

The Changing Context of Palliative Care

Regina Mc Quillan



'To cure sometimes, to relieve often, to comfort always'

Anon 16th century

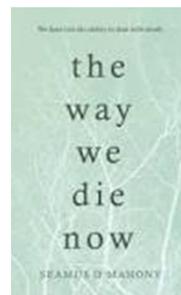


Rudolf Virchow



"Physicians are the natural attorneys of the poor, and social problems fall to a large extent within their jurisdiction."

Seamus O'Mahony



'narrative therapy' and 'dignity therapy' medicalize dying

Specialist Palliative Care

- Models of care delivery
- 'True' collaboration
- Challenges to become 'general' rather than 'oncology' palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care

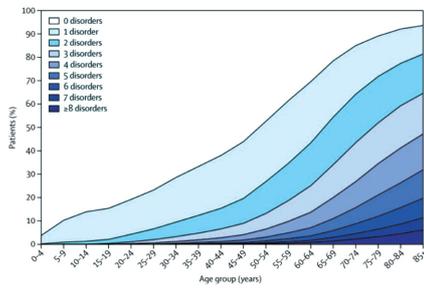


Patients

- Increased numbers
- Increased life-span
- Increased multimorbidity
- Patient-centred care
 - Autonomy
 - Advance care planning
 - Patient engagement- in service development, planning and delivery
 - Patient reported outcome measurement



Multimorbidity and Age

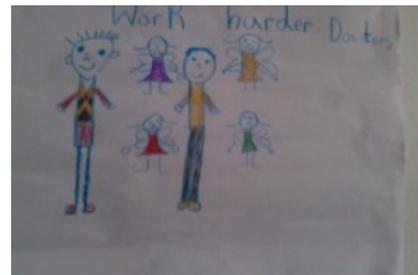


Human Resources



Local shortages

- GPs in north Dublin
- Nursing staff in Dublin
- Nursing home staff
- Community carers (home care packages)



Who is doing what and for whom?



Increased palliative care needs

- Based on routine mortality data
- 80% of deaths in Ireland are from chronic life-limiting illnesses
- Have palliative care needs

Kane et al 2014

Specialist palliative care workload

- Greater patient complexity
 - Multi-morbidity
 - Non-malignant
 - Increasing complexity of cancer care
 - new drugs – ‘ibs’
- Generalist support
 - Consult service
 - Formal education
 - Informal education

Specialist Palliative Care

- Models of care delivery
- ‘True’ collaboration
- Challenges to become ‘general’ rather than ‘oncology’ palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care

Generalist Palliative Care

- National Advisory Committee on Palliative Care (2001)
- Palliative Care Competency Framework National Clinical Programme for Palliative Care (2011)
- Palliative Care Needs Assessment Framework NCPPC (2015)

BMJ helping doctors make better decisions

Search | Latest content

Palliative care in chronic illness

We need to move from prognostic paralysis to active total care

Adopting patient centred supportive care: possible questions

- What's the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- If things got worse, where would you like to be cared for?

BMJ. 2005 March 19; 330(7492): 611–612. doi: [10.1136/bmj.330.7492.611](https://doi.org/10.1136/bmj.330.7492.611)
 PMID: PMC554893 [Scott A Murray](#), [Kirsty Boyd](#), [Aziz Sheikh](#),



The NEW ENGLAND JOURNAL of MEDICINE

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.
 N Engl J Med 2013; 368:1173-1175
[March 28, 2013](#) DOI: 10.1056/NEJMp1215620

Representative Skill Sets for Primary and Specialty Palliative Care.

- Primary Palliative Care**
 - Basic management of pain and symptoms
 - Basic management of depression and anxiety
 - Basic discussions about
 - Prognosis
 - Goals of treatment
 - Suffering
 - Code status
- Specialty Palliative Care**
 - Management of refractory pain or other symptoms
 - Management of more complex depression, anxiety, grief, and existential distress
 - Assistance with conflict resolution regarding goals or methods of treatment
 - Within families
 - Between staff and families
 - Among treatment teams
 - Assistance in addressing cases of near futility

Stroke

Palliative and End of Life Care in Stroke.

A Statement for Healthcare Professionals from the American Heart Association/American Stroke Association

Holloway et al, 2014 <http://stroke.ahajournals.org/content/45/6/1887>



Heart Failure

Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology



Tiny Jaarsma et al, www.escardio.org/static_file/Escardio/Subspecialty/HFA/documents/hfa-palliative-care-statement.pdf



American Thoracic Society
We help the world breathe PULMONARY • CRITICAL CARE • SLEEP

An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses

[Am J Respir Crit Care Med.](http://www.atsjournals.org/doi/10.1164/rccm.200605-587ST) 2008 Apr 15;177(8):912-27. doi: 10.1164/rccm.200605-587ST

Neurological Disease

Chronic and progressive neurological disease – EAPC 2016

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=0nu5V5-9q88%3D>

Palliative Care in Parkinson's Disease

<https://www.ucc.ie/en/parkinsonscare/guidelines/>

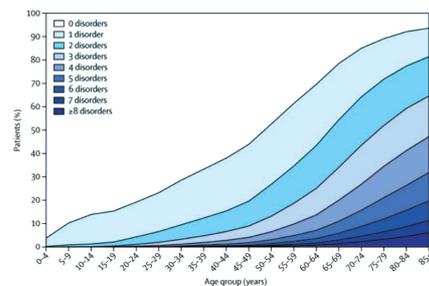


'Frailty'

- Frail
- Dementia
- Nursing home residents



Multimorbidity and Age



Long Term Care Settings

- Generalist
- Education
- Consultation



Challenges In Nursing Homes

- Workforce recruitment
- Workforce retention
- Education
- Organization culture
- Funding models
- Regulatory concerns



Nursing Home/Long Term Care

- Clements Ward, St Mary's Hospital
- Link nurse project, in partnership with local nursing homes (joint project with other hospices)
- Quality Improvement project in 3 HSE long stay settings
- Palliative care courses for staff caring for older people



National

- ECHO project – AllHPC, Our Lady's Hospice and 22 nursing homes
- Northwest – local higher education, specialist palliative care, nursing homes, based on Palliative Care Needs Assessment Tool.



Education and training to enhance end-of-life care for nursing home staff.

- Systematic review
- Education valued by staff
- Existing education programmes appear unlikely to improve outcomes
- Evidence of effectiveness not robust
- Need to design credible education programmes and evaluate effectiveness

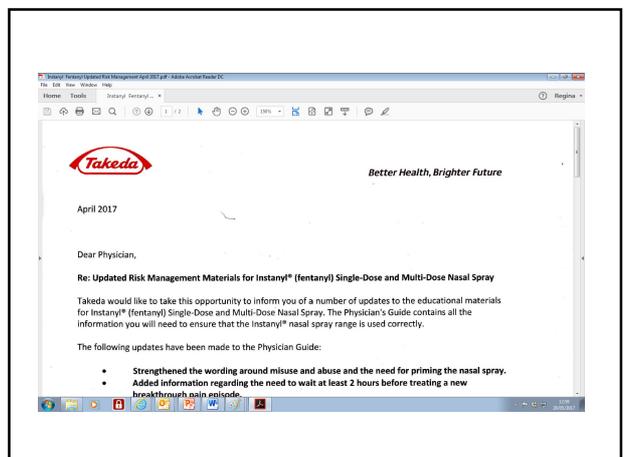
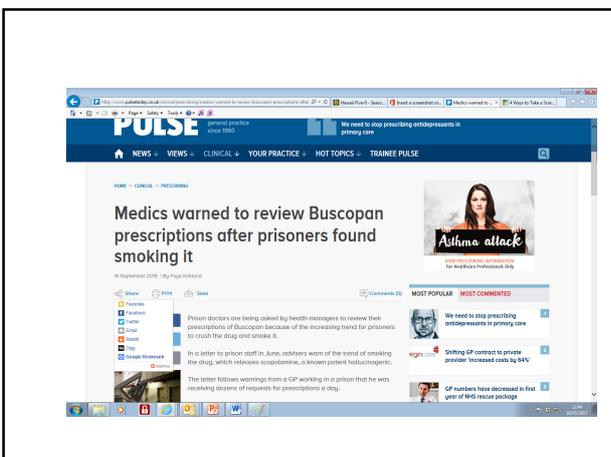
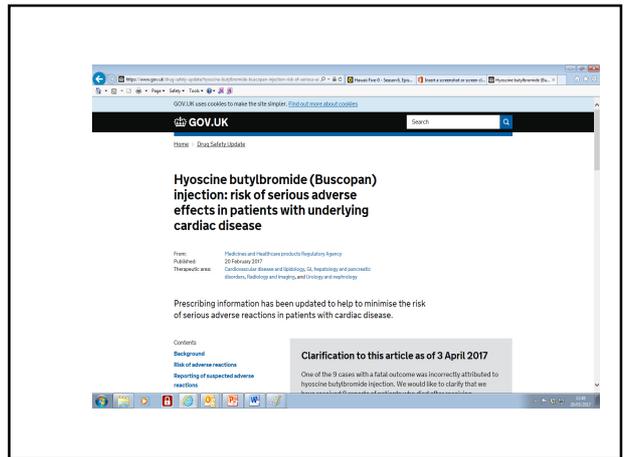
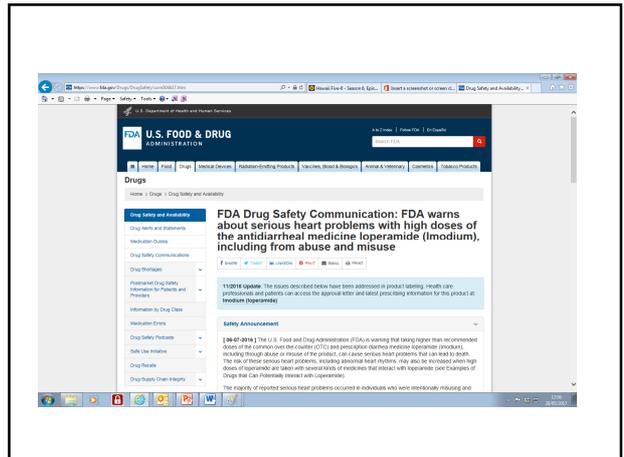
Anstey et al BMJ Pall and Supportive Care 2016



Specialist Palliative Care

- Models of care delivery
- 'True' collaboration
- Challenges to become 'general' rather than 'oncology' palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care





Opioids

- USA prescription of opioids has X4 since 2009
- Deaths from prescription opioids has X4
- 91 people die of opioid overdose every day
- CDC has issued guidance for the management of chronic benign pain; advise against using more than 90mg/day/morphine; advise against using more than 3 months

www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm#B1_down



Cannabis – A Trojan Horse?



- Drive to legalize
- Promoted as ‘anti-cancer’
- Lack of clarity about ‘cannabis oil’
 - If no THC, not illegal
 - If no THC, ?any effect

<http://www.irishtimes.com/life-and-style/health-family/can-cannabis-cure-cancer-the-proof-isn-t-out-there-1.3083541>

Challenges

- Use of licenced/unlicenced drugs
- Knowledge of drugs
- Awareness of risk/benefit
- ‘the man in Rush’



Repurposing Medications for Hospice/Palliative Care Symptom Control Is No Longer Sufficient: A Manifesto for Change

- 1) Access to symptom-control drugs in the WHO Essential Medicines list deserves support from national policies and professional guidelines.
- 2) The optimal use of currently available symptom-control drugs cannot yield acceptably high rates of net benefits.
- 3) There is a need to identify subgroups that are likely to benefit from available medications and provide rigorous empirical support for indications, dosing, and route of administration for clinical practice.
- 4) New therapies are needed requiring an accelerated effort to investigate the pathophysiology and pharmacogenetics of distressing symptoms.
- 5) Smarter ways to promote new knowledge into practice are needed. We need to improve clinical characterization and biomarker technology to bring the best drugs to the right patients every time.

Currow et al JPSM 2016



Rapid Pharmacovigilance in Palliative Care

A prospective observational study understanding the burden of adverse reactions and their symptoms at end of life.

RAPID has just started Macrogol study

paccsc@flinders.edu.au



Specialist Palliative Care

- Models of care delivery
- ‘True’ collaboration
- Challenges to become ‘general’ rather than ‘oncology’ palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care



Patient

- Increased numbers
- Increased life-span
- Increased multimorbidity
- Patient-centred care
 - Autonomy
 - Advance care planning
 - Patient engagement- in service development, planning and delivery
 - Patient reported outcome measurement



Patient centred care

- Patient needs and wishes for healthcare service configuration
- Patients and families different needs
- Patient and family research



Patient centred care

- Patient outcome measures



Patient centred care

- Patient outcome measures
- Patient reported outcome measures



Patient centred care

- Patient outcome measures
- Patient reported outcome measures
- Patient centred outcome measures



Patient centred care

- Patient outcome measures
- Patient reported outcome measures
- Patient centred outcome measures
- Failure of 'Pain as the Fifth Vital Sign'



Right to Try and Right to Die



Autonomy

Liberalism

- Classic liberalism – no interference from anyone, church, state, corporations. In USA, often called libertarian, and are 'right wing'
- Neo-liberalism – sees government as protection from other interference and are 'left wing'

Haindt, The Righteous Mind, 2012



Autonomy

- Both liberals and libertarians promote autonomy
- Left and right wing can support same ideas, for example, same sex marriage and assisted suicide



Autonomy

- Absolute?
- Rights of individuals in context of rights of society?
- Conscientious objection?



Autonomy

- Absolute?
- Rights of individuals in context of rights of society?
- Conscientious objection?
 - Not always recognized by law or ethicists
 - Recent court ruling in Sweden



Empathy

- Our biases
- Poor judgement
- See an individual, not a society

<http://www.irishtimes.com/life-and-style/health-family/empathy-is-for-the-long-haul-think-about-it-1.3086419>



Right to Try

- Promoted in USA by the Goldwater Institute
- Stories of dying children and heroic adults
- Drugs which have been through Phase 3 trials be made available for people with incurable or terminal illness
- Most states have passed laws



Right to Try

But

- 'false hope'
- Risks of harms
- Costs
- Recent FDA review – no 'additional' drugs available via this mechanism- all claimed 'new' drugs available in other programmes



Right to die



Autonomy-Right to Die

- Widely promoted in 'liberal' media
- Mainly illegal worldwide (most recently rejected in Maine and Tasmania in 2017)
- Rejected by High Court in Ireland – societal concerns



Dying with Dignity Bill 2015



- Incurable and progressive illness, likely to die from illness or complications
- Prescription for self-administration
- Administer by doctor or assisting health professional (a nurse)
- A 'medical procedure'

Specialist Palliative Care

- Models of care delivery
- 'True' collaboration
- Challenges to become 'general' rather than 'oncology' palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care



Culturally appropriate care



'Economist' World Ranking

- End of life healthcare environment
- Public awareness of palliative care
- Open doctor-patient communication
- DNAR policy



Common or Multiple Futures for End of Life Care around the World?

- Post-colonial
- Recognize plurality
- Different solutions

Zaman et al. SocSciMed 2016



Culturally appropriate care

- Delivered by healthcare professionals
- Patient/family needs
- Needs of others
- Professional responsibilities



'Economist' World Ranking

- Ireland rates highly
- But- The Economist supports assisted suicide- will we fall in rankings?



Specialist Palliative Care

- Models of care delivery
- 'True' collaboration
- Challenges to become 'general' rather than 'oncology' palliative care
- Challenges of new treatments in oncology, including bio-markers and more precision in treatment
- Challenge of early involvement
- Patient centred care
- Culturally appropriate care



Specialist Palliative Care

- Reflective practice
- Avoid the 'man in Rush'
- Engagement with consultation processes
- Engagement with research (see AIHPC priorities)



References

Kane PM, Davison BA, Ryan K, McQuillan R, Higginson IJ, Murtagh FEM, on behalf of BuildCARE, The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Nonmalignant Conditions, JPSM (2014)

[Palliat Med. 2015 Oct;29\(9\):861-2. Addition to transmucosal fentanyl: is it a cause for concern in cancer pain management? Cahill K¹, Shehab RM², Hassan A³, Lowrey A⁴, McQuillan B⁵.](https://pubmed.ncbi.nlm.nih.gov/25918612/)

http://www.ema.europa.eu/docs/en_GB/document_library/Briefing_material/2013/07/WC500146614.pdf

<http://www.gov.uk/drug-safety-update/hyoscine-butylbromide-buscopan-injection-risk-of-serious-adverse-effects-in-patients-with-undisclosed-cardiac-disease>

<https://www.fda.gov/oc/oc/safety/oc/safety/oc/s04657.htm>

http://www.ema.europa.eu/ema/index.jsp?url=pages/medicines/human/referrals/Domperidone-containing_medicines/human_referral_prac_000021.jsp&mid=WC0b01a05805c516f

<http://www.jpsmjournal.com/article/20885-392416131197-6/fulltext>

www.hse.ie/en/about/WhyHSE/InOurArea/WhatWeDo/PalliativeCareProgramme/

The Righteous Mind: Why Good People Are Divided by Politics and Religion, Moral

<http://www.irishtimes.com/life-and-style/health-family/empathy-is-for-the-long-haul-think-about-it-1.3086419>

