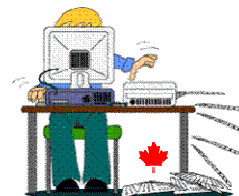


Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

27 May 2013 Edition | Issue #307



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Preferred place of death: Scroll down to [Specialist Publications](#) and 'Dying at home – is it better?: A narrative appraisal of the state of the science' (p.11), in *Palliative Medicine*.

Canada

Family battles Sunnybrook hospital over comatose man's right to live

ONTARIO | *Metro News* (Toronto) – 23 May 2013 – Joaquim Silva Rodrigues wants to live. It's what the 73-year-old Catholic man repeatedly told his family he wanted after he was diagnosed with a rare disease called progressive supranuclear palsy two years ago. It's what his wife and son have demanded on his behalf from his physicians at Sunnybrook Health Sciences Centre where he lies today, motionless and speechless. It's a position those physicians now challenge. On 14 May, they placed a note in Rodrigues's medical chart saying he has "no reasonable hope of recovery or improvement" and that they have decided to withhold mechanical ventilation in the event of a medical emergency requiring life-saving treatment. That change in status was made unilaterally, without the consent of his family. And that dispute has triggered the latest in a series of life-and-death conflicts between Sunnybrook physicians and patients. An ongoing [*Toronto Star*] investigation into end-of-life care in Canada has documented five previous disputes at Sunnybrook¹ – one currently before the Supreme Court of Canada – placing the hospital at the centre of a growing debate that has confounded the medical and legal communities, patients and their families. Rodrigues was diagnosed with progressive supranuclear palsy in the spring of 2010, his son and substitute decision-maker, Roger Rodrigues, told a three-member panel of the Consent & Capacity Board, a provincial body that mediates and issues rulings on end-of-life disputes.² <http://metronews.ca/news/toronto/682191/family-battles-sunnybrook-hospital-over-comatose-mans-right-to-live/>

1. Listing of *The Toronto Star* articles: <http://www.thestar.com/search.html?q=Hassan+Rasouli> Alternatively: <http://www.thestar.com/search.html?q=Consent+and+Capacity+Board%27>
2. *JOURNAL OF CRITICAL CARE*, 2013;28(1):22-27. 'Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario.' There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. The authors found substitute decision makers rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with [the Ontario] Health Care Consent Act. [Noted in Media Watch, 17 December 2012] <http://www.sciencedirect.com/science/article/pii/S0883944112003152>

N.B. News media coverage and commentaries in specialist publications in the fields of bioethics and medicine on the issue of consent and the withdrawal or withholding of life-sustaining treatment have been regularly noted in Media Watch.

U.S.A.

Creating a successful, sustainable structure for a national not-for-profit hospice provider

CARING FOUNDATIONS | Online – Accessed 21 May 2013 – It is time for a new model for community-based not-for-profit hospice providers. Caring Foundations is building a national not-for-profit organization with the goal of creating a national hospice and end-of-life care provider larger in size than any of the national chains – all of which are investor-owned companies. Today's two largest investor-owned hospice providers, Gentiva and Vitas, are themselves being challenged by a number of other investor-owned organizations that are expanding through an aggressive strategy of buying and merging smaller local and regional for-profit operators. In the next three to five years, Caring Foundations believes this strategy likely will result in the formation of an additional two to five large national hospice chains, all of which will be investor-owned companies, each of which will rival or exceed Gentiva and Vitas in size. That handful of players then will be poised to dominate the entire hospice field. Caring Foundations believes that, in such an environment, the sustainability of today's community-based, not-for-profit hospice provider model is unlikely. <http://caringfoundations.org/content/creating-successful-sustainable-structure-national-not-profit-hospice-provider>

Noted in Media Watch, 6 May 2013:

- *THE WASHINGTON TIMES* | Online – 2 May 2013 – **'Feds sue hospice chain for false Medicare claims.'** The Justice Department filed a lawsuit against the largest for-profit hospice chain in the U.S., charging the company knowingly submitted false claims for services not necessary, not actually provided or not performed in accordance with Medicare requirements. <http://www.washingtontimes.com/news/2013/may/2/feds-sue-hospice-chain-false-medicare-claims/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE HUFFINGTON POST* | Online – 22 May 2013 – **'Assisted suicide legalization supported by half of Americans, poll says.'** A new poll finds that a measure similar to the Vermont legislation would see more support than opposition.¹ 50% of Americans say that they think it should be legal for a doctor to assist a terminally ill patient in committing suicide if the patient requests it, while 29% said it should be illegal. The survey was conducted before the Vermont bill was signed into law. http://www.huffingtonpost.com/2013/05/22/assisted-suicide-legalization_n_3314849.html?utm_hp_ref=politics
 1. HuffPost/YouGov poll conducted 10-11 May 2013. http://big.assets.huffingtonpost.com/toplines_assistedsuicide_0510112013.pdf
- VERMONT PUBLIC RADIO | Online – 21 May 2013 – **'End-of-life bill signed, but physicians taking cautious approach in implementation.'** A bill allowing terminally ill patients to get medication to end their lives became law with Governor Peter Shumlin's signature. Although the law [the Patient Choice & Control at the End of Life Act] takes effect immediately, it may be some time before it's used. Doctors and hospitals say they're looking carefully at whether and how to participate. "There's a lot of work to be done between essentially the bill that we've got now and getting physicians to that point," said Dr. Phil Brown, vice president for medical affairs at the Central Vermont Medical Center in Berlin. Brown said hospital officials will consult with lawyers and the hospital's ethics committee before the institution decides how to proceed or even whether it will participate. <http://digital.vpr.net/post/end-life-bill-signed-physicians-taking-cautious-approach-implementation>

N.B. Vermont is the fourth state in the U.S. to make it legal for a physician to prescribe lethal medication for a terminally ill, mentally competent patient who wants to end his life. It is also the first state to approve the practice through legislation, instead of via a public referendum (as in Oregon and Washington) or a court decision (in Montana).

International

Kirk [Church of Scotland] investigates funeral costs

U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 25 May 2013 – The Church of Scotland is to investigate the spiralling cost of laying the dead to rest amid claims pensioners are being forced into choosing cremations because they are cheaper than traditional burials. It follows concerns some people are falling foul of a postcode lottery with funeral costs ranging from £1,000 in the Borders council area to £2,000 in South Lanarkshire. Higher costs have led to fears of an increase in the number of pauper's graves, with rising costs blamed on adding further pressure on council budgets. <http://www.heraldscotland.com/news/home-news/kirk-investigates-funeral-costs.21173122>

Noted in Media Watch, 28 January 2013:

- U.K. (ENGLAND) | *Yorkshire Evening Post* (Leeds) – 22 January 2013 – **'Pauper's funerals at record levels.'** Soaring funeral costs and the effects of the recession have left hundreds of families in Leeds unable to afford to give their loved ones a final farewell. <http://www.yorkshireeveningpost.co.uk/news/latest-news/top-stories/leeds-in-2013-pauper-s-funerals-at-record-levels-1-5340428>

Noted in Media Watch, 2 July 2012:

- U.K. | Dying Matters – Accessed 28 June 2012 – **'Paupers' funerals "set to rise."** The number of so-called "paupers" funerals' is set to rise in the as the disparity between the rising cost of funerals and the state contribution puts increasing pressure on an already stretched system. <http://www.dyingmatters.org/news/paupers-funerals-set-rise>

End-of-life care in Australia

Big cash injection for palliative care

AUSTRALIA (TASMANIA) | ABC News – 22 May 2013 – The Federal Government has announced what it says is the biggest ever injection of money into Tasmania's palliative care sector. It will make \$50 million available for palliative care providers over the next four years. The money is part of a \$325 million health package announced by the Commonwealth last year. The Mental Health & Ageing Minister, Mark Butler, says demand for end-of-life care is growing faster in Tasmania than elsewhere and the state's system is a test case for other jurisdictions. Mr. Butler says the funding will help services provide home-based care. <http://www.abc.net.au/news/2013-05-22/big-cash-injection-for-palliative-care/4706108>

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | *Daily Liberal* (Dubbo) – 24 May 2013 – **'Dying shame: Orange hospital to shift palliative care patients to Molong.'** In a shock announcement palliative care beds will be moved from Orange hospital to Molong, forcing family and friends of terminally ill patients to travel from Orange to be with their loved ones in their final days. <http://www.dailyliberal.com.au/story/1525140/dying-shame-orange-hospital-to-shift-palliative-care-patients-to-molong/?cs=112>
- AUSTRALIA (TASMANIA) | ABC News – 24 May 2013 – **'Rally urges return of palliative unit.'** The model being proposed by the Friends of Northern Hospice Group would see a 10-bed facility established on the grounds of the Launceston General Hospital. It has been six years since Launceston's only palliative hospice closed. <http://www.abc.net.au/news/2013-05-24/rally-urges-return-of-palliative-unit/4711296?section=tas>

Specialist Publications

'Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries' (p.10), in *Palliative Medicine*.

Elder care in the U.K.

Care cap becoming "irrelevant" as "crisis-mode" system excludes all but a few

U.K. | *The Daily Telegraph* – 21 May 2013 – The number of elderly people receiving help with their care has dropped by a fifth in just four years as cash-strapped councils have begun "rationing" support only to those at "crisis-point," a report by a leading think-tank shows.¹ Criteria for support have become so tight long-awaited Government reforms, including a cap on the amount people should have to spend on care, could become "irrelevant" because only those in most dire need would ever qualify. A total of 231,000 fewer elderly people are receiving help with their care than four years ago despite a surge in the numbers reaching old age. The report welcomes the reforms being implemented in the wake of the landmark Dilnot Commission to prevent people being forced to sell their homes.² But it warns that for many people, money is no longer the "primary concern" because they cannot even qualify for care until they are so frail that they can no longer live in their own home. It adds that, even with the Dilnot reforms, the care system is becoming "dysfunctional," something people only rely on as a last resort rather than a source of care. <http://www.telegraph.co.uk/health/elderhealth/10068789/Care-cap-becoming-irrelevant-as-crisis-mode-system-excludes-all-but-a-few-report-finds.html>

1. 'Paying for social care: Beyond Dilnot,' The King's Fund, May 2013. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_summary/social-care-funding-paper-may13.pdf
2. POLITICS U.K. | Online – 4 July 2011 – **'The middle England issue: Report aims to fix elderly care.'** Andrew Dilnot's report on elderly care argues that spending on people's care costs should be capped at £35,000, although it accepts any level between £25,000 and £50,000.¹ [Noted in Media Watch, 11 July 2011] <http://www.politics.co.uk/news/2011/07/04/the-middle-england-issue-report-aims-to-fix-e>
 1. *Fairer Care Funding*, Report of the Commission on Funding of Care & Support, July 2011. http://www.ilis.co.uk/uploaded_files/dilnot_report_the_future_of_funding_social_care_july_2011.pdf

How commissioners can ensure home care respects human rights

COMMUNITY CARE | Online – 23 May 2013 – Many home care service users are having their human rights breached because of disregard for their privacy or dignity, tasks not being carried out by staff because of lack of time and inadequate support to eat or drink. That was the conclusion of the Equality & Human Rights Commission's 2010-2011 inquiry into home care for older people.¹ The commission has published a guide for commissioners to ensure home care services pay for respect and promote human rights.² <http://www.communitycare.co.uk/articles/23/05/2013/119201/how-commissioners-can-ensure-home-care-respects-human.htm>

1. 'Close to home: An inquiry into older people and human rights in home care,' Equality & Human Rights Commission. [Noted in Media Watch, 28 November 2011] <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/close-to-home-report/>
2. 'Guidance on human rights for commissioners of home care,' Equality & Human Rights Commission. <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/guidance-on-human-rights-for-commissioners-of-home-care/>

Quotable Quotes

Where, after all, do universal human rights begin? In small places, close to home... Unless these rights have meaning there, they have little meaning anywhere. Eleanor Roosevelt (1884-1962)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (NEW SOUTH WALES) | ABC News – 23 May 2013 – '**Upper house votes down voluntary euthanasia bill.**' Legislation to allow voluntary euthanasia in New South Wales has been defeated in the state upper house. The Rights of the Terminally Ill bill ... would have let terminally ill people who still retain their decision making capacity request assistance to die. The bill was defeated 23 votes to 13. <http://www.abc.net.au/news/2013-05-23/upper-house-votes-down-voluntary-euthanasia-bill/4709020>
- IRELAND | *The Irish Post* – 20 May 2013 – The majority of Catholics want assisted suicide to be legalised, a major poll has found. The survey, carried out by YouGov for the Westminster Faith Debates, revealed that 56% of Catholics believe the law should be changed to give people with incurable diseases the right to ask a close friend or relative to help them commit suicide without facing prosecution. <http://www.irishpost.co.uk/news/majority-of-catholics-favour-assisted-dying>

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Vigils for the dying: Origin and functions of a persistent tradition

ILLNESS, CRISIS & LOSS, 2013;21(2):109-124. By viewing vigils for the dying as wake behavior, the different social conduct observed around vigils for the dying can be viewed more systematically and predictably. Vigils represent so much more than ways to manage loss and grief or to shore up support at a difficult time for the dying and their families. Vigils help establish the reality of death, protect and advocate for the dying person, and can express dissent and re-exert control over the circumstances of dying and death. The implications of these various social functions are discussed in relation to their conceptual limitations and implications for further empirical research. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,10;journal,1,74;linkingpublicationresults,1:103734,1>

Mercy Ship – a wave of healing

INTERNATIONAL MARITIME HEALTH, 2013;64(1):36-40. Mercy Ships is an international charity founded in 1978 as the maritime division of Youth With a Mission and operates as the largest non-governmental hospital ship in the world. The merchant vessel 'Africa Mercy' provides free health care, community development projects, community health education, agriculture projects, and palliative care for terminally ill patients. Manned by volunteers and equipped through donations Mercy Ships brings physical and spiritual healing to the poor and needy in port cities around the world. <http://czasopisma.viamedica.pl/imh/article/viewFile/34254/25086>

Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



The journey of discovering compassionate listening

JOURNAL OF HOLISTIC NURSING | Online – 17 May 2013 – This article presents the concept of "compassionate listening" in critical life moments to gain insight into the process of listening with compassion. This insight evolved through a process of layered reflection using a series of texts, particularly stories that captured critical moments in working with people who were facing crisis situations or who were dying. Writing and reflecting on these stories enabled the author to identify how he engaged with patients and their loved ones as a palliative care nurse specialist ... to explore how compassionate listening could be used to ascertain their needs, particularly when they were unable or unsure of how to proceed. <http://jhn.sagepub.com/content/early/2013/05/17/0898010113489376.abstract>

Quotable Quotes

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore ... most of us would rather forget our own vulnerability ... Listening is hard but it is also a fundamental moral act. Arthur Frank, *The Wounded Story Teller: Body, Illness and Ethics* (University of Chicago Press, 1995).

Of related interest:

- *ILLNESS, CRISIS & LOSS*, 2013;21(2):95-108. **'Hospital chaplains and embodied listening: Engaging with stories and the body in healthcare environments.'** This article illuminates how a largely overlooked group of healthcare professionals – hospital chaplains – engage in listening, along with what they perceive it means to listen well. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,10;journal,1,74;linkingpublicationresults,1:103734,1>

Health care in the U.K.

Culture, compassion and clinical neglect: Probity in the National Health Service after Mid Staffordshire

JOURNAL OF MEDICAL ETHICS | Online – 23 May 2013 – Speaking of the public response to the deaths of children at the Bristol Royal Infirmary before 2001, the *British Medical Journal* commented that the National Health Service (NHS) would be "all changed, changed utterly." Today, two inquiries into the Mid Staffordshire Foundation Trust suggest nothing changed at all.¹ Many patients died as a result of their care and the stories of indifference and neglect there are harrowing. Yet Bristol and Mid Staffordshire are not isolated reports. In 2011, the Health Services Ombudsman reported on the care of elderly and frail patients in the NHS and found a failure to recognise their humanity and individuality and to respond to them with sensitivity, compassion and professionalism.² Likewise, the Care Quality Commission and Healthcare Commission received complaints from patients and relatives about the quality of nursing care. These included patients not being fed, patients left in soiled bedding, poor hygiene practices, and general disregard for privacy and dignity. Why is there such tolerance of poor clinical standards? We need a better understanding of the circumstances that can lead to these outcomes and how best to respond to them. The authors discuss the findings of these and other reports and consider whether attention should be devoted to managing individual behaviour, or focus on the systemic influences which predispose hospital staff to behave in this way. They consider whether we should look further afield to cognitive psychology to better understand how clinicians and managers make decisions? <http://jme.bmj.com/content/early/2013/05/22/medethics-2012-101048.abstract>

1. 'Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013] <http://www.midstaffspublicinquiry.com/report>
2. *Care and Compassion?* Parliamentary & Health Service Ombudsman, February 2011. [Noted in Media Watch, 21 February 2011] <http://www.ombudsman.org.uk/about-us/media-centre/press-releases/2011/?a=6666>

The decisional capacity of the adolescent: An introduction to a critical reconsideration of the doctrine of the mature minor

JOURNAL OF MEDICINE & PHILOSOPHY, 2013;38(3):249-255. Do adolescents have the decisional capacity of adults? Or, are they in crucial ways still immature, that is, are they deficient decision makers? This question has been answered in quite different ways in medical versus criminal law. In medical law, an exception from the requirement of parental consent was crafted to allow adolescents to make decisions in restricted circumstances associated with quasi-medical emergencies. Over the last few decades, this exception has grown into an almost blanket acceptance of the decisional capacity of adolescents under the age of 18 and generally over the age of 14 to give valid consent to treatment. <http://jmp.oxfordjournals.org/content/38/3/249.extract>

Noted in Media Watch, 18 March 2013:

- *JAMA PEDIATRICS* | Online – 11 March 2013 – '**Tackling taboo topics: How to have effective advanced care planning discussions with adolescents and young adults with cancer.**' <http://archpedi.jamanetwork.com/article.aspx?articleid=1663077>
- *PEDIATRIC BLOOD & CANCER*, 2013;60(5):715-718. '**When silence is not golden: Engaging adolescents and young adults in discussions around end-of-life care choices.**' <http://onlinelibrary.wiley.com/doi/10.1002/pbc.24490/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 14 January 2013:

- U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | National Institute of Mental Health – 7 January 2013 – '**Guide offers a blueprint for end-of-life conversation with youth.**' <http://www.nimh.nih.gov/science-news/2013/guide-offers-a-blueprint-for-end-of-life-conversation-with-youth.shtml>

Family dynamics

End-of-life planning in a family context: Does relationship quality affect whether (and with whom) older adults plan?

JOURNALS OF GERONTOLOGY B SERIES: PSYCHOLOGICAL SCIENCES & SOCIAL SCIENCES | Online – 20 May 2013 – Medical professionals typically approach advance care planning (ACP) as an individual-level activity, yet family members also may play an integral role in making decisions about older adults' end-of-life care. [In this study] parents with problematic parent-child relationships were less likely to complete ACP, and marital satisfaction was positively associated with completion of both advance directives and discussions. Happily married persons were more likely to appoint their spouse as durable power of attorney for health, whereas persons who received ample emotional support from children were mostly likely to appoint an adult child. <http://psychsocgerontology.oxfordjournals.org/content/early/2013/05/20/geronb.gbt034.abstract>

Noted in Media Watch, 2 April 2012:

- REUTERS | Online – 28 March 2012 – '**Cancer docs often don't notice family discord.**' Doctors caring for lung cancer patients are often unaware when patients and their family caregivers disagree about the best course of treatment, according to a new study.¹ <http://www.reuters.com/article/2012/03/28/us-cancer-docs-idUSBRE82R1BR20120328>
 1. 'Oncologists' assessments of lung cancer patient and family disagreements regarding treatment decision making,' *Lung Cancer*, 8 March 2012. Oncologists were more successful in detecting absence of conflict than the presence of conflict. [http://www.lungcancerjournal.info/article/S0169-5002\(12\)00068-2/abstract](http://www.lungcancerjournal.info/article/S0169-5002(12)00068-2/abstract)

Cont.

Of related interest:

- *NURSING ETHICS* | Online – 23 May 2013 – '**Narrative analysis of the ethics in providing advance care planning.**' The authors' objective was to better understand the values and ethical dilemmas surrounding advance care planning through stories told by registered nurses and licensed social workers, who were employed as care managers within Area Agencies on Aging. The authors identified seven themes representative of their work with consumers and families: humility, respect, responsibilities, boundaries, empowerment, courage, and veracity. <http://nej.sagepub.com/content/early/2013/05/16/0969733013486795.abstract>
- *NURSING ETHICS* | Online – 23 May 2013 – "**Busyness" and the preclusion of quality palliative district nursing care.**' Ethical care is beginning to be recognised as care that accounts for the views of those at the receiving end of care. However, in the context of palliative and supportive district nursing care, the patients' and their carers' views are seldom heard. <http://nej.sagepub.com/content/early/2013/05/16/0969733013485109.abstract>

Palliative care for lung disease: Start early, stay late

THE LANCET RESPIRATORY MEDICINE | Online – 17 May 2013 – Palliative care ... should be the rule, not the exception. Medical care given to patients in the 21st century is advanced. Pharmaceutical companies use new techniques to develop drugs tailored to specific diseases. Likewise, surgical interventions involving robotics and laser technologies are used in intricate procedures, which save lives. Unfortunately, at the end of life when all reasonable curative interventions have failed, many patients with end-stage lung disease still die in pain after much suffering. [http://www.thelancet.com/journals/lanres/article/PIIS2213-2600\(13\)70083-3/fulltext#article_upsell](http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(13)70083-3/fulltext#article_upsell)

Noted in Media Watch, 10 December 2012:

- *EUROPEAN RESPIRATORY REVIEW*, 2012;21(126):347-354. '**Palliative care in COPD patients: Is it only an end-of-life issue?**' The presence of acute or chronic respiratory failure is often seen as a terminal phase of chronic obstructive pulmonary disease. A great variability in end-of-life practice is observed in these patients mainly because physicians are not always able to correctly predict survival. <http://err.ersjournals.com/content/21/126/347.abstract>
- *THORAX*, 2012;67(Suppl.):A166-A167 | Online – '**Death and the respiratory physician: Challenges to providing optimal end-of-life care by generalists.**' There is a pressing need for greater expertise in general palliative care amongst hospital doctors. Patients with COPD and other progressive respiratory conditions have extensive palliative care needs. http://thorax.bmj.com/content/67/Suppl_2/A166.2.abstract

Stability of cardiopulmonary resuscitation and do-not-resuscitate orders among long-term nursing home residents

MEDICAL CARE | Online – 16 May 2013 – High-quality care for long-term nursing home residents should include discussions and follow-up on patients' end-of-life care wishes. Yet, recent changes to the Minimum Data Set data collection exclude this information from routine assessment of patients mandated by the Centers for Medicare & Medicaid Services, making the provision of high-quality end-of-life care less likely. The authors examined the stability of cardiopulmonary resuscitation (CPR) and do-not-resuscitate (DNR) orders to offer guidance to policy and care practice developments. Long-term nursing home patients who enter with full-code CPR have a high probability of changing their status to DNR during their stay. High-quality care should offer them the opportunity to revisit their choice periodically, documenting changes in end-of-life choices when they occur, ensuring that care will match patients' wishes. As the Minimum Data Set plays a prominent role in patients' care, Centers for Medicare & Medicaid Services should consider reinstating information about advance directive in it. http://journals.lww.com/lww-medicalcare/Abstract/publishahead/Stability_of_Cardiopulmonary_Resuscitation_and.99284.aspx

End-of-life care in ICU

Care at the end of life: Room for improvement, ideas for change

MEDICAL NEWS TODAY (U.S.) | Online – 23 May 2013 – The decision to limit life support in patients in the intensive care unit (ICU) appears to be significantly influenced by physician practices and/or the culture of the hospital, suggests new findings from researchers at the Perelman School of Medicine at the University of Pennsylvania presented at the recent American Thoracic Society International Conference. A retrospective analysis of over 269,000 ICU patients from the Project IMPACT database revealed a substantial variation in decisions to forgo life-sustaining therapies rates among 153 ICUs in the U.S. – which suggests many factors unrelated to the patient or family may be affecting such decisions, particularly for patients who are unable to participate in decision making. "Patient factors such as severity of illness, age, race, and functional status explain a significant amount of the variability in decisions to forgo life-sustaining therapies, but it is likely that ICU culture and physician practices also play a major role," said Caroline M. Quill, a fellow in the department of Pulmonary, Allergy & Critical Care at Penn Medicine. "My sense is because patients in the ICU are often unable to participate in decision-making, the influence of providers and the ICU culture may be even greater than the patient or family preference." One in five Americans die during or shortly after an ICU stay, with many them dying following a decision to forgo life support. Though these decisions are common, the influences on these decisions are not well understood. <http://www.medicalnewstoday.com/releases/260840.php>

Noted in Media Watch, 13 May 2013:

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2013;22(3):263-266. **'Is dying in an ICU a sign of poor quality end-of-life care?'** The main reason given to support the argument that death in an ICU is poor quality end-of-life care is data that indicate home is the preferred site of death for many patients. <http://ajcc.aacnjournals.org/content/22/3/263.extract>

Noted in Media Watch, 1 April 2013:

- *CRITICAL CARE MEDICINE* | Online – 20 March 2013 – **'Hospital variation and temporal trends in palliative and end-of-life care in the ICU.'** In this retrospective cohort study of the authors found significant inter-hospital variation in ratings and delivery of palliative care, consistent with prior studies showing variation in intensity of care at the end of life.. http://journals.lww.com/ccmjournals/Abstract/publishahead/Hospital_Variation_and_Temporal_Trends_in.97882.aspx

End-of-life care in the U.K.

Hospice funding must reflect the number of deaths that occur there

NURSING TIMES (U.K.) | Online – 24 May 2013 – The government has again given charitable hospices in the U.K. money to improve their facilities, with 176 adult and children's hospices receiving 68% funding for projects already approved and under way. The rest must be found via the usual fundraising means. In effect, therefore, the government is subsidising planned capital improvement projects for which hospices have already budgeted. The emotional pull of the hospice movement, funded by the community, independent of the National health Service, is immensely strong in the U.K., but the number of people who die in hospices is relatively small when compared with those in other places: 4-6% overall and 16.4% of cancer deaths. The largest percentage of deaths from all diagnoses are still in hospital (51%) and at home (22%). Is this the wisest way to spend such a vast sum of money when clearly the largest need is elsewhere? <http://www.nursingtimes.net/nursing-practice/clinical-zones/end-of-life-and-palliative-care/hospice-funding-must-reflect-the-number-of-deaths-that-occur-there/5059061.article?blocktitle=Practice-comment&contentID=6854>

Cont.

Noted in Media Watch, 15 April 2013:

- U.K. | London 24 News – 10 April 2013 – **'London hospices receive share of £60million from government.'** Fourteen London hospices which provide end of life care for children and adults have been given a share of £60million to improve care environments and settings. http://www.london24.com/news/london_hospices_receive_share_of_60million_from_government_1_2013673

End-of-life care in the U.K.

Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries

PALLIATIVE MEDICINE | Online – 23 May 2013 – Health-care costs are growing, with little population-based data about people's priorities for end-of-life care, to guide service development and aid discussions. The authors examined variations in people's priorities for treatment, care and information across seven European countries [England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain]. In total, 9,344 individuals were interviewed. Most people chose "improve quality of life for the time they had left," ranging from 57% to 81%. Only 2-6% said extending life was most important, and 15% said quality and extension were equally important. Prioritising quality of life was associated with higher education in all countries, experience of caregiving or bereavement, prioritising pain/symptom control over having a positive attitude and preferring death in a hospice/palliative care unit. Those prioritising extending life had the highest home death preference of all groups. Health status did not affect priorities. Across all countries, extending life was prioritised by a minority, regardless of health status. Treatment and care needs to be reoriented with patient education and palliative care becoming mainstream for serious conditions such as cancer. <http://pmj.sagepub.com/content/early/2013/05/23/0269216313488989.abstract>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 21 May 2013 – **'How many people need palliative care? A study developing and comparing methods for population-based estimates.'** Understanding the need for palliative care is essential in planning services. Expert panel review [of all deaths in England, January 2006–December 2008] identified changing practice (e.g., extension of palliative care to more non-cancer conditions), changing patterns of hospital/home care and multiple, rather than single, causes of death as important. The authors refined methods to estimate a minimum of 63.03% of all deaths needing palliative care. <http://pmj.sagepub.com/content/early/2013/05/20/0269216313489367.abstract>

Development of a supportive care measure for economic evaluation of end-of-life care using qualitative methods

PALLIATIVE MEDICINE | Online – 22 May 2013 – An imperative to assess the economic impact of care at the end of life is emerging in response to national policy developments in a number of settings. Current focus on health benefits in economic evaluation may not appropriately capture benefits of interventions at the end of life. No instruments are available for measuring such benefits for economic evaluation of end-of-life care. Interviews [with study participants] suggested that the important domains to include within this framework from the perspective of those approaching the end-of-life are choice/having a say in decision-making, love and affection/being with people who care, freedom from physical suffering, freedom from emotional suffering, dignity and self-respect, support, and preparation. A full descriptive system comprising seven questions, each representing one attribute, was developed. Economic evaluation should reflect the broader benefits of end-of-life care. Although the supportive care measure developed here requires validation and valuation, it provides a substantial step forward in appropriate economic evaluation of end-of-life care. <http://pmj.sagepub.com/content/early/2013/05/22/0269216313489368.abstract>

Dying at home – is it better: A narrative appraisal of the state of the science

PALLIATIVE MEDICINE | Online – 22 May 2013 – Meeting patients' preferences and creating home-like environments has been a major concern for hospice and palliative care since its inception. During the 20th century, in many countries, hospital deaths increased and home deaths reduced. Despite the fact that this trend has been halted or reversed in some countries (notably the U.S., Canada and, more recently, the U.K.) in the last 5-20 years, a home death is still a distant reality for the majority, even though evidence shows it is the most commonly preferred place to die. Epidemiological studies identified factors associated with home death, including affluence, patients' preferences, provision of home care and extended family support. Evidence about the benefits of home care is conflicting, but recent data suggest that holistic well-being may be greater at home. The authors call for further analyses of variations in place of care and place of death and robust studies on how patients and families formulate and change preferences over time. Regular monitoring of outcomes, quality and costs of palliative home care is urged. <http://pmj.sagepub.com/content/early/2013/05/22/0269216313487940.abstract>

Of related interest:

- *BRITISH JOURNAL OF COMMUNITY NURSING*, 2013;18(5):258. '**Coordination in end-of-life care.**' While most people spend most of their last year of life at home cared for by their family and primary health professionals with occasional visits to hospital out-patient departments (National Audit Office, 2008), it seems that support is not optimal for all. Indeed, some people are admitted to hospital in the absence of sufficient support at home or where the lack of care coordination results in an overwhelming burden upon families and poor quality care in the home setting. <http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=98718>

Family caregiver learning – how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets

PALLIATIVE MEDICINE | Online – 21 May 2013 – Family caregivers learn through ... trial and error, actively seeking needed information and guidance, applying knowledge and skills from previous experience, and reflecting on their current experiences. Caregivers generally preferred and appreciated a supported or guided learning process that involved being shown or told by others, usually learning reactively after a crisis. Findings inform areas for research to identify effective, individualized programs and interventions to support positive learning experiences for family caregivers. <http://pmj.sagepub.com/content/early/2013/05/20/0269216313487765.abstract>

Noted in Media Watch, 20 May 2013:

- *PALLIATIVE MEDICINE* | Online – 13 May 2013 – '**Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study.**' The authors' findings support the inclusion of preparedness in support models for family caregivers in palliative care. <http://pmj.sagepub.com/content/early/2013/05/03/0269216313486954.abstract>

Noted in Media Watch, 17 December 2012:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 December 2012 – '**The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study.**' Family carers need to be supported in their central role of caring for patients at the end of life, but brief practical tools to assess their support needs have been missing. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00750-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00750-6/abstract)

Noted in Media Watch, 11 June 2012:

- *QUALITY HEALTH RESEARCH*, 2012;22(7):1007-1015. '**"It's like we're grasping at anything": Caregivers' education needs and preferred learning methods.**' Four categories of educational needs were identified: a) respite; b) caregiving essentials; c) self-care; and, d) the emotional aspects of caregiving. <http://qhr.sagepub.com/content/22/7/1007.abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *PAIN PRACTICE* | Online – 22 May 2-13 – 'Linguistic analysis of face-to-face interviews with patients with an explicit request for euthanasia, their closest relatives, and their attending physicians: The use of modal verbs in Dutch.' Linguistic analysis can help medical professionals to better understand their communicative skills, styles, and approach to patients in end-of-life situations. <http://onlinelibrary.wiley.com/doi/10.1111/papr.12076/abstract>

Worth Repeating

Funeral rites in the British deaf church: A case of disenfranchised grief?

JOURNAL OF CONTEMPORARY RELIGION, 2010;25(2):267-280. This article is based on material collected as part of a PhD thesis, undertaken at the Centre for Deaf Studies at the University of Bristol, which focuses on funeral customs in the British deaf community. A particular custom related to mourning in the deaf church is holding a religious memorial service for community members who have died, usually about a month after the funeral. This article explores why the memorial service has developed and why it continues to hold such an important place in the lives of this group of deaf people. It examines this religious ritual in relation to Kenneth Doka's concept of "disenfranchised grief" and suggests that the main reason for the importance of the memorial service to the deaf Community is the frequent exclusion of deaf mourners from full participation in funeral services.^{1,2} <http://www.tandfonline.com/doi/abs/10.1080/13537901003750951>

1. *Disenfranchised grief: Recognizing hidden sorrow.* (Massachusetts: Lexington Books, 1989)
2. *Disenfranchised grief: New directions, challenges, and strategies for practice.* (Illinois: Research Press, 2002)

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

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