aspect of care, which is variously referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care.^{6,12} This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, when personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect.¹³ Not being treated with dignity and respect can undermine a sense of value or worth.² Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients



All Settings Challenge

- Community
- Hospice
- Nursing home
- Hospital

ORIGINAL ARTICLE |  Open Access |  

Palliative and end-of-life educational interventions for staff working in long-term care facilities: An integrative review of the literature

Kieko Iida MSc, PGDip, BSc, RN, Assumpta Ryan PhD, MEd, BSc(Hons), RN, PGCTHE, FHEA, Felicity Hasson PhD, PGDip MSc, BA(Hons) ... [See all authors](#) ▾

First published: 12 September 2020 | <https://doi.org/10.1111/opn.12347>

ORIGINAL ARTICLE

Evaluating a dignity care intervention for palliative care in the community setting: community nurses' perspectives

Sonja McIlfratrick, Michael Connolly, Rita Collins, Tara Murphy, Bridget Johnston and Philip Larkin

The roles, responsibilities and practices of healthcare assistants in out-of-hours community palliative care: A systematic scoping review

Anne Fee, Deborah Muldrew, Paul Slater, more...

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First Published June 15, 2020 | Review Article | [Find in PubMed](#) |  Check for updates

<https://doi.org/10.1177/0269216320929559>

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Original Article |  Full Access |

Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: a cross-sectional survey

Esther-Ruth Beck MSc, RN ✉, Sonja McIlfratrick PhD, RN, Felicity Hasson PhD, Gerry Leavey PhD

First published: 20 December 2016 | <https://doi.org/10.1111/jocn.13690> | Cited by: 4

New models of care –across boundaries



The NEW ENGLAND JOURNAL *of* MEDICINE

Perspective

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

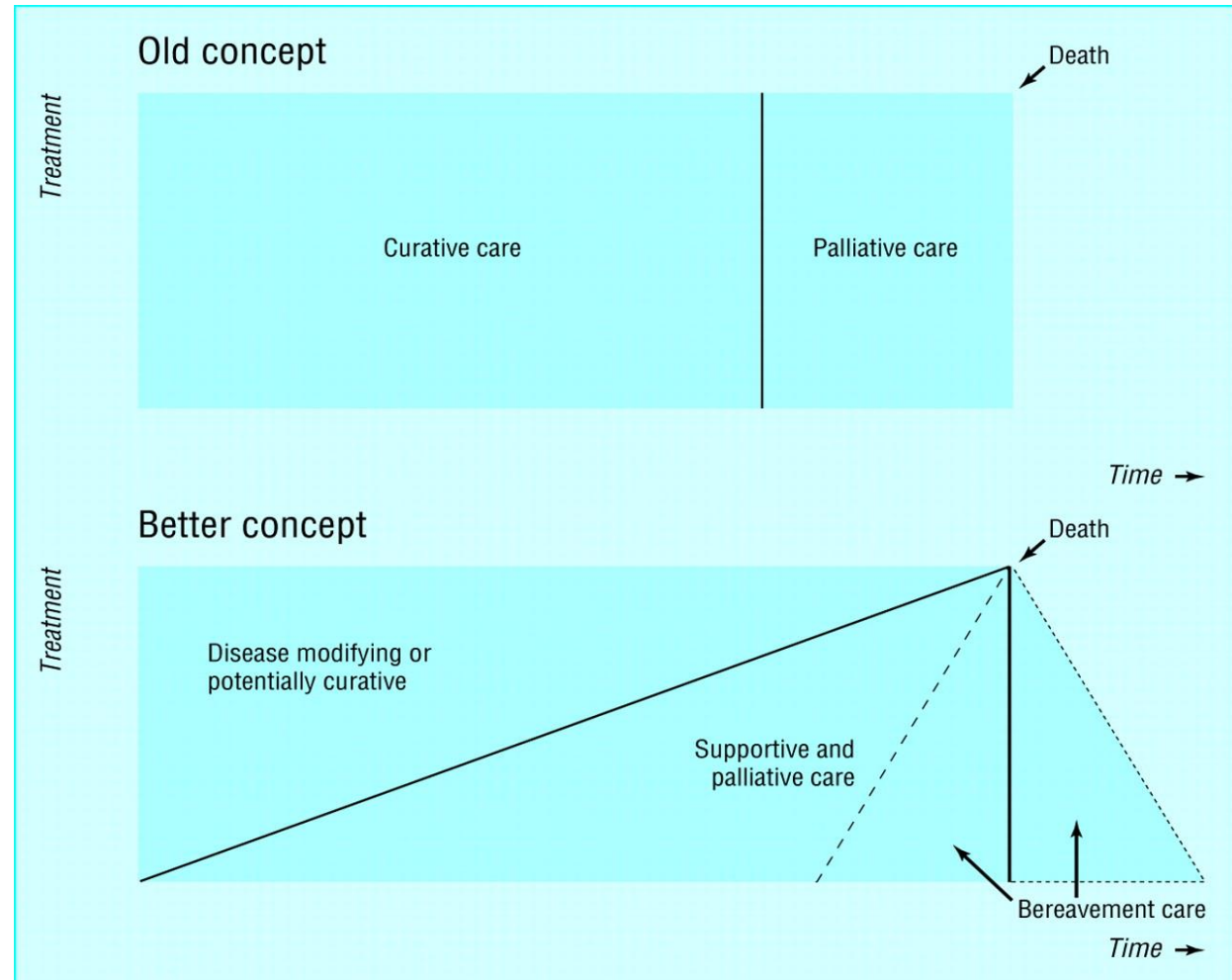
Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Palliative care, a medical field that has been practiced informally for centuries, was recently granted formal specialty status by the American

meeting, addressing veiled existential distress, and managing refractory symptoms. Now that the value of palliative care has been

All Times Challenge

- An evolving model of Palliative Care



All Times Challenge: Public Health and Palliative care

- FINDINGS
 - Wide variability in understanding - Despite all the policy and initiatives worldwide and regionally with regards to ACP, the public are still largely not aware of the term, and of those who are aware, it is connected with death and the very end of life.
- Enhancing awareness:
- Addressing key barriers: 'taboo'
- Publicity & understanding
- Importance of education, particularly with a community focus

Exploring public awareness and perceptions of palliative care: A qualitative study

Sonja McIlfatrick, Helen Noble, Noleen K McCorry, more...

Show all authors

First Published September 11, 2013 | Research Article

Check for updates

<https://doi.org/10.1177/0269216313502372>

Article information

Altmetric 17

McIlfatrick et al. *BMC Palliative Care* 2013, 12:34
<http://www.biomedcentral.com/1472-684X/12/34>

BMC
Palliative Care

RESEARCH ARTICLE

Open Access

Public awareness and attitudes toward palliative care in Northern Ireland

Sonja McIlfatrick^{1*}, Felicity Hasson², Dory McLaughlin³, Gail Johnston⁷, Audrey Roulston⁴, Lesley Rutherford^{3,5}, Helen Noble³, Sheila Kelly⁶, Avril Craig⁸ and W George Kemohan²



Palliative Care Public Health

The Lancet Commissions 

- Published in 2022
- Took a global perspective, commissioners from across the world
- Looks beyond palliative care and healthcare services
- Structural issues such as gender, race and power considered alongside relationships, communities, health care services, consumerism and economics
- Uses a systems approach to understand challenges
- Critical perspectives but also hopeful and intentional

Report of the *Lancet* Commission on the Value of Death: bringing death back into life



*Libby Sallnow, Richard Smith, Sam H Ahmedzai, Afsan Bhadelia, Charlotte Chamberlain, Yali Cong, Brett Doble, Luckson Dullie, Robin Durie, Eric A Finkelstein, Sam Guglani, Melanie Hodson, Bettina S Husebø, Allan Kellehear, Celia Kitzinger, Felicia Marie Knaul, Scott A Murray, Julia Neuberger, Seamus O'Mahony, M R Rajagopal, Sarah Russell, Eriko Sase, Katherine E Sleeman, Sheldon Solomon, Ros Taylor, Mpho Tutu van Furth, Katrina Wyatt, on behalf of the Lancet Commission on the Value of Death**

Key Messages from the report

1. Dying in the 21st century is a paradox- overtreated and undertreated
2. Death, dying and grieving today have become unbalanced
3. Links with climate crisis- the delusion that we are in control of, not part of nature
4. Rebalancing death and dying depends on changes across 'death systems'
5. Disadvantaged and powerless suffer most from imbalance
6. Five principles of 'realistic utopia' -a new vision for how death and dying could be
7. Challenge of transforming how people die and grieve today has been recognised and responded to –but more concerted effort is needed
8. Radical changes across all death systems are a collective responsibility

“At the core of this rebalancing must be relationships and partnerships between people who are dying, families, communities, health and social care systems, and wider civic society”

What does this mean for palliative care?

Recognise our position in wider systems

- Palliative care services
- Compassionate communities
- Opioid reform policy

Understand the levers we can change and make links with others

- Building death literacy
- Suffering
- Move beyond equality to equity
- Social and structural determinants



Snallow et al

What are the lessons that can be learnt and future opportunities?



- Workforce challenges =new boundaries and innovations in education eg of Advanced Nursing practice role
- Digital technology –role of Virtual reality and simulation –what role for education and what contribution for clinical practice?
- Promoting equity of access= realistic utopia of the Lancet Commission on Death- what are implications for palliative care and across boundaries?
- Final reflections on lessons to overcome barriers

Health Workforce Need: Education & Training

Review Article



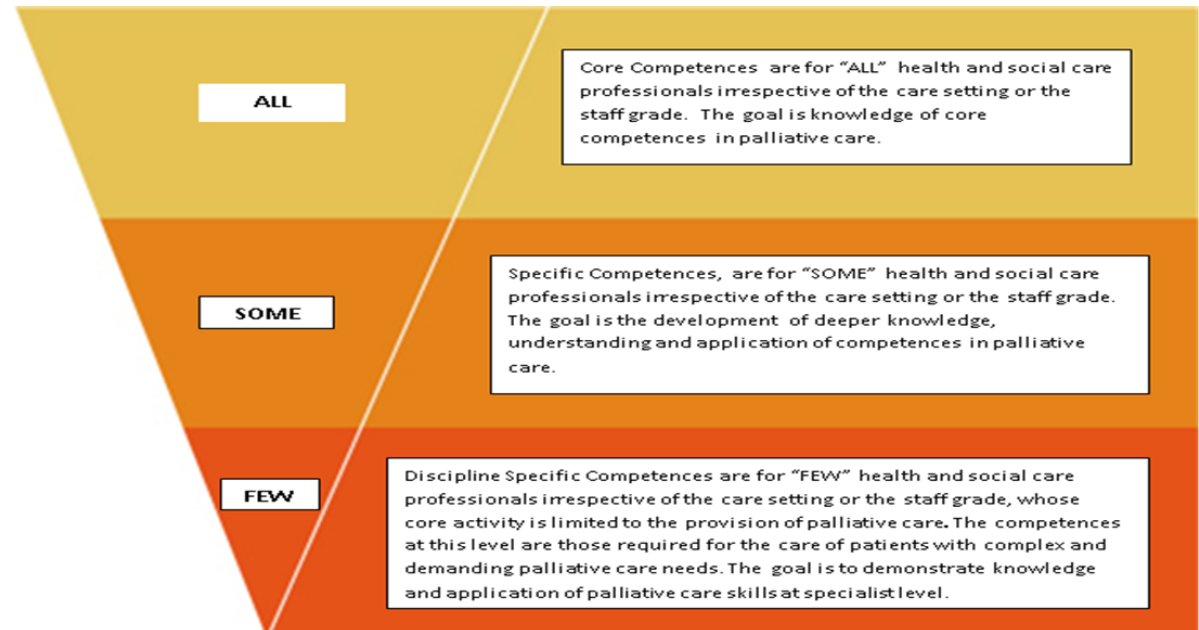
Nursing competencies across different levels of palliative care provision: A systematic integrative review with thematic synthesis

Palliative Medicine
2020, Vol. 34(7) 851–870
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Minna Hökkä^{1,2}, Sandra Martins Pereira^{3,4,5}, Tarja Pölkki⁶,
Helvi Kyngäs¹ and Pablo Hernández-Marrero^{3,4,5}

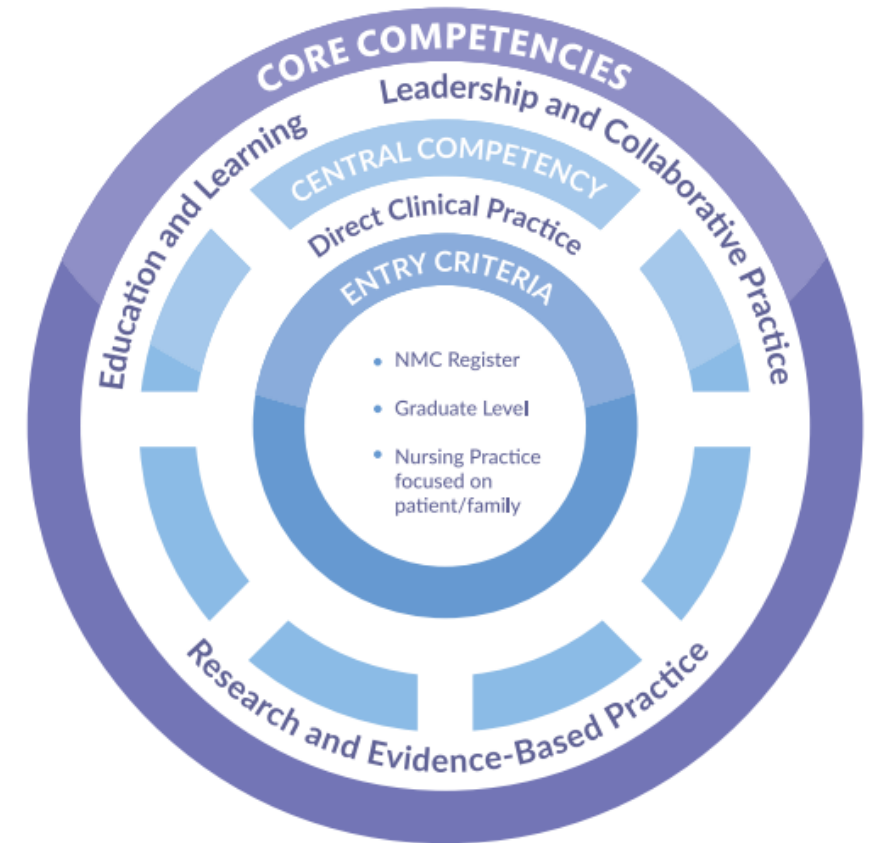
Competencies are:

- Leadership
- Communication
- Collaboration
- Clinical
- Ethico-legal
- Psycho-social
- Spiritual



Workforce Challenges: Role of ANP

<p>Direct clinical practice</p> <ul style="list-style-type: none"> •Autonomous working •Person centred approach •Clinical judgement in complex care •Monitor and report quality issues 	<p>Leadership</p> <ul style="list-style-type: none"> •Develop and sustain partnerships and networks •Engage stakeholders •Provide professional/clinical advice •Demonstrate resilience •Develop robust governance systems
<p>Education</p> <ul style="list-style-type: none"> •Keep skills and knowledge up to date •Educate, supervise, and mentor colleagues •Lead on audit and evaluation strategies 	<p>Research and EBP</p> <ul style="list-style-type: none"> •Contribute to research to monitor and improve healthcare •Critically appraise the outcomes of research/evaluation •Advocate and contribute to the development of a supportive research culture



Based upon the work of Hamric et al (2009)

Evidence Base –ANP in Palliative Care

<p>Strengths</p> <p>APRNs are a valuable source of extending palliative care into oncology (Ferrell, 2021)</p> <p>Improving early palliative care consultation (Sabolish, 2022) and end of life care prognostic discussions (Kalowes, 2015)</p>	<p>Challenges</p> <p>Traditional educational preparation was insufficient in preparing them for their specialty role within palliative care (Pawlow, 2018)</p>
<p>Opportunities</p> <p>Development of education and training programmes in palliative care for mid-career ANPs (Dahlin, 2016)</p> <p>Ideally placed to complete “Physician Orders for Life Sustaining Treatment” forms (Hayes, 2017)</p> <p>ANPs can remove delays in death pronouncement times (Jackson, 2019)</p>	<p>Recommendations</p> <p>Continuous training to improve skills e.g. communication (Fliedner, 2021)</p> <p>Building ANPs as leaders within the healthcare organisation’s strategic plan (Elliot, 2017)</p>

Digital technology –emerging area!



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of Palliative Nursing

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International Journal of Palliative Nursing, Vol. 28, No. 3 · Research

Using virtual reality in palliative care: a systematic integrative review

Hannah Carmont , Sonja McIlfratrick

Published Online: 22 Apr 2022 | <https://doi.org/10.12968/ijpn.2022.28.3.132>

Palliative Medicine

 Impact Factor: 4.4
5-Year Impact Factor: 5.5 [JOURNAL HOMEPAGE](#)

 Open access |  | [Review article](#) | First published online May 30, 2022

How effective is virtual reality technology in palliative care? A systematic review and meta-analysis

[Jiping Mo](#), [Victoria Vickerstaff](#), (...), and [Nicola White](#)   [View all authors and affiliations](#)

[Volume 36, Issue 7](#) | <https://doi.org/10.1177/02692163221099584>



Emerging evidence base for use in health care education



Some evidence base for clinical practice



Limited sample sizes and low quality studies mean efficacy needs further research

The realistic utopia of Lancet Commission

- The social and structural determinants of death, dying and grieving are tackled
- Dying is understood to be a relational and spiritual process rather than simply a physiological event
- Networks of care lead support for people dying, caring and grieving
- Conversations and stories about everyday death, dying and grief become common
- Death is recognised as having value



One final thought!

- You matter because you are you and you matter to the last day of your life. We will do everything we can to help you die peacefully and to help you live until you die”.

Dame Cicely Saunders

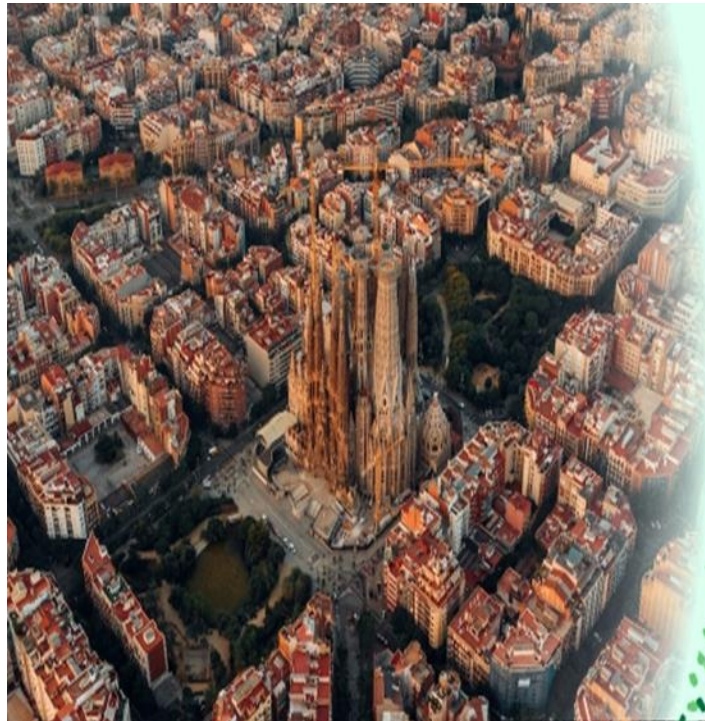


1918 - 2005



**13th World Research Congress of the European
Association for Palliative Care**

**Thank you, hope you will join us next year in
Barcelona!**



EAPC 2024
13th World Research Congress

16-18th May, 2024
Barcelona - Spain



#EAPC2024