

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’

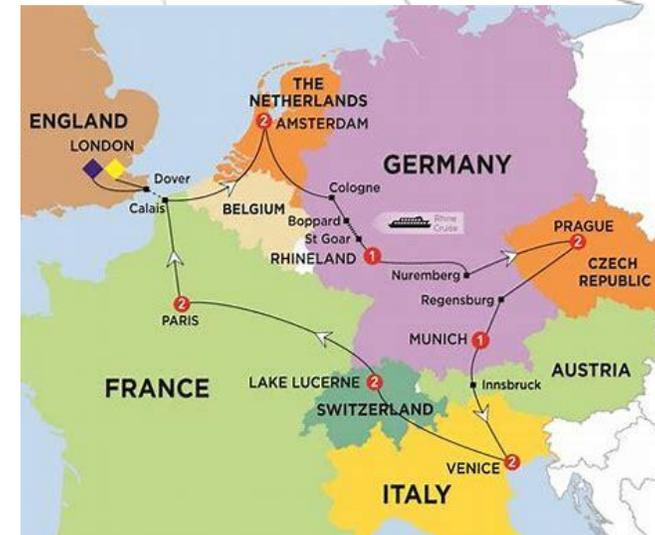
Clare Henry, CE, National Council for Palliative Care, UK



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.

Palliative Care as a Public Health issue



PALLIATIVE CARE PALLIATIVE CHRONIC CONDITIONS
CHRONIC DISEASES ADVANCED CHRONIC CARE INTEGRATED
Palliative Care Palliative Chronic Conditions Chronic Diseases
Advanced chronic care Integrated Care Comprehensive Compa
Empathy Suffering Frailty Pain Family Teamwork Services Pro
Public Health Community Emotional Spiritual Social Ethical
Research Education Quality People Care Families Illness
Communication Behaviour Resourcing Sustainability Interdisciplin
Availability Interdisciplinary Patients Symptoms
Management
Accessibility Health Care
Advance Care Planning
Patient Per
Integrated Care Support
Interdisciplinary Pa
Decision-making Autono

Building Integrated Palliative Care Programs and Services
Edited by Xavier Gómez-Batiste & Stephen Connor

CÁMERA DE CUERPOS PALACIO DE LA SALUD
WHO
wipa
Building Palliative

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 WHA19.22 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 514 and 541² 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,³

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: assuring adequate access for medical and scientific purposes,⁴ and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines,⁵

Also taking into account resolution 2005/21 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics,⁶

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,⁷

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 prevention-based 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,⁸

¹ Document A/67/11.

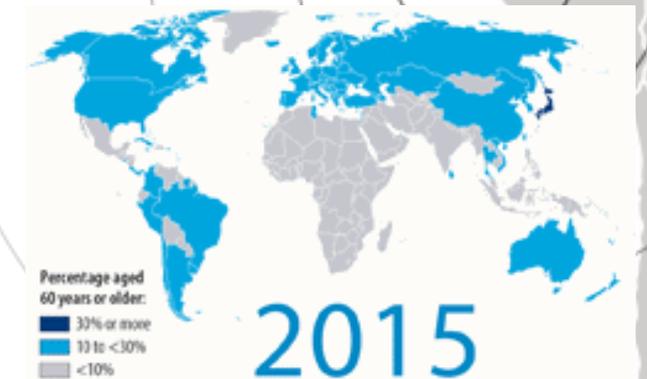
² Document E/NCN/2003/10, para 1.

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

'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.

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

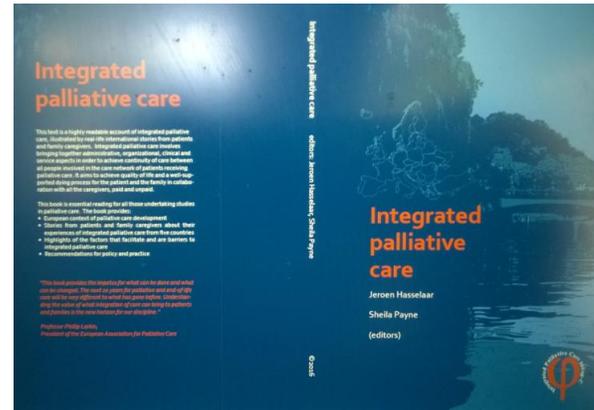
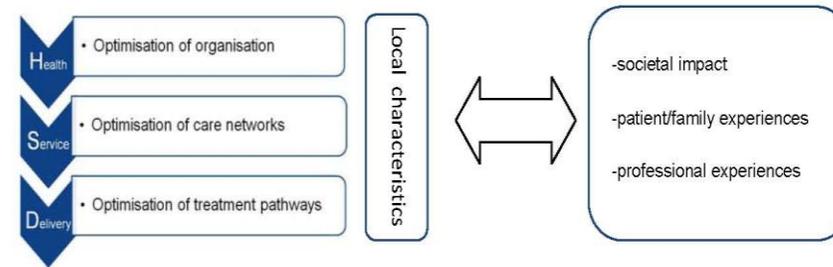


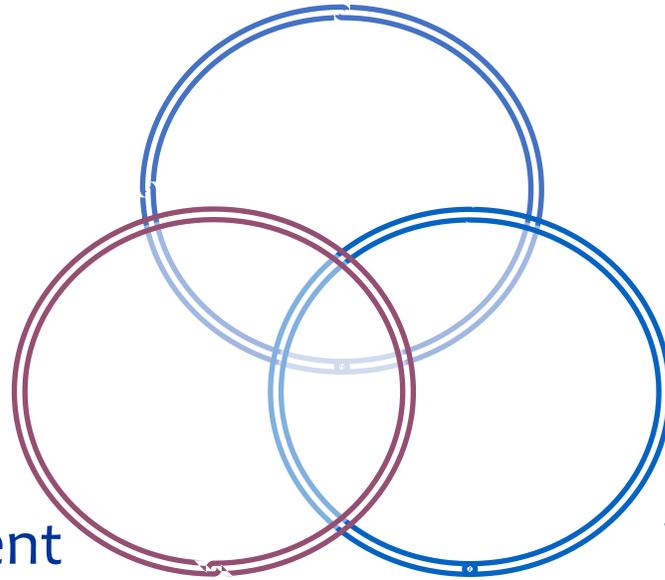
Figure 2: Identification of best practices in integrated palliative care delivery



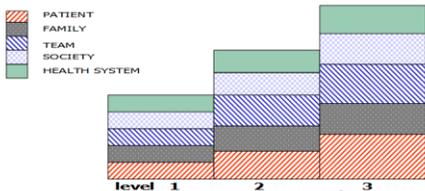
“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realise **continuity of care** between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a **well-supported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

Practitioners who exhibit

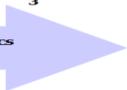
Critical thinking



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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sagepub.com/journalsPermissions.nav
DOI: 10.1177/1049909118782221
sagepub.com/home/hjhp
SAGE

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 To put it mildly, "the lack of male volunteers in hospice work . . . [is] strikingly apparent."^{4(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.⁵ 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."^{6(p19)} 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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Research



- Collaboration is key to our success
- ‘le fil rouge’ - from bench to bedside... and back
- A shared wisdom with a common purpose
- Establishes our worth in terms of academia and science
- Values the unique contribution of inclusivity
- Research capacity – the next generation??

Collaboration: Securing a future for palliative care research

There is potentially something to be gained for everyone by increasing palliative care research collaboration. In a recent editorial in *BMJ Supportive & Palliative Care*, Higginson¹ reviews current challenges for palliative care research, both in terms of the UK's research agenda responsiveness to national policy and through key messages to funding agencies to ensure that research efforts translate into better patient and family care at the end of life. A specific call for greater collaboration (both nationally and internationally) is made. She is not the first. An editorial by Stein Kazan² in 2008 at the advent of the European Palliative Care Research Collaborative (EPCRC) called for 'an international arena for palliative care research'. Has this been achieved? Particularly at this time of contention for the United Kingdom in light of the recent referendum decision to leave the European Union (EU) and the vacuum that leaves in terms of a clear understanding of its implications for future research partnership, it is critical to understand how robust international collaboration can be achieved and what practical steps are needed to foster success.

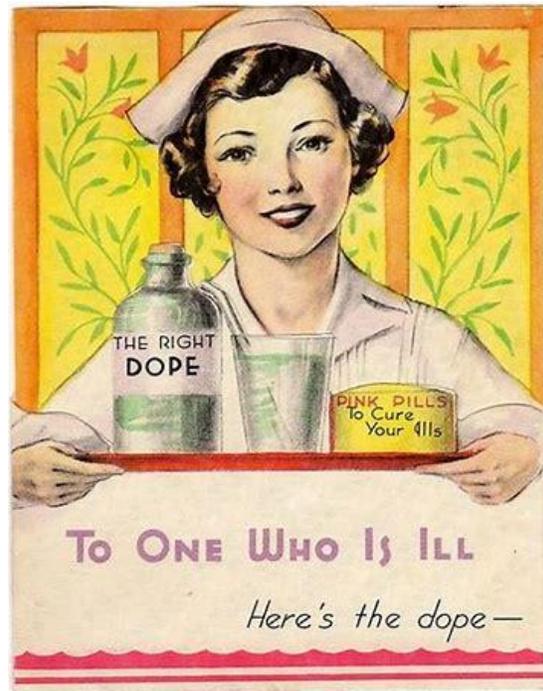
There are some good examples of where an international collaborative approach leads to a stronger evidence base and better patient outcomes. The International Palliative Care Family Care Research Collaborative (IPCRC) led by the Centre for Palliative Care in Melbourne is one example.³ Projects such as the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) project, led by Kings College London, have equally brought international expertise together to enhance the evidence base. A recent Delphi study involving 64 experts from 30 countries provided clarity on the core variables of a palliative care population.⁴ From the EU, cross-country collaborations have linked care providers, university partners and voluntary and statutory agencies to address the complexity of palliative and end of life care.⁵ In all cases, the benefits of shared working are combined expertise, developing common tools and evidence base, and broader reach and impact of findings. Collaborations such as these enable sharing of methodological expertise, greater conceptual clarity, and cohesive wide-reaching dissemination of robust and timely information. Overall, a case for international collaboration and its benefits for palliative care would seem to be made. However, effective collaboration requires a careful consideration of the factors which influence its success or failure and, most importantly, what messages that has for current and future palliative care research.

Collaboration comes in many kinds, so we should not look simply to international collaboration. Research in palliative care is not unique in terms of method and application. Many disciplines (mental health, paediatrics, older person care) experience similar challenges in research with complex populations. Public health, social sciences and health economics offer a range of expertise highly relevant for palliative research. Collaborative sharing of experience and method enhance and strengthen both process and outcome of palliative care research. This also challenges a singular disease-oriented research agenda suggesting palliative care as only relevant to specific groups at specific times (i.e. end of life). The argument for earlier intervention of palliative and rehabilitation models across a lifespan approach to research endorses widening the potential vista of national and international research collaboration and opportunity. Paediatric palliative care offers a good example here, where collaboration opens the possibility to innovative studies reflective of the changing pattern of disease and treatment in childhood life-limiting and life-threatening illness.⁶

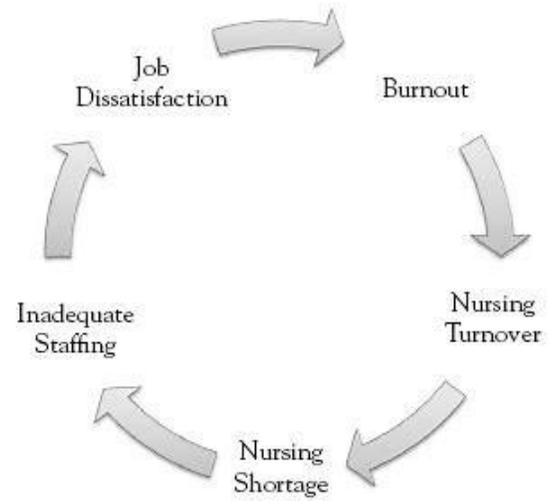
A further critical question relates to the development of research capacity, and there is an urgent need to consider how we prepare the next generation of researchers. The lack of senior academic appointments in palliative care both in the United Kingdom and across the EU, particularly at professional level, means that we risk losing the benefits that academic leadership brings – an opportunity to embed palliative care into curricula, access to a diverse range of funding streams, support for research development and, of course, inter- and cross-sectional collaboration. To be competitive in EU and International programme grants, cross-speciality collaboration is essential to meet the breadth of expertise these calls increasingly seek. As a discipline, we now need greater strategic academic leadership, one which embeds palliative care research as a career trajectory in its own right, rather than an addendum to clinical practice roles and functions. Developing strong

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

ONE WHICH REMEMBERS...



ONE WHICH LISTENS AND RESPONDS – TO SELF AND OTHERS

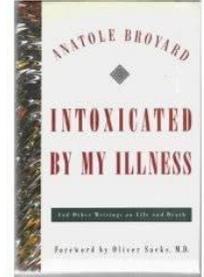


ONE WHICH CONTINUALLY SEEKS NEW HORIZONS



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.