

Palliative Care 2020

Towards integration of palliative care in an age-friendly EU

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Models for the organization of palliative care in patients with cancer and with dementia.

Steve Iliffe

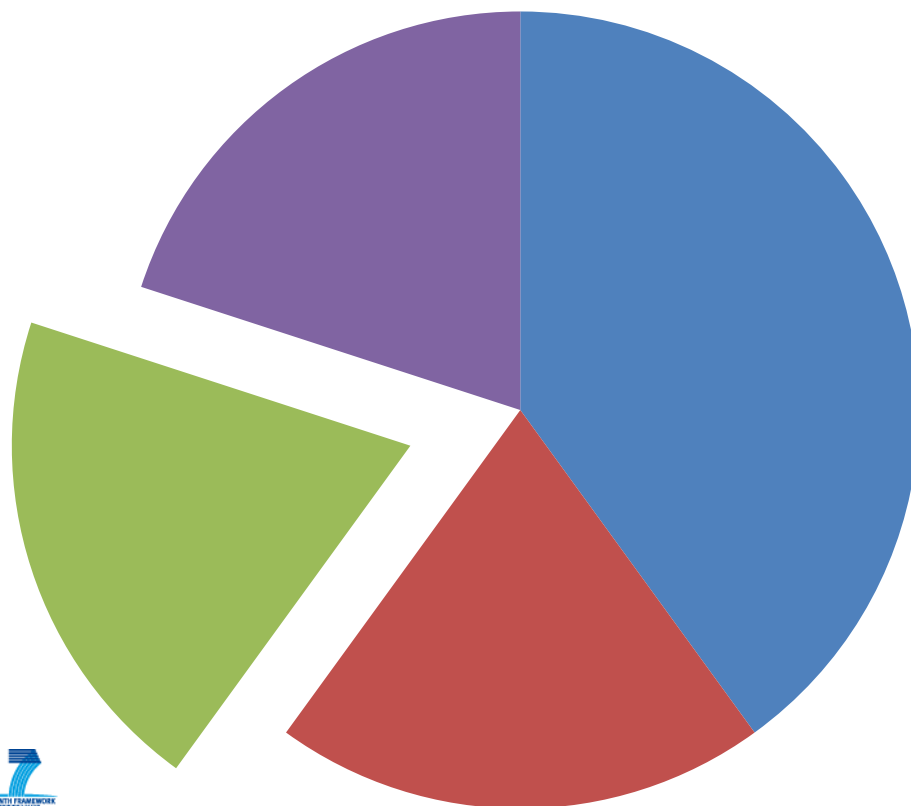
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On behalf of the IMPACT team

The IMPACT team

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- **London, England:** Steve Iliffe, Nathan Davies, Laura Maio, Mareeni Raymond, Jill Manthorpe, Peter Crome, Alex Warner, Sam Ahmedzai.
- Plus participants from Spain, Belgium, France and Poland

Background 1: Scale

Causes of death



- "progressive dwindling"
- Long term conditions
- Sudden death
- Cancer

Bowman C, Meyer J. Formative Care: Defining the purpose and clinical practice of care for the frail. *J R Soc Med.* 2014 Mar;107(3):95-8.

Background 2: Urgency

Survival time with dementia

Median 7.1 years with Alzheimer's dementia, 3.9 years with vascular dementia.

Fitzpatrick et al Survival following dementia onset: Alzheimer's disease and vascular dementia. J Neurological Sciences 2005; 15:229-30

4.5 years from symptom onset

Xie J et al Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. BMJ 2008; 336: 258- 262

3.5 years from diagnosis

Rait et al, Survival of people with clinical diagnosis of dementia in primary care: cohort study 2010 Aug 5;341:c3584.

Background 3: History

- Different ways to develop palliative care
- Hospice-based or hospital-based?
- Public-private funding mixes
- All IMPACT nation palliative care services are embedded in & integrated with national health care systems

Centeno C, et al EAPC Atlas of Palliative Care in Europe 2013 European Association for Palliative Care with The Universities of Navarra and Glasgow, 2013

Clark D, et al Common threads? Palliative care service developments in seven European countries Palliative Medicine 2000;14:479-490

Background 4: Problems

- Transfer of skills into community settings
- Expansion of specialist care to include 80% of deaths unlikely
- Specialisation in palliative care leads to great gains but also deskills generalists.
- Highly politicised clinical service, in some countries

Quill TE, Abernethy AP Generalist plus specialist palliative care – creating a more sustainable model. NEJM 2013; DOI:10.1056/NEJM1215620

welcome review of the pathway to death

By DAILY MAIL COMMENT

PUBLISHED: 22:15 GMT, 24 October 2012 | UPDATED: 07:36 GMT, 25 October 2012

Comments (14) | Share +1 0 | Tweet 0 | Like 3

Until now, the medical Establishment has contemptuously dismissed public disquiet over the Liverpool Care Pathway, the official guidelines under which patients judged to be dying are left without treatment, food or fluids.

In a hugely welcome change of approach, however, the Association of Palliative Medicine has ordered a review of the concerns expressed by countless bereaved relatives, with a promise to explore ways of improving practice.

Among those anxieties, one of the most oft repeated – highlighted in heartbreaking accounts to the Mail – is that loved ones have been put on the LCP without the consent or knowledge of their families.



HOW MAIL HIGHLIGHTED THE STORY

Two doctors must agree to use of 'death pathway'

The Mail, October 2

A LONELY DEATH ON THE 'CARE' PATHWAY

October 15

Police probe the death of mother on care pathway'

October 11

My diary of Mum's awful death on the Liverpool Care Pathway

October 20

Doctors to act on Care Pathway: After Mail campaign, investigation is launched into controversial guidelines on 'hastening death'

- Major review to be conducted by the Association for Palliative Medicine
- Inquiry will 'identify and explore concerns' over care for dying patients
- Growing fears that the system is a way of speeding up death of terminally ill
- System involves withdrawal of food and fluids as well as medical treatment

By STEVE DOUGHTY, SOCIAL AFFAIRS CORRESPONDENT

PUBLISHED: 21:58 GMT, 24 October 2012 | UPDATED: 22:20 GMT, 24 October 2012

Comments (206) | Share +1 0 | Tweet 44 | Like 200

A major review was announced last night into the Liverpool Care Pathway, the controversial 'end of life' treatment regime.

The Association for Palliative Medicine, which represents 1,000 doctors who work in hospices and specialist hospital wards, will 'identify and explore concerns' over the system of caring for patients in their final days.

The Mail has highlighted the growing fears of patients' relatives and many doctors that the care pathway is really a way of hastening the deaths of terminally ill patients.

Methods 1: Overview

Using quality indicators to improve the organization of palliative cancer and dementia care in Europe

- **Literature reviews** and **interviews**
- **Modelling** palliative care for people with dementia or with cancer
- Developing quality indicator sets (**technology development, co-design**)
- Field testing QIs in primary care, care homes, hospitals and hospices (**before and after study**)

Methods 2: Literature

Overview of reviews:

Raymond M et al Palliative and end of life care for people with dementia - lessons for clinical commissioners PHCR&D 2014; 15; 406-17

Raymond M et al Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. Dementia 2014 Jan 1;13(1):96-110.

Carers perspectives:

Davies N et al Quality end of life care for dementia: What have family carers told us so far? A narrative synthesis Palliative Medicine 2014; 28(7):919-930

Education for palliative care for people with dementia:

Raymond M et al Evaluating educational initiatives to improve palliative care for people with dementia: a narrative review Dementia 2014; 13(3): 364-379

European policies on palliative care for people with dementia: *ongoing*

Methods 3: Synthesis

Thematic analyses of interviews

Literature reviews

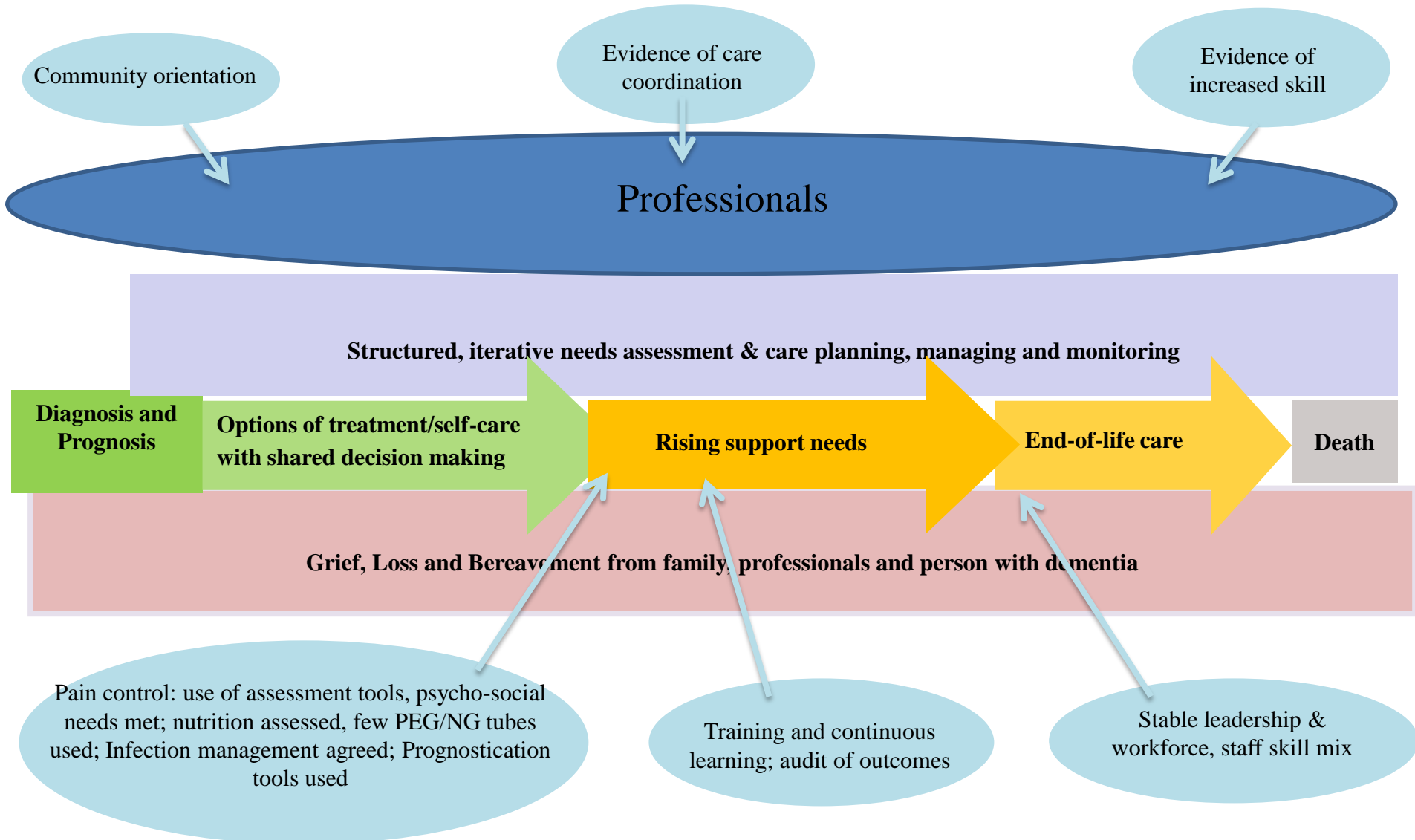
Consensus conference using **modified nominal group** techniques

Followed by a **modified Delphi process**

Iliffe S et al Modelling the landscape of palliative care for people with dementia: a European mixed methods study BMC Palliative Care 2013 Aug 12;12(1):30

Findings 1

Quality indicators of good palliative care related to process & structure



Findings 2: Key themes

- Division of labour/skill transfer
- Care planning/staff engagement – the example of the Liverpool Care pathway
- Management of risk & complexity/assessment skills
- Boundaries & transitions/prognostication
- Bereavement/dying well

Findings 3: Skill sharing

Easier for some countries than others?

- Extensive French community services allow outreach by palliative care (also Norway)
- Primary care gatekeepers (UK, Netherlands) have special obstacles to skill sharing
- Hospital-based specialist palliative care has disadvantages (Germany)

Policy options

- Focus first on nursing homes & home care services
- Reduce isolation from mainstream palliative care
- Embedded support or episodic in-reach?
- Adult learning, not training
- Communities of practice emerge before formal systems

Thank you for listening!
<http://www.impactpalliativecare.eu/>