

Perspectives internationales de soins palliatifs: au-delà des langues, au-delà des frontières

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Overview of the presentation

- Key challenges to address: solutions to be found
- What are the global messages from our plenary speaker sessions?
- Our future: where are we going and how do we get there

Key challenges to address: solutions to be found

40 million people need palliative care worldwide

2.1 million children need palliative care worldwide

'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'

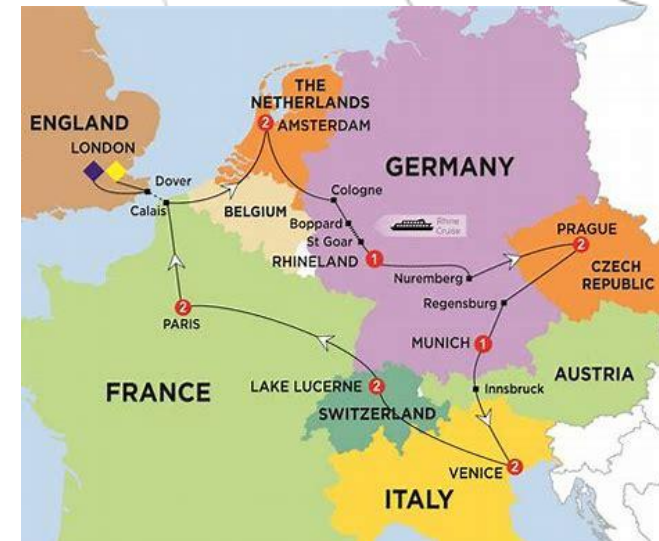
Clare Henry, CE, National Council for Palliative Care, UK



EUROPE IN A GLOBAL CONTEXT



- A conglomeration of nations with common values and aspirations
- A set of countries with different cultures, languages, beliefs and needs
- Connected and committed
- Strength in cohesion



Sometimes the language is confusing...

- One Voice...One Vision...?



European Association for Palliative Care
Non-governmental organisation (NGO) recognised by the Council of Europe

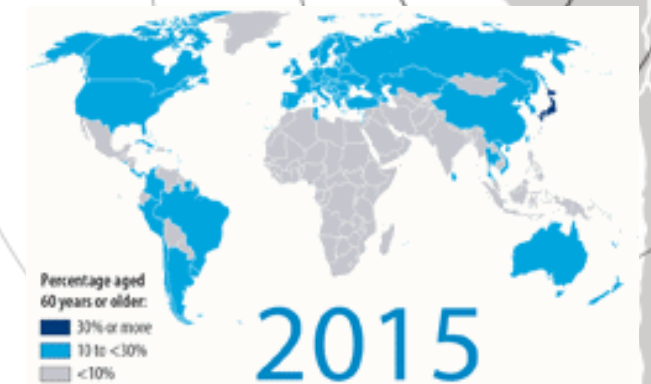
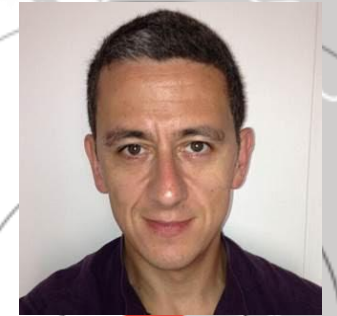
Strengths and Weaknesses



- **Strengths**
- Palliative care reduces hospital admissions, costs and the inadequate use of emergency services
- Promotes a more responsive, comprehensive and judicious delivery of care
- **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.

PRIMARY PALLIATIVE CARE: MODELS OF EARLY PALLIATIVE CARE

- Beyond cancer to frailty and non-malignancy
- Universal coverage = Primary Care AND Public Health
- Home as the basis of care, wherever that is
- Why early palliative care is necessary: palliative care from diagnosis to death

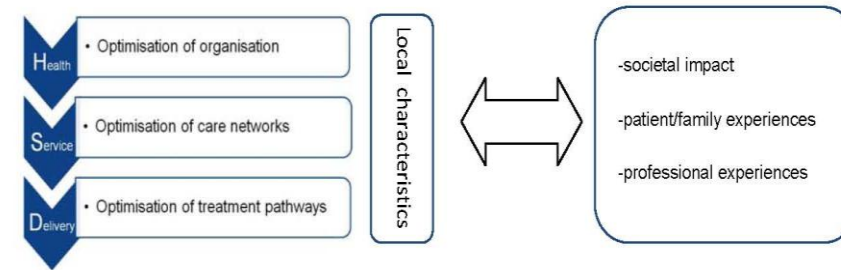


<https://www.ed.ac.uk/usher/primary-palliative-care/videos/health-and-care-professionals>

INTEGRATION OF PALLIATIVE CARE



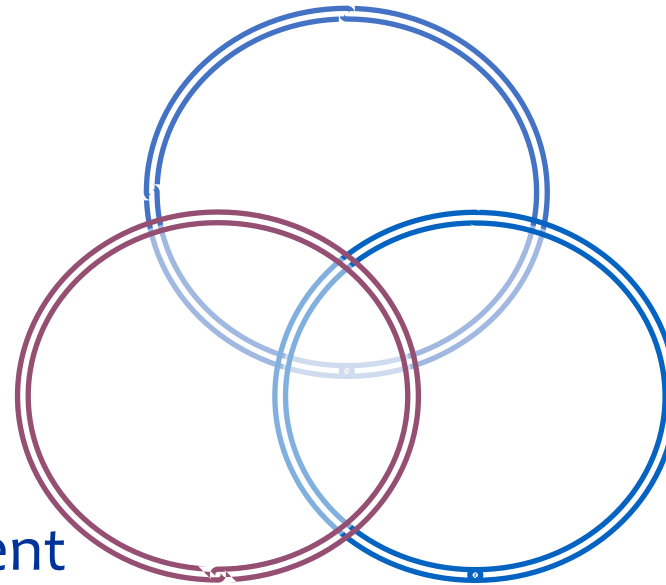
Figure 2: Identification of best practices in integrated palliative care delivery



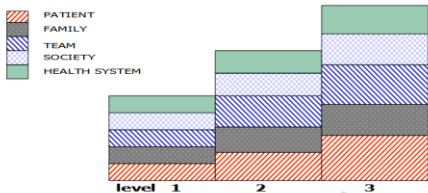
“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realise **continuity of care** between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a **well-supported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

Practitioners who exhibit

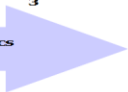
Critical thinking



DIMENSIONS OF THE PALLIATIVE CARE LEARNING PROCESS



self-awareness + communication + ethics



The European Association for Palliative Care is a membership organisation dedicated to the promotion and development of palliative care throughout Europe

Vision

One voice, one vision. A world without preventable suffering where those with life-threatening illnesses and their families have timely access to high quality palliative care as an integral part of the healthcare system

Mission

To influence, promote and advocate for the delivery of high quality palliative care across the life span by fostering and sharing palliative care research, policy, education and evidence-based practice

Core Values

Strive for excellence in palliative care
Value interdisciplinary working and representation
Respect diversity
Work collaboratively

What are the global messages from our plenary speaker sessions?

SPIRITUAL CARE: AN EQUILIBRIUM OF CARE 'GIVING'



Respite Care

- A lost vision at a critical time?
- A misplaced understanding of the value of respite care?
- A shift in health system planning which values acuity over complexity
- Have we lost something that we need to reclaim?



Volunteering



- Please can we change the text....!
- An international driver in the delivery of palliative care
- The voice of a palliative care organisation



Medical Journals

American Journal of Hospice & Palliative Care
14
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DOI: 10.1177/1049909118782221
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A Few Good Men: It's Not Easy Recruiting Male Hospice Palliative Care Volunteers

Stephen Claxton-Oldfield, PhD, CT¹, Willa McCaffrey-Noviss, BSc¹, and Robert Hicks¹

Abstract
Two studies were conducted to explore how to engage male volunteers in hospice palliative care. Four male hospice palliative care volunteers were interviewed in study 1. The men agreed that a direct approach is best when it comes to recruiting male volunteers, especially a personal story or testimonial. Two different volunteer position descriptions were created for study 2: one description was similar to what might appear on a community-based hospice palliative care program's web site or in a newspaper ad looking for visiting hospice palliative care volunteers; the other description was in the form of a personal testimonial ostensibly written by a male hospice palliative care volunteer describing his role through examples of interactions he has had with patients and patients' family members. Twenty-five males responded to each description. Both of the descriptions generated low and nonsignificantly different levels of interest in becoming a hospice palliative care volunteer. Believing this work to be too emotionally demanding and not having enough time for volunteering were the two most commonly given reasons for not wanting to become a hospice palliative care volunteer. Suggestions for future recruitment efforts are discussed.

Keywords
hospice, palliative care, volunteers, males, recruitment

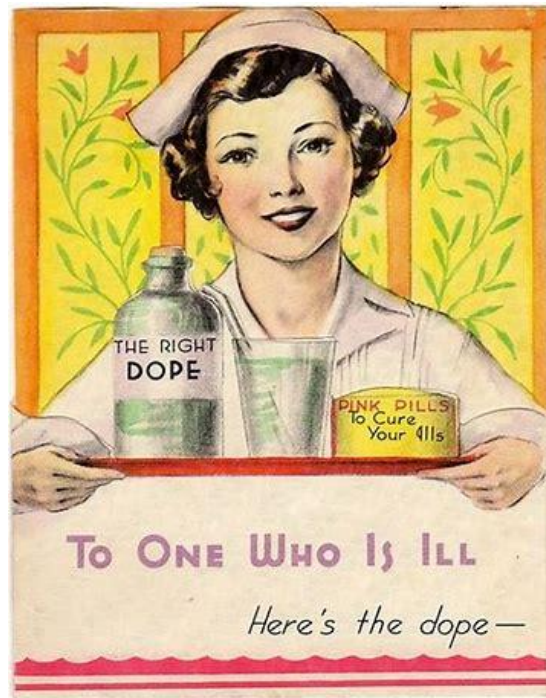
Ask the coordinator/manager of just about any hospice palliative care volunteer program to take a look around the room during their next volunteer meeting and take notice of what they see and, chances are, the handful of males in the room is going to be very hard to miss. Why? Because volunteering in hospice palliative care, in particular, volunteering to work directly with terminally ill patients and their families, is a gendered activity, with many females and very few males. In a recent national survey of Canadian hospice palliative care volunteer training, the 58 respondents (mostly coordinators) reported a total of 3388 direct patient/family contact volunteers; those who knew the breakdown of direct patient/family contact volunteers by gender reported that 27% were female and 370 were male.¹ Similar results were found in a national survey of American hospice volunteer training by Wittemberg-Lyles et al.² which was responded to by 59 hospice organizations. A total of 6652 volunteers were under the direction of the responding managers, with the overwhelming majority of volunteers (5362) being female. A typical breakdown by volunteer gender for most hospice palliative care programs in Canada and the United States appears to be about 80% to 90% female and 10% to 20% male. This is not just a situation in North America either. For example, in the United Kingdom, Australia, New Zealand, France, and Germany, females make up the vast majority of the participants in any given study involving hospice palliative care volunteers.³⁻⁷ To put it mildly, "the lack of male volunteers in hospice work . . . [is] strikingly apparent."^{8(p18)} As a side note, females also make up the overwhelming majority of coordinators/managers of hospice palliative care volunteer programs in Canada.¹

Despite the changing tide of gender roles, the overrepresentation of females among direct patient/family contact volunteers may be due, in part, to traditional gender role socialization and experience that encourage women to be caring, nurturing, and supportive.⁹ As Auger notes, throughout time and across settings, females have been "recognized as the primary knowers of how care for, nurture, and support the dying."^{10(p17)} Besides being female, a typical Canadian hospice palliative care volunteer is also middle-aged or older. Middle-aged and older females who conform to the traditional female gender role of homemaker may have more free time to do volunteer work, especially after their children have grown up and left home. In contrast, the traditional male gender role centers with the breadwinner (paid employment) expectation, with no time for

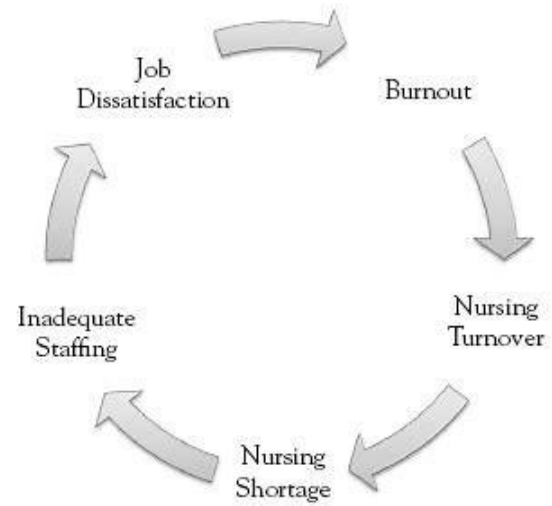
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Our future: Where are we going and how do we get there?

ONE WHICH REMEMBERS...



ONE WHICH LISTENS AND RESPONDS – TO SELF AND OTHERS

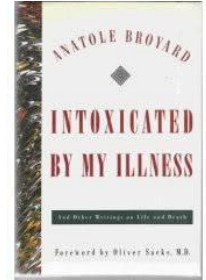


ONE WHICH CONTINUALLY SEEKS NEW HORIZONS



Ils sont nés les infirmiers de pratique avancée !

A final thought from Anatole Broyard



- ‘The knowledge that you're ill is one of the momentous experiences in life. You expect that you're going to go on forever, that you're immortal. Freud said that every man is convinced of his own immortality. I certainly was. I had dawdled through life up to that point, and when the doctor told me I was ill it was like an immense electric shock. I felt galvanized. I was a new person. All my old trivial selves fell away, and I was reduced to essence’

Intoxicated by my illness and other writings on life and death 1992

Fawcett Columbine, New York.