A Global overview of palliative care since WHA resolution 2014

Scott A Murray, St Columba’s Hospice Chair
Primary Palliative Care Research Group, University of Edinburgh, Scotland, UK
http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/
WHA 2014: integration of palliative care all settings

• WHO office – special Technical Advisory group to advise on how best to integrate palliative care in all settings
• Xavier, Stephen and now Eric involved as leading MOs
• 2 documents awaited

• “Palliative care services: where to start. A practical guide”
• “Improving access to palliative care”
• Fact sheet re improving access to palliative care
• Little calling to account in 2016
2 other documents being co-edited by Xavier, Lucas, others

- **Basic principles of Palliative Care**
- **Building integrated palliative care programs and services**

- **Various challenges persist in the understanding of “integrated care”**
- **WHO Centers should be in the vanguard eg, Kerela, Barcelona, Kings, but there is none addressing integration**
country level responses

• The resolution has been great for advocacy
• Second African Health ministers conf 2016, Uganda
• Initiatives at Continent levels, Europe, America, Africa
• Initiatives in specific countries encouraged with support
• Learn about these today through presentation

Liz Grant

University of Edinburgh, UK
UN declaration on NCDs

• Need for member states to pursue comprehensive strengthening of health systems, including the importance of rehabilitation and palliative care

• SDG framework may be used for advocacy, even better than MDGs. Vocabulary compatible with palliative care
Let's face up to it, let's talk!
When well, when we get ill, when dying.
Good for families, for health service and for society.

WORLD MORTALITY RATE HOLDS STEADY AT 100%
Resources for Palliative Care

Please access the home page of the Primary palliative Care Research Group

http://www.ed.ac.uk/usher/primary-palliative-care

Please explore the site to understand the big issues in palliative care.

Please see http://www.ed.ac.uk/usher/primary-palliative-care/resources for learning resources

And http://www.ed.ac.uk/usher/primary-palliative-care/recent-publications for recent publications
PALLIATIVE CARE

5 key challenges to meet by 2020 the next decade

1. All illnesses
2. All times
3. All dimensions
4. All settings
5. All nations
LA GRANDE DANSE MACABRE

DES HOMMES ET DES FEMMES
• All conditions
Heart
doi:10.1136/heartjnl-2014-306724

Review

Future care planning: a first step to palliative care for all patients with advanced heart disease

M A Dervir, S A Murray, K J Boyd

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A “good death” with irreversible liver disease: Talking with patients and families about deteriorating health and dying

Kirsty Boyd M.B.Ch.B.(Hon.), F.R.C.P. (Edin.), M.Med.Sci.,
Barbara Kimbell Ph.D.,

First published: 28 July 2015   Full publication history
DOI: 10.1002/clld.479  View/save citation
Cited by: 0 articles   Check for new citations
Fig 2 Trajectory for severe acute brain injury—patients present with a crisis that may result in early death (often after a decision to withdraw life sustaining treatments) or survival with a high degree of disability.

Claire J Creutzfeldt et al. BMJ 2015;351:bmj.h3904
Multidimensional trajectories in frail older persons

Anna Lloyd PhD – Exploring the changing multidimensional experiences of frail older people towards the end of life, University of Edinburgh, 2015
Why do older people get less palliative care than younger people?

Anna Lloyd, Marilyn Kendall, Emma Carduff, Debbie Cavers, Barbara Kimbell and Scott A Murray have analysed data from four studies into the end-of-life experiences of people with glioma, bowel cancer, liver failure and frailty. They found that patients aged 70 and over received less palliative care. Why?

The WHO claims that older people suffer because of a lack of access to palliative care and has called for a palliative care approach to be adopted in their care.1 Across all conditions, people over the age of 85 are less likely to access palliative care than people below the age of 85.2 Evidence to have their preferences for place of death recorded, or to actually die there.9 We thus set out to explore access to palliative care, pain and symptom control, quality and experience of care, and actual and preferred place of death in older people compared with younger people.
“The Gay Gordon” (by Scotland’s Ceilidh Band)
“Tango Toscana” (by Quartet San Francisco)
DVORAK – “Two Waltzes, Op. 54” (by Musicians from Marlboro)
2 Early and late palliative care

Caring for people with organ failure: 3 stages

Stage 1 Physically well

Stage 2 Active supportive and palliative care

Stage 3 Terminal care

- Sentinel events
- Care Plan
- Gold standards Framework
- Last weeks or days Care
- Death

Time
Supportive & Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to identify people at risk of deteriorating and dying with one or more advanced conditions for palliative care needs assessment and care planning.

We find out about what is important to these people and their families, introduce timely supportive and palliative care that is integrated with other treatments, and discuss future care planning.
Improving access to palliative care using clinical indicators: SPICT™ downloads
Improving access to palliative care using clinical indicators: registered users

Current total: 3,345 members
### SPICT 2010

- Surprise question
- 2 or more admissions in 6/12
- Weight loss >10% in 6/12
- Lives in care home or needs care at home

- Specific tests - albumin, INR, PaO\(_{2m}\), lung function tests, eGFR

### SPICT 2016

- At risk of deteriorating and dying
- Unplanned admissions
- Significant weight loss; low BMI
- Any setting – dependent on others for care – physical and mental health problems
- More carer support needs
- Persistent symptoms despite optimal treatment of underlying condition(s)
- Person or family ask for palliative care, treatment withdrawal/limitation or a focus on quality of life.
- Any condition if limited reversibility
Improving access to palliative care using clinical indicators

SPICT-App

The SPICT™ Tool is now available as a free app on iOS for iPhone and iPad, and as an app for Android.

Download SPICT-App

- SPICT indicators
- Patient profiles
- Assessment & Care planning
- Talking with patients and families
We must deal with this empty space
Percentage of patients with a key information summary (KIS) and on GP palliative care register at death, and if so when the KIS or formal palliative care was started.
3. All dimensions

physical  psychological

social  spiritual

Grant E, Murray SA, Sheikh A. Spiritual dimensions of dying in different cultures. *BMJ* 2010;341:4859.
Dignity and Distress towards the End of Life across Four Non-Cancer Populations

Harvey Max Chochinov1,2‡*, Wendy Johnston3☯, Susan E. McClement2,4☯, Thomas F. Hack4☯, Brenden Dufault5☯, Murray Enns1☯, Genevieve Thompson2,4☯, Mike Harlos6☯, Ronald W. Damant7☯, Clare D. Ramsey8,9☯, Sara Davison10☯, James Zacharias9,11☯, Doris Milke12,13,14☯, David Strang15,16☯, Heather J. Campbell-Enns2,17☯, Maia S. Kredentser2,18☯
DOI:10.1371/journal.pone.0147607

Each of the study populations revealed unique and distinct patterns of physical, psychological and existential distress.
Multidimensional Trajectory of Organ failure

Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer J Pain Sympt Man 2007; 34: 393-402
Multidimensional trajectories in frail older persons

Change over time - years

Well being

Distress

Existential

Psychological

Social

Physical

Anna Lloyd PhD – Exploring the changing multidimensional experiences of frail older people towards the end of life, University of Edinburgh, 2015
Fig 1 Unmet spiritual need cycle may result in increased demand and service use.

"I think I have to be punished for the wrongs that I have done"

"Fear and dread come over you, it's a horrible feeling, absolute total fear because nobody wants to know when they are going to die"

(2) Spiritual distress

Patient recognising her own angst but feeling unable to address it or access help: "I think I more or less said to the doctor, well if you don’t come I say there’s an easier way"

(1) Unmet spiritual needs

(3) Increase in physical and emotional symptoms

"I feel down, like an emptiness in my stomach. I get this dead feeling in my stomach"

(4) Increase in use of health services

"I’m not really depressed and yet the doctors gave me antidepressants"

Grant L et al. BMJ 2010;341:bmj.c4859

©2010 by British Medical Journal Publishing Group
In one year at St Columba's Hospice...

1,145 patients used our services

34% of people staying in the inpatient unit were discharged to their homes, care homes or another care provider

The Day Services team welcomed 137 new patients

The Community Nurse Specialist Team visited 497 patients

The counselling team supported 156 patients and family members
Palliative care, a medical field that has been practiced informally for centuries, was recently granted formal specialty status by the American College of Physicians. Now that the value of palliative care has been appreciated and endorsed, the challenge is to develop a model of care that is accessible to all patients with serious illness. Such a model would entail a generalist plus specialist approach, where primary care providers deliver routine care and specialists offer interventions for complex problems. This perspective aims to outline the key components of a sustainable model for palliative care.
### Representative skill set for generalist and specialist palliative care

<table>
<thead>
<tr>
<th>Generalist palliative care</th>
<th>Specialist palliative care</th>
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</thead>
<tbody>
<tr>
<td><strong>Identification of cases</strong></td>
<td>• Management of refractory pain or other symptoms</td>
</tr>
<tr>
<td>• Basic management of pain and symptoms</td>
<td>• Management of more complex depression, anxiety, grief and existential distress</td>
</tr>
<tr>
<td>• Basic management of depression and anxiety</td>
<td>• Assistance with conflict resolution regarding goals or methods of treatment within families</td>
</tr>
<tr>
<td>• Basic discussions about: Prognosis Goals of treatment Suffering Planning for dying</td>
<td>• Between families and staff</td>
</tr>
<tr>
<td></td>
<td>• Among treatment teams</td>
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OUR VISION: A TEACHING/RESEARCH-BASED CARE HOME

This document sets out a vision for establishing a teaching/research-based care home in Lothian, Scotland.

THE VISION FOR TEACHING/RESEARCH-BASED CARE HOME

Our Vision

We aim to demonstrate high quality care, training and research to showcase excellence in the care home sector in order to change the overall perception of care homes, and to encourage a career pathway in the care of frail older people. The five core objectives are:

SERVICE PROVISION
To provide high quality, innovative care for frail older people requiring 24-hour care, including care for people with dementia and those at the end of life, in order to showcase expert holistic care.

KNOWLEDGE AND SKILL DEVELOPMENT
To develop greater knowledge, skill and expertise for staff in care homes through innovative training approaches in order to transform the care home culture. Such a focus would be extended to health and social care workers supporting frail older people in their own homes.

TRAINING OF UNDERGRADUATE/POSTGRADUATE STUDENTS
To provide a typical setting for multi-disciplinary training in chronic illnesses and multimorbidity for medical, nursing, social work students, and other health professions, including pharmacists, dieticians, speech and language therapists, dentists, physiotherapists, and occupational therapists in collaboration with local universities (Napier University, Queen Margaret University and the University of Edinburgh).

RESEARCH
To be a Centre for multi-disciplinary research, practice development and quality improvement programmes working in partnership with nearby universities and other sponsors, in collaboration with other care homes across the region.

COMMUNITY ENGAGEMENT
To be part of a local community, engaging with and enabling people to volunteer in care home work, to promote individual and carer resilience and offer support to families caring for frail older people living in care homes, at home, and including innovative respite care.
Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care

Scott A Murray¹, Adam Firth², Nils Schneider³, Bart Van den Eynden⁴, Xavier Gomez-Batiste⁵, Trine Brogaard⁶, Tiago Villanueva⁷, Jurgen Abela⁸, Steffen Eychmuller⁹, Geoffrey Mitchell¹⁰, Julia Downing¹¹,¹², Libby Sallnow¹³, Erik van Rijswijk¹⁴, Alan Barnard¹⁵, Marie Lynch¹⁶, Frederic Fogen¹⁷ and Sébastien Moine¹⁸
Countries with survey completed

- Albania
- Armenia
- Belgium
- Denmark
- Germany
- Ireland
- Malta
- Netherlands
- Portugal
- Serbia
- Switzerland
- UK
- Ukraine
- Spain
- France
- Luxembourg
- Norway
- Poland
- Sweden
- Norway
- Finland
- Ireland
- Greece
- Turkey
- Cyprus
- Malta
TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN THE COMMUNITY

PURPOSE OF THIS DOCUMENT

This resource is being developed by the EAPC in liaison with WONCA to help support and guide individuals and organisations in Europe and possibly worldwide seeking to further develop palliative care services in primary care settings. The principles outlined in the EAPC Prague Charter and particularly that access to palliative care as a human right underpins this work. In 2014 the WHO has recommended that palliative care should be integrated in primary care services, and this toolkit gives practical guidance on the steps required.

WHY IS DEVELOPING PALLIATIVE CARE IN THE COMMUNITY IMPORTANT?

More patients will benefit from palliative and end-of-life care if it is delivered in the community by Primary Healthcare Teams. For this to happen GPs and nurses working together in the community will require training and support by specialist palliative care teams. They will also need adequate time, financial and practical resources, and the ability to prescribe morphine when appropriate.

Primary Care has a unique position and potential to deliver effective palliative care to patients. It can:

• Reach patients with all life-threatening illnesses
• Start early in the course of life-threatening disease.
• Meet all dimensions of need: physical, social, psychological and spiritual
• Provide care in clinics, care homes and at home thus preventing unnecessary hospital admissions
• Support family carers and provide bereavement care
Brazil: time for palliative care in the community!

Brazil has a tremendous opportunity to integrate palliative care into its community healthcare services. Santiago Rodríguez Corrêa, Carla Mazuko, Mayara Floss, Geoffrey Mitchell and Scott A Murray describe the rationale behind, and opportunities for, developing primary palliative care in the country.
Developing palliative care in the community in Japan

**Funder:** Japan Student Services Organization  
**PhD candidate:** Ai Oishi. **Supervisors:** Scott Murray, Liz Grant

Primary care plays a central role in community health, and has potential to provide early and integrated palliative care for people with all diagnoses in the community. This research will describe the current extent that primary care and family physicians provide palliative care in the community to individual patients according to need. The potential role of the GP to also take a public health role will also be explored.
Integrating and strengthening palliative care in Africa

KENYA
We are partnering with hospitals in Nyeri, Homa Bay and Eldoret
MORE

UGANDA
We are partnering with hospitals in Gulu, Gombe and Kabale
MORE

ZAMBIA
We are partnering with hospitals in Lusaka, Mazabuka and Ndola
MORE

RWANDA
We are partnering with hospitals in Kigali, Rwamagana and Kibagabaga
MORE
‘We speak but it’s superficial’ Patients’ perspectives of doctor-patient communication: a serial qualitative interview study of patients’ living with advanced heart failure in Kenya

Kellen Kimani - PhD Researcher $^{1,2}$
Supervisors: Dr Liz Grant $^{2,3}$; Prof Scott A Murray $^{2}$

$^{1}$School of Public Health, University of Nairobi
$^{2}$Primary Palliative Care Research Group, University of Edinburgh
$^{3}$Global Health Academy, University of Edinburgh

K.N.Kimani@sms.ed.ac.uk
7 New public health (HPPC)

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Opioid overdose death epidemic sensationalised at the cost of pain patients

The impact of a new public health approach to end-of-life care

Libby Salnow is a clinician and doctoral researcher at St Joseph's Hospice, London, and the University of Edinburgh, Scotland, UK. Here, she explains the background to her longer research article selected as 'Editor's choice' in the March issue of Palliative Medicine.

Public health or community development approaches to health care have been practised since the 1980s. More recently, attention on them has increased as evidence has emerged of the power they have to influence a wide range of outcomes. These include wellbeing, mortality and health service usage. We have been relatively slow to harness the energy that these approaches bring in end-of-life care. This is despite the fact that many early palliative care services were formed by groups of committed volunteers, reflecting their interest to engage in a solution around better
Compassionate Neighbours

- Over 140 trained
- Waiting lists for training and matching
- 28 languages spoken by trainees
- 60 matched in community
- Monthly supervisions
- Weekly coffee mornings
- Newsletter
- Graduations
- Terminology
Schools are organising ‘death clubs’ to teach children how to manage their feelings

Kate Foster

CHILDREN as young as nine are being given school lessons about death in a radical scheme to help them cope better with bereavement.

School trips to hospices, class talks about dead relatives and even school “death clubs” are being trialled under the scheme.

The move has been launched to make children better equipped to cope when someone they know dies.

Experts say children have unmet needs around death and bereavement and that including the subject in schools will promote end-of-life and bereavement experiences to children.
Resources for Palliative Care

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Please explore the site to understand the big issues in palliative care.

Please see http://www.ed.ac.uk/usher/primary-palliative-care/resources for learning resources

And http://www.ed.ac.uk/usher/primary-palliative-care/recent-publications for recent publications
Transforming primary care

From a prescriptive contract to an enabling contract
I began to realize how important it was to be an enthusiast in life. If you are interested in something, no matter what it is, go at it full speed. Embrace it with both arms, hug it, love it and above all become passionate about it. Lukewarm is no good.

-Roald Dahl