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.*

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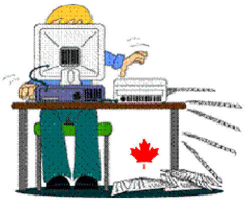

Compiled & Annotated by Barry R. Ashpole

Prognosis: Scroll down to Specialist Publications and 'International palliative care experts' view on phenomena indicating the last hours and days of life' (p.15), in *Supportive Care in Cancer.*

Canada

Half of terminal cancer patients die in hospital, report says

CBC NEWS | Online – 30 April 2013 – About half of deaths among terminal cancer patients in Canada happen in hospital. The Canadian Institute for Health Information [CIHI] looked at end-of-life care for people with cancer across the country, excluding Quebec. More than 25,000 people – or 45% of all cancer deaths – died in acute-care hospitals in 2011-2012, the institute said in its report.[1] "What our study found was a bit of a mismatch between where patients said they wanted to die, which was at home, and where they did spend their last days," said Kathleen Morris, the group's director of health system analysis and emerging issues. "Many of the lessons learned from this study extend to anyone at end of life. People are looking for a well co-ordinated system, to have consistent caregivers, to have their pain managed and to be provided with the support they need." The percentage of cancer patients who die in hospital ranges from 69% in Manitoba to 39% in British Columbia. http://www.cbc.ca/news/health/story/2013/04/30/cancer-palliative-care.html

Work needed to improve end-of-life care, report suggests

THE GLOBE & MAIL | Online – 30 April 2013 – One of the most positive aspects of the CIHI report is that there is little evidence of overtreatment at end-of-life for cancer patients. The data show that only 3% of patients received chemotherapy in their final two weeks of life and only 8% died in the intensive-care unit. But ... these numbers suggests the vast majority of terminal cancer patients are stable and their palliative care could be administered outside of the hospital. http://www.theglobeandmail.com/life/health-and-fitness/health/work-needed-to-improve-end-of-life-care-report-suggests/article11641870/

Noted in Media Watch, 21 March 2011:

JOURNAL OF CLINICAL ONCOLOGY | Online – 14 March 2011 – **'Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada'** Among 227,161 patients, 22.4% experienced at least one incident of potentially aggressive end of life care. Analyses showed with each successive year, patients were significantly more likely to encounter some [form of] aggressive intervention. http://jco.ascopubs.org/content/early/2011/03/14/JCO.2010.31.9897.abstract

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1. 'End of Life Hospital Care for Cancer Patients,' Canadian Institute for Health Information, April 2013. https://secure.cihi.ca/free_products/Cancer_Report_EN_web_April2013.pdf

Cont.

Representative sample of recent articles on preferred place of death:

Noted in Media Watch, 25 February 2013:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 February 2013 – **'The preferred place of last days: Results of a representative population-based public survey.'** This survey revealed 70.8% [of Albertans] preferred to be at home near death; while 14.7% preferred a hospice/palliative care facility, 7.0% a hospital, and 1.7% a nursing home; 5.7% had no stated preference. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0262

Noted in Media Watch, 2 November 2011:

- *BMC PALLIATIVE CARE* | Online – 4 November 2011 – **'Documentation of end-of-life care and preferred place to die discussions in the final weeks of life.'** While there was evidence discussions relating to end of life care and preferred place to die had taken place in around half of the audited case notes, there appeared a lack of a systematic approach to the recording of discussions with patients or carers about these kinds of issues.http://www.biomedcentral.com/content/pdf/1472-684x-10-18.pdf

Noted In Media Watch, 17 January 2011:

- *PALLIATIVE MEDICINE* | Online – 12 January 2011 – **'Achieving the preferred place of care for hospitalized patients at the end of life.'** Data highlights the need to distinguish between preferred place of care and preferred place of death. Patients' wishes regarding PPC change as death approaches. A greater number of patients wished to die in hospital than was expected.http://pmj.sagepub.com/content/early/2010/12/01/0269216310387459.abstract

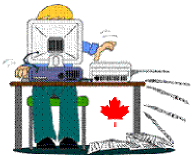
Specialist Publications

'Determinants of place of death: A population-based [in British Columbia] retrospective cohort study' (p.9), in *BMC Palliative Care.*

Of related interest:

'Toward a population-based approach to end-of-life care surveillance in Canada: Initial efforts and lessons' (p.12), in *Journal of Palliative Care.*

'A population-based study on advance directive completion and completion intention among citizens of the western Canadian province of Alberta' (p.12), in *Journal of Palliative Care.*



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

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch

U.S.A.

The cancer of optimism

THE NEW YORK TIMES | Online OpEd – 4 May 2013 – Physicians are thought to be the harbingers of bad tidings, the people who use cold words like "prognosis." But studies show that they are just as capable of emotions as their patients are. According to a study in 2000 ... about two-thirds of doctors overestimate the survival of terminally ill patients.[1] A study ... a year later found that many doctors didn't quite tell patients the truth about their prognosis.[2] Doctors were up front about their patient's estimated survival 37% of the time; refused to give an estimate 23% of the time; and, told patients something else 40% of the time. Around 70% of the discrepant estimates were overly optimistic. This optimism is far from harmless. It drives doctors to endorse treatments that most likely won't save patients' lives, but may cause them unnecessary suffering and inch their families towards medical bankruptcy. Studies have shown patients almost universally prefer to be told the truth. If physicians cannot deliver the hard facts, not only do they deprive their patients of crucial information, but they also delay the conversation about introducing palliative care. http://www.nytimes.com/2013/05/05/opinion/sunday/the-cancer-of-optimism.html?pagewanted=all&_r=0

Specialist Publications

'Palliative and end-of-life care: Where are we now?' (p.8), in *American Journal of Nursing.*

Of related interest:

'Dismissing the immortality myth: Improving care and incidentally reducing costs' (p.9), in *American Journal of Medicine.*

'Palliative care misunderstandings "astonishingly high"' (p.9), in *Clinical Oncology*.

'Lower costs documented in hospitals with palliative care programs' (p.9), in *Family Practice News.*

'Making the case for palliative care' (p.9), in *Physicians Weekly.*

1. 'Extent and determinants of error in doctors' prognoses in terminally ill patients: Prospective cohort study,' *British Medical Journal*, 19 February 2000. http://www.bmj.com/content/320/7233/469

2. 'Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death,' *Annals of Internal Medicine*, 2001;161(6):868-874. http://archinte.jamanetwork.com/article.aspx?articleid=647723

For-profit hospice

Feds sue hospice chain for false Medicare claims

THE WASHINGTON TIMES | Online – 2 May 2013 – The Justice Department filed a lawsuit against the largest for-profit hospice chain in the U.S., charging that the company knowingly submitted false claims to Medicare for services that were not necessary, not actually provided or not performed in accordance with Medicare requirements. The government's complaint alleges that Chemed and Vitas Hospice set goals for the number of crisis care days that were to be billed to Medicare and used aggressive marketing tactics and pressured staff to increase the numbers of crisis care claims submitted to Medicare, without regard to whether the services were appropriate or were actually being provided. The complaint contends that Vitas billed three straight days of crisis care for one patient, even though the patient's medical records do not indicate the patient required crisis care and show that the patient was playing bingo part of the time. http://www.washingtontimes.com/news/2013/may/2/feds-sue-hospice-chain-false-medicare-claims/

Cont.

Representative sample of recent articles on for-profit hospice:

Noted in Media Watch, 11 June 2012:

- *HEALTH AFFAIRS*, 2012;31(6):1286-1293. **'U.S. hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status.'** In this longitudinal study, the authors found one-fifth of Medicare-certified hospices active in 1999 had closed or withdrawn from the program by 2009, and more than 40% had experienced one or more changes in ownership. The most prominent trend was the shift in ownership type from non-profit to for-profit ownership. http://content.healthaffairs.org/content/31/6/1286.abstract

Noted in Media Watch, 16 April 2012:

- FLORIDA | *Palm Beach Post* – 14 April 2012 – **'Hospice profits raise questions about Medicare volunteer rule.'** Volunteers sometimes help for-profit hospitals and other businesses, but hospice is unique. It is the only service that requires volunteers to provide at least 5% of the hours spent caring for patients in order to qualify for Medicare payments. http://www.palmbeachpost.com/health/hospice-profits-raise-questions-about-medicare-volunteer-rule-2305341.html

Noted in Media Watch, 6 February 2012:

- *CONNECTICUT POST* | Online – 3 February 2012 – **'Should shareholder concerns govern end-of-life care?'** The proliferation of for-profit hospices ... has turned the hospice marketplace into a $14 billion growth industry with over 18,000 for-profit hospice providers. Having shareholders thrust into the patient-care equation creates conflicts of interest when it comes to how those profits are made. http://www.ctpost.com/news/article/Should-shareholder-concerns-govern-end-of-life-2999642.php

- *MCKNIGHT'S LONG-TERM CARE NEWS & ASSISTED LIVING* | Online – 2 February 2012 – **'Marketing by hospices to be focus of federal investigation.'** Once a little-known component of the healthcare sector, hospice care has blossomed into a $14 billion industry. But, some critics are taking issue with the way such growth has been achieved. http://www.mcknights.com/marketing-by-hospices-to-be-focus-of-federal-investigation/article/225053/

Noted in Media Watch, 30 January 2012:

- FLORIDA | *Palm Beach Post* (OpEd) – 22 January 2012 – **'Take the profit out of dying.'** In 2006, when the Legislature and then-Governor Jeb Bush allowed for-profit hospices to operate in Florida, this paper predicted that the move would undermine the successful hospice model. Six years later, it has done exactly that. http://www.palmbeachpost.com/opinion/editorials/take-the-profit-out-of-dying-2118554.html

Compassionate release program mismanagement has let federal prisoners die waiting, report finds

HUFFINGTON POST | Online – 1 May 2013 – Mismanagement of the Bureau of Prisons' compassionate release program has resulted in terminally ill inmates dying before their requests for release could be approved, according to a Justice Department Inspector General report.[1] Between 2006-2011, 28 terminally ill inmates died before the Bureau director had decided on requests that had already been approved by a warden or regional director. The report, released by Inspector General Michael E. Horowitz, found that the program was "inconsistently" implemented. http://www.huffingtonpost.com/2013/05/01/compassionate-release-program_n_3192650.html?utm_hp_ref=politics

1. 'The Federal Bureau of Prisons' Compassionate Release Program,' U.S. Department of Justice Office of the Inspector General, April 2013. http://www.justice.gov/oig/reports/2013/e1306.pdf

Deathbed singers, threshold choirs, grow to comfort sick and dying

HUFFINGTON POST | Online – 1 May 2013 – Death used to happen solely at home or in a hospital, with company limited to family, close friends and clergy. Solemn music would be reserved, perhaps, for the funeral. But as the options for the end of life have grown to include hospice, palliative care and other avenues that recognize not only physical but also emotional and spiritual well-being, Ellen Synakowski and like-minded volunteers are offering another service to the dying... http://www.huffingtonpost.com/2013/05/02/deathbed-singers-threshold-choirs-death_n_3187291.html?utm_hp_ref=religion

End-of-life care in California: You don't always get what you want

CALIFORNIA HEALTHCARE FOUNDATION | Online – April 2013 – Research on end-of-life care in California from 2003 to 2010 found wide variation from region to region and hospital to hospital. And patients did not always get the care they preferred. This report documents research on end-of-life care for Medicare beneficiaries, and analyses it in light of what is known about Californian's preferences for care as they approach death. The research found sharp variation that cannot be explained by differences among patients in age, sex, or race. In general, the overall intensity of the care rose; dying patients in the hospital had many more physician visits on average, and they spent more days in an intensive care unit. http://www.chcf.org/Publications/2013/04/EOL-What-You-Want/

International

Elder care in Ireland

Health chiefs insist mass care home closures are not a done deal

U.K. (NORTHERN IRELAND) | *The Belfast Telegraph* – 1 May 2013 – The two men at the centre of the controversy over the mass closure of residential care homes across Northern Ireland have insisted the radical proposals are not a done deal. In an apparent rebuff to health trusts planning to shut all the facilities under their control, Health Minister Edwin Poots has insisted that it will be up to him alone to rubber-stamp any action. And the man who drew up the radical plans to revamp Northern Ireland's health service, John Compton, denied allegations from Stormont's Health Committee that those pushing the scheme had "moved the goalposts." The plans are part of a wide-ranging reform of elderly care provision across Northern Ireland. The Transforming Your Care programme – headed up by Mr. Compton, chief executive of the Health & Social Care Board – was endorsed by Mr. Poots, who said 50% of residential care homes in Northern Ireland can expect to close. http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/health-chiefs-insist-mass-care-home-closures-are-not-a-done-deal-29236470.html

Noted in Media Watch, 29 April 2013:

- U.K. (NORTHERN IRELAND) | *The Belfast Telegraph* – 26 April 2013 – **'Trust to shut all elderly care homes.'** The Northern Health & Social Care Trust has confirmed speculation that it would be stopping the provision of all residential care services in the long-term. http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/trust-to-shut-all-elderly-care-homes-29222095.html

Terminally ill hit by new benefit rule

U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 29 April 2013 – A charity has called for Motor Neurone Disease [MND] sufferers to be exempted from fitness-to-work tests being carried out on behalf of the Department for Work & Pensions. Around 130 Scots a year are diagnosed with MND, but only 400 are alive at any one time, as the disease is a terminal neurological illness. Sufferers usually quickly become severely disabled due to debilitating symptoms and have an average life expectancy of 14 months after diagnosis. But, unlike terminal cancer patients, those with the condition are not exempt from medical testing for fitness to work under the Government's welfare reforms. Until the recent shake-up of the benefits system, MND sufferers had been automatically awarded Incapacity Benefit. http://www.heraldscotland.com/news/health/terminally-ill-hit-by-new-benefit-rule.20926752

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (NEW SOUTH WALES) | *Big Pond News* – 2 May 2013 – **'MPs to debate "right to die."'** Members of the state government and opposition are expected to get a conscience vote on the ["right to die"] issue, making it more likely the laws will pass. The bill will be debated in parliament next week. The Northern Territory became the first place in Australia to legalise euthanasia in 1995 but it was overturned a short time later by the commonwealth. http://bigpondnews.com/articles/Politics/2013/05/02/NSW_MPs_to_debate_right_to_die_868831.html

- U.K. | *The Daily Telegraph* – 30 April 2013 – **'National Health Service fears fuelling support for assisted suicide, poll suggests.'** Fears about standards care for terminally ill people are fuelling support for the legalisation of assisted suicide, a study suggests.[1] More than a third of those who said they support a change in the law cited a belief dying people cannot expect to receive "decent" care at the end of their lives among their reasons. And while a conviction that people in the 21st century should have a "right to choose" how and when they die dominated the thinking of supporters of assisted dying, only a minority of opponents cited traditional arguments based on life being "sacred." The findings emerge from detailed polling of more than 4,000 people by YouGov on behalf of the organisers of the regular Westminster Faith Debates. http://www.telegraph.co.uk/health/healthnews/10026314/NHS-fears-fuelling-support-for-assisted-suicide-poll-suggests.html

  1. 'Should we legislate to permit assisted dying?' Westminster Faith Debate, April 2013. http://www.religionandsociety.org.uk/events/programme_events/show/press_release_westminster_faith_debate_6_should_we_legislate_to_permit_assisted_dying

- IRELAND | *The Independent* (Dublin) – 29 April 2013 – **'Marie Fleming loses Supreme Court right-to-die case.'** A woman in the final stages of Multiple Sclerosis has lost her landmark challenge to Ireland's legal ban on assisted suicide. A full, seven-judge Supreme Court gave its ruling in the so called "right to die" action brought by Ms. [Marie] Fleming who wants to be helped to end her life at a time of her choosing. Chief Justice Susan Denham said that there is no constitutional right to commit suicide or to arrange for the termination of one's life at the time of their own choosing. Judge Denham added that there was nothing in the judgment to prevent the State from introducing legislative measures, with appropriate safeguards, to deal with cases such as Ms. Flemings. http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html

  N.B. Supreme Court ruling in *Fleming vs. Attorney General and the Director of Public Prosecutions*.http://www.supremecourt.ie/Judgments.nsf/1b0757edc371032e802572ea0061450e/94ff4efe25ba9b4280257b5c003eea73?OpenDocument

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

Nudging and informed consent

AMERICAN JOURNAL OF BIOETHICS | Online – 3 May 2013 – Libertarian paternalism's notion of "nudging" refers to steering individual decision making so as to make choosers better off without breaching their free choice. If successful, this may offer an ideal synthesis between the duty to respect patient autonomy and that of beneficence, which at times favors paternalistic influence. A growing body of literature attempts to assess the merits of nudging in health care. However, this literature deals almost exclusively with health policy, while the question of the potential benefit of nudging for the practice of informed consent has escaped systematic analysis. This article focuses on this question. While it concedes that nudging could amount to improper exploitation of cognitive weaknesses, it defends the practice of nudging in a wide range of other conditions. http://www.tandfonline.com/doi/abs/10.1080/15265161.2013.781704

N.B. This issue of the journal includes several articles on the issue of informed consent. Contents page: http://www.tandfonline.com/toc/uajb20/current

Of related interest:

- *GERIATRIC MENTAL HEALTH CARE* | Online – 23 April 2013 – **'End of one's life – decision making between autonomy and uncertainty.'** At the end of life in western medicine often a decision has to be made about treatment options and the therapeutic strategy. The concept of autonomy ... is a significant role in the decision-making process. Competing issues can be involved in end-of-life decisions and the patient and his/her relatives are often overwhelmed by the situation. http://www.sciencedirect.com/science/article/pii/S2212969313000165

2013 Alzheimer's disease [U.S.] facts and figures

ALZHEIMER'S & DEMENTIA, 2013;9(2):208-245. An estimated 5.2 million Americans have Alzheimer's disease (AD). Approximately 200,000 people younger than 65 years with AD comprise the younger onset AD population; 5 million comprise the older onset AD population. Throughout the coming decades, the baby boom generation is projected to add about 10 million to the total number of people in the U.S. with AD. AD is the sixth leading cause of death in the U.S. and the fifth leading cause of death in Americans age 65 years or older. Between 2000 and 2010, the proportion of deaths resulting from heart disease, stroke, and prostate cancer decreased 16%, 23%, and 8%, respectively, whereas the proportion resulting from AD increased 68%. A projected 450,000 older Americans with AD will die in 2013, and a large proportion will die as a result of complications of AD. http://www.alzheimersanddementia.com/article/S1552-5260(13)00076-9/fulltext#abstract

Alzheimer's disease facts and figures

Use and costs of hospice care

Medicare is the primary source of payment for hospice care, but private insurance, Medicaid, and other sources also pay for hospice care. In 2009, 6% of all people admitted to hospices in the U.S. had a primary hospice diagnosis of AD (61,146 people). An additional 11% of all people admitted to hospices in the U.S. had a primary hospice diagnosis of non-AD dementia (119,872 people). Hospice length of stay has increased during the past decade. The average length of stay for hospice beneficiaries with a primary hospice diagnosis of AD increased from 67 days in 1998 to 106 days in 2009. The average length of stay for hospice beneficiaries with a primary diagnosis of non-AD dementia increased from 57 days in 1998 to 92 days in 2009. Average per-person hospice care payments across all beneficiaries with AD and other dementias were 10 times as great as average per-person payments for all other Medicare beneficiaries ($1821/person compared with $178/person).

Cont.

Noted in Media Watch, 25 March 2013:

- U.S. | National Public Radio – 19 March 2013 – **'Alzheimer's 'epidemic' now a deadlier threat to elderly.'** Alzheimer's disease is now the sixth leading cause of death in the U.S., and figures released by the Alzheimer's Association show that deaths from the disease increased by 68% between 2000 and 2010. "It's an epidemic, it's on the rise, and currently [there is] no way to delay it, prevent it or cure it," says Maria Carrillo, a neuroscientist with the Association. http://www.npr.org/blogs/health/2013/03/19/174651566/alzheimers-epidemic-now-a-deadlier-threat-to-elderly

Exploring the dreams of hospice workers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 April 2013 – Nine adults who worked at least one year with patients at U.S. hospice centers completed an in-person audio-taped dream session focusing on a dream about a patient. Patients were generally manifestly present in participants' dreams, and dreams were typically realistic (i.e., not bizarre). In the dream, the dreamer typically interacted with the patient as a caretaker but was also typically frustrated by an inability to help as fully as desired. Dreams gave dreamers insight into the stress of hospice work, their own fears of death, and inter-/intrapersonal interactions beyond hospice work. http://ajh.sagepub.com/content/early/2013/04/29/1049909113487253.abstract

U.S. Institute of Medicine initiative

Palliative and end-of-life care: Where are we now?

AMERICAN JOURNAL OF NURSING, 2013;113(5):21-23. In 1997, the Committee on Care at the End of Life at the Institute of Medicine (IOM) issued *Approaching Death: Improving Care at the End of Life*. Everyone is entitled to a "decent or good death," the committee wrote, one without avoidable suffering, a death that's in line with patients' and families' values and "reasonably consistent with clinical, cultural, and ethical standards." Now, 16 years later, a new IOM committee ... has been convened.[1] The Committee on Transforming End-of-Life Care ... will take input from professionals and the public and issue a new report within 18 months. The goals named in the 1997 report might sound like the standard of care in this country, especially since the establishment of the modern hospice movement in the 1970s. So why is a new report needed? Physician Christine Cassel said ... that health care has become increasingly aggressive in promoting life-saving treatments, with hospitals erecting "huge glossy buildings" funded by technology companies, but "nobody puts up a billboard outside their academic medical center saying, 'We're the best place to die.' It's very hard to celebrate that." A part of the committee's task ... will be to discern how to transform the current "value equation" so that institutions place as much emphasis on the patient's and family's experience of death and dying as they do on saving lives. http://journals.lww.com/ajnonline/Fulltext/2013/05000/Palliative_and_End_of_Life_Care___Where_Are_We.13.aspx

1. Committee on Transforming End-of-Life Care, Institute of Medicine, website: http://www.iom.edu/Activities/Aging/TransformingEndOfLife.aspx

Noted in Media Watch, 14 January 2013:

- U.S. | *Marin Independent Journal* (Novato, California) – 10 January 2013 – **'National Institute of Medicine will recommend ways to improve end-of-life care.'** In a national move that portends improvement of care for the dying, an expert panel assembled by the Institute of Medicine announced that it will recommend ways to improve end-of-life care in America. The Institute seeks changes in federal policy, financing and hospital practices that will bring care into line "with individual values and preferences to promote high-quality, cost-effective care at the end of life." The Institute's action comes amid heightened media attention on end-of-life care. http://www.marinij.com/ci_22348648/institute-medicine-will-recommend-ways-improve-end-life

Cont.

Of related interest:

- *AMERICAN JOURNAL OF MEDICINE*, 2013;126(5):368-369. **'Dismissing the immortality myth: Improving care and incidentally reducing costs.'** As physicians and patients talk realistically about actions regarding prognoses including death, rather than accepting the default unspoken myth of immortality, multiple benefits will accrue. A marked reduction in overall costs of health care will occur, freeing significant amounts of money to be spent on other medical and social priorities. The much more important outcome will be that patients will be better served as they receive exactly the type and level of care that they want. Physicians also will achieve greater professional satisfaction, reminding them of the reasons that they initially entered the profession. http://www.amjmed.com/article/S0002-9343(13)00004-1/fulltext

- *CLINICAL ONCOLOGY* | Online – 1 May 2013 – **'Palliative care misunderstandings "astonishingly high."'** Two studies have revealed between 60% and 80% of patients receiving palliative therapy with radiation or chemotherapy for incurable cancer do not understand the intent of treatment is palliative, not cure.[1,2] The studies highlight a communication chasm between doctors and patients. Oncologists say it is unclear who is to blame; the gap surprised some. http://www.clinicaloncology.com/ViewArticle.aspx?d=Current%2BPractice&d_id=155&i=April+2013&i_id=949&a_id=22960

    1. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. [Noted in Media Watch, 29 October 2012] http://www.nejm.org/doi/full/10.1056/NEJMoa1204410

    2. 'Patient beliefs about palliative radiation therapy (RT) in incurable lung cancer,' *International Journal of Radiation Oncology*, 2012;84(3):Supplement 1. http://www.redjournal.org/article/S0360-3016(12)00954-6/fulltext

- *FAMILY PRACTICE NEWS* (U.S.) | Online – 30 April 2013 – **'Lower costs documented in hospitals with palliative care programs.'** Hospitals with PC programs had lower treatment intensity on average at the end of life than did those without PC, in a national sample of 3,593 hospitals. ICU length of stay in the last 6 months of life was 0.4 days shorter and hospice length of stay 1.6 days longer at hospitals with PC versus those without. The study strengthens claims that palliative care cuts costs, and is the first to examine the impact of palliative care in such a large national sample of hospitals. http://www.familypracticenews.com/news/practice-trends/single-article/lower-costs-documented-in-hospitals-with-palliative-care-programs/9b507957aeab5fdbd16ed0b3cb965911.html

- *PHYSICIANS WEEKLY* (U.S.) | Online – 29 April 2013 – **'Making the case for palliative care.'** According to Dr. [Jennifer S.] Temel, more information about the nature and elements of early PC [palliative care] in ambulatory care is needed. "The integration of PC with standard oncologic care may have a different emphasis and focus than traditional inpatient or consultative PC," she says. Earlier and longer collaborative relationships between PC clinicians and patients may allow the time and opportunity to face complex issues like treatment decisions and advanced care planning rather than focus mostly on acute symptom management and imminent death. A study by Dr. Temel and colleagues looked at the content of clinic visits of early integrated PC in patients with metastatic non-small cell lung. According to the study results, the role of palliative care is distinct from that of oncology, but the entities are complementary.[1] http://www.physiciansweekly.com/palliative-care/

    1. 'Early palliative care in advanced lung cancer: A qualitative study,' *JAMA Internal Medicine*, 2013;173(4):283-290. http://archinte.jamanetwork.com/article.aspx?articleid=1566605

Determinants of place of death: A population-based retrospective cohort study

BMC PALLIATIVE CARE | Online – 1 May 2013 – Data on deaths in British Columbia between 2004 and 2008 were obtained from the Vital Statistics Agency. Of the 153,111 deaths, 16.5% occurred at home, 29.0% in extended care, 51.0% in hospital and 3.5% occurred elsewhere. This study shows that age, sex, marital status, rural versus urban residence, cause of death and place of birth are significant determinants of death at home, in extended care facility or in the hospital. http://www.biomedcentral.com/content/pdf/1472-684X-12-19.pdf

"I'm so angry and frightened to be at this stage in my life": Observations of grief and loss in community advance care planning group education

BMJ SUPPORTIVE & PALLIATIVE CARE, 2013;3(2):239-240. A qualitative approach was used with participant observation and reflective journaling to record events within the implementation of advance care planning (ACP) workshops. Loss and grief themes included fear of death, loneliness, suffering, and vulnerability. Grief experiences included watching loved ones be palliated or die in a way that did not match personal values. Loss and grief for older people outside the context of bereavement is under researched. Despite recognition of depression in the elderly there is scarcity in the literature of general grief and loss experiences and how this may impact the engagement and participation in ACP training. There are both historical and sociological grief and loss issues for this generation which require exploration for successful engagement in ACP planning. http://spcare.bmj.com/content/3/2/239.2.short

> **N.B.** This issue of the journal includes the abstracts of papers to be presented at an upcoming conference of the International Society of Advance Care Planning & End of Life Care (Melbourne, Australia, 9-11 May). Contents page: http://spcare.bmj.com/content/3/2.toc#AbstractsACPELabstracts (Scroll down to 'Abstracts')

Virtual hospice

Developing hospice care over a distance in highland Scotland: A knowledge exchange process

COMPUTER-HUMAN INTERACTION 2013 CONFERENCE (Abstract) | Online – Accessed 2 May 2013 – This paper describes a piece of collaborative research that aimed to develop an implementation plan for a virtual hospice. The aim of the virtual hospice in this case is to extend the reach of hospice facilities provided by the Highland Hospice in Inverness, Scotland. The authors chose a knowledge exchange process that included Hospice staff at every step. They began with a workshop that scoped out all of the potential virtual hospice services, which were condensed into a core set of five services. The authors then conducted interviews with selected Hospice staff. The final step involved presenting our recommendations to the hospice, including a storyboard of how the virtual hospice might operate in practice. They took the hospice's feedback and incorporated it into a final report. http://dl.acm.org/citation.cfm?id=2468427

Path toward economic resilience for family caregivers: Mitigating household deprivation and the health care talent shortage at the same time

THE GERONTOLOGIST | Online – 30 April 2013 – Rising costs and a workforce talent shortage are two of the health care industry's most pressing challenges. In particular, serious illnesses often impose significant costs on individuals and their families, which can place families at an increased risk for multi-generational economic deprivation or even an illness-poverty trap. At the same time, family caregivers often acquire a wide variety of health care skills that neither these caregivers nor the health care industry typically use. As these skills are marketable and could be paired with many existing medical certifications, this article describes a possible "path toward economic resilience" (PER) through a program whereby family caregivers could find meaningful employment using their new skills. The proposed program would identify ideal program candidates, assess and supplement their competencies, and connect them to the health care industry. The authors provide a set of practical steps and recommended tools for implementation, discuss pilot data on the program's appeal and feasibility, and raise several considerations for program development and future research. Their analysis suggests that this PER program could appeal to family caregivers and the health care industry alike, possibly helping to address two of our [i.e., U.S.] health care system's most pressing challenges with one solution. http://gerontologist.oxfordjournals.org/content/early/2013/04/26/geront.gnt033.abstract

Cont.

Of related interest:

- *SUPPORTIVE CARE IN CANCER* | Online – Accessed 29 April 2013 – **'Association between hope and burden reported by family caregivers of patients with advanced cancer.'** The aim of this study ... was to describe the level of FC [family caregiver] burden using the Caregiver Reaction Assessment (CRA).[1] The variance in each of the CRA sub-scales [i.e., "impact on finances," "impact on daily schedule," and "impact on health"] was explained by different factors. Total explained variance ranged from 5.5 % ("lack of family support") to 31.8 % ("impact on daily schedule"). http://link.springer.com/article/10.1007/s00520-013-1824-5

  1. Caregiver Reaction Assessment Instrument. http://www.thecarenet.ca/docs/CaregiverReactionAssessmentForm.pdf

Preparing for the unexpected: Violence in the home care environment, one home care agency's story

HOME HEALTHCARE NURSE | Online – 30 April 2013 – Home care and hospice agencies, bound by regulations, prepare for emergencies and disasters by creating policies and protocols for management of emergency situations, perhaps conducting table top or other types of drills, and discussing hazards likely to impact home care. Is this preparation merely an exercise to meet a requirement or is it life-saving preparation? For one home care agency, the emergency exercise saved the day as the scenario enacted in the drill was actually lived out a few weeks following the exercise-a scenario the agency leaders hoped they would never face. This account explores how the agency prepared to meet the emergent situation and details lessons learned in the aftermath. http://journals.lww.com/homehealthcarenurseonline/Abstract/publishahead/Preparing_for_the_Unexpected__Violence_in_the_Home.99976.aspx

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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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.

End of life care in New Zealand

"Where do I go from here?" – A cultural perspective on challenges to the use of hospice services

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 3 May 2013 – Do hospice services as shaped by a western perspective adequately fulfil the needs of persons from non-Western cultures? Based on a Western view of palliative care, the vision outlined in the New Zealand Palliative Care Strategy (2001) is to deliver palliative care services, including hospice services, to all patients and their families requiring them in the context of an increasingly pluralistic and multicultural society. It is predicted that over the next two decades the proportion of people identifying as Māori, Pacific and Asian will dramatically increase within New Zealand. Ministry of Health information provided through a GAP analysis identified hospices as facing access-to-care pressures for Māori, Pacific and Asian patients. It is therefore critical to identify the challenges to hospice service access for Māori, Asian and Pacific patients. Challenges to hospice service utilisation reported in the findings [of this study] include a lack of awareness in the communities of available services, as well as continuing misconceptions concerning the nature of hospice services. Language barriers were particularly reported for Asian patients and their families. Issues concerning the ethnic representativeness of the hospice services staff were raised. The findings highlight the importance of patient and family knowledge of hospice care for utilisation of services. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12038/abstract

Toward a population-based approach to end-of-life care surveillance in Canada: Initial efforts and lessons

JOURNAL OF PALLIATIVE CARE, 2013;29(1):13-21. This paper describes a project undertaken by the Hospice Palliative End-of-Life Care Surveillance Team Network – one of four Cancer Surveillance and Epidemiology Networks established by the Canadian Partnership Against Cancer in 2009 to create information products that can be used to inform cancer control. The project was designed to improve the quality and use of existing electronic patient databases in its member organizations. The project's intent was to better understand terminally ill cancer patients in their final year of life, with non-cancer as comparison. The network created an early design for a Web-based end-of-life care surveillance system prototype. Using a flagging process, anonymized data sets on cancer/non-cancer palliative patients and those who died in 2008-2009 were extracted and analyzed. The Australian palliative approach was adapted as the conceptual model based on the data sets available. Common data elements were defined then mapped to local data sets to create a common data set. Information products were created as online reports. Throughout the project, members were engaged in knowledge translation. Overall, the project was well received by network members. Journal contents page: http://www.criugm.qc.ca/journalofpalliativecare/

A population-based study on advance directive completion and completion intention among citizens of the western Canadian province of Alberta

JOURNAL OF PALLIATIVE CARE, 2013;29(1):5-12. Determining what proportion of the public has completed an advance directive and which population subgroups complete or do not complete such a directive is crucially important for planning purposes. A telephone survey was conducted with 1,203 Albertans who met gender, age, and other requirements for a representative sample. When asked, "Do you have a living will or personal directive?" 43.6% reported having completed a directive and 42.1% indicated that they planned or intended to complete one. Completion rates increased with age. Widowed, self-employed, and retired people, and those who had lost a family member or friend and had other select end-of-life experiences and viewpoints were significantly more likely to have completed one. Although older people more often had an advance directive, personal life-and-death experiences should be recognized as major influences on directive completion. Journal contents page: http://www.criugm.qc.ca/journalofpalliativecare/

Cont.

Of related interest:

- *PALLIATIVE MEDICINE*, 2013;27(5):387-388. **'Planning a personalised future with dementia: "the misleading simplicity of advance directives."'** The number of people diagnosed with dementia is increasing, the condition may significantly shorten life expectancy, and concerns have been raised about the quality of end-of-life care people with dementia receive. Contemporaneously, the dementia care agenda across the world has shifted towards earlier and more timely diagnosis. Given the paucity of disease modifying treatment, it has been suggested that one benefit of diagnosis is that it allows the person to plan for their future care while they still have capacity. In their methodologically rigorous article, Louise Robinson and colleagues explore key issues of ACP for people with dementia in a large representative sample of professionals...[1] http://pmj.sagepub.com/content/27/5/387.extract

    1. *PALLIATIVE MEDICINE* | Online – 21 November 2012 – **'Professionals' experiences of advance care planning in dementia and palliative care, "a good idea in theory but …"'** The majority [of participants] expressed uncertainty over the general value of advance care planning, whether current service provision could meet patient wishes, their individual roles and responsibilities and which aspects of advance care planning were legally binding; the array of different advance care planning forms and documentation available added to the confusion. In dementia care, the timing of when to initiate advance care planning discussions was an added challenge. [Noted in Media Watch, 26 November 2012] http://pmj.sagepub.com/content/early/2012/11/15/0269216312465651.abstract

- *PALLIATIVE MEDICINE* | Online – 29 April 2013 – **'A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation.'** Participants [in semi-structured interviews and one focus group] endorsed the question prompt list as acceptable and useful. Feedback resulted in two distinct versions of the question prompt list, accommodating differences between Australian and U.S. approaches to end-of-life discussions, highlighting the appropriateness of tailoring communication aides to individual populations. http://pmj.sagepub.com/content/early/2013/04/23/0269216313483659.abstract

- *TECHNICAL COMMUNICATION QUARTERLY*, 2013;22(3):195-218. **'"Standing in Terri Schiavo's Shoes": The role of genre in end-of-life decision making.'** This article reports the findings from analysis of end-of-life court cases and case files from one state public guardianship administrator as well as interviews with guardians or surrogates to identify how language and principles of the courts are operationalized in end-of-life decisions for those who are unable to make decisions for themselves. The authors found that physicians and guardians worked well within the requirements of the genre to ensure the best interests for those whom they represent. http://www.tandfonline.com/doi/abs/10.1080/10572252.2013.760061

    Noted in Media Watch, 13 September 2010:

    - *JOURNAL OF MEDICAL ETHICS*, 2010;36(9):571-573. **'How the public responded to the Schiavo controversy.'** This paper reports the results of a content analysis of letters to editors published in the four most prolific American newspapers for the Schiavo controversy. Opinions expressed in the letters sampled strongly supported the use of living wills and strongly condemned public attention to the case as well as political interventions. http://jme.bmj.com/content/36/9/571.abstract

    Noted in Media Watch, 5 April 2010:

    - ASSOCIATED PRESS | Online – 30 March 2010 – **'5 years after Schiavo, few make end-of-life plans.'** 5 years after the court fight allowing Schiavo to die most Americans still don't draft the documents that spell out how far caregivers should go to keep them alive artificially.http://www.google.com/hostednews/ap/article/ALeqM5iGq41NTRuJK_ygTwJOM54fM256XQD9EOQ7KG1

End-of-life care in Singapore

Impact of a palliative care initiative on end-of-life care in the general wards: A before-and-after study

PALLIATIVE MEDICINE | Online – 29 April 2013 – Data on deaths in the general wards of our hospital in 2007 revealed infrequent discussions on end-of-life care and excessive burdensome interventions. A physician order form to withhold inappropriate life-sustaining interventions was initiated in 2009. The use of the form was facilitated by staff educational sessions and a palliative care consult service. This study aimed to evaluate the impact of these interventions in 2010. There was an increase in orders to withhold life-sustaining therapies, such as cardiopulmonary resuscitation (66.2%-80.0%). There was a decrease in burdensome interventions such as antibiotics (44.9%-24.9%), and a small increase in palliative treatments such as analgesia (29.1%-36.7%). There were more discussions on the role of cardiopulmonary resuscitation with conversant patients (4.6%-10.2%) and families (56.5%-79.8%). On multivariate analysis, the physician order form independently predicted orders to withhold cardiopulmonary resuscitation. http://pmj.sagepub.com/content/early/2013/04/23/0269216313484379.abstract

Ethics of palliative care in Romania from principles to practice

PHILOSOPHIA, 2013;Spring:15-21. Analysis reveals the ambiguous way in which medical decisions are made in relation to the fundamental principles of bioethics [i.e., respect for – autonomy, nonmaleficence, beneficence and justice], the ineffective management of the physical, psychological, social and spiritual needs (in the context of personal values, cultural, religious beliefs of patients and their families), the effects of communication difficulties, ineffective or insufficient professionalism of care staff, deficient legislation, and the lack of visibility of the commissions of clinical ethics activity. http://www.ceeol.com/aspx/issuedetails.aspx?issueid=6432e41e-febe-415f-bdff-d9a7ef71d0ea&articleId=45a28ec3-14d2-4925-a1fd-f0dfdce7b572

Noted in Media Watch, 8 October 2012:

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 October 2012 – **'Palliative care in Romania: Between poor resources and poor management.'** Palliative care must compete with other serious healthcare issues, including the highest European Union incidences for tuberculosis, infant mortality, and uterine cervix cancer mortality. Therefore, the evolution of palliative care in Romania was largely the result of important input from non-governmental organizations, now the main providers of palliative care services, including education on the subject. http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000030

Psychosocial service use: A qualitative exploration from the perspective of rural Australian cancer patients

SUPPORTIVE CARE IN CANCER | Online – Accessed 3 May 2013 – Rural cancer patients want their unique needs to be recognised and to be treated differently to their urban counterparts. There is a need for more targeted and rurally relevant information for rural cancer patients, both to inform them of, and change their attitudes towards, psychosocial services. Five key themes were identified [in this study]: 1) psychosocial support is highly valued by those who have accessed it; 2) having access to both lay and professional psychosocial support is vitally important; 3) accessing psychosocial services is made difficult by several barriers (lack of information about services, initial beliefs they are unnecessary, feeling overwhelmed and concerns about stigma and dual relationships); 4) medical staff located in metropolitan treatment centres are not sufficiently aware of the unique needs of rural patients; and, 5) patients require better access to psychosocial services post-treatment. Methods through which rural patients believe access to psychosocial services could be improved include: 1) providing more rural-specific information on psychosocial care; 2) improving communication between health care providers and referral to psychosocial services; and, 3) making psychosocial services a standard part of care. http://link.springer.com/article/10.1007/s00520-013-1812-9

International palliative care experts' view on phenomena indicating the last hours and days of life

SUPPORTIVE CARE IN CANCER, 2013;21(6):1509-1517. Experts from different professional backgrounds identified a set of categories describing a structure within which clinical phenomena can be clinically assessed, in order to more accurately predict whether someone will die within the next days or hours. However, these phenomena need further specification for clinical use. The study generated 194 different phenomena, perceptions and observations. Fifty-eight phenomena achieved more than 80% expert consensus and were grouped into nine categories. Twenty-one phenomena were determined to have "high relevance" by more than 50% of the experts. Based on these findings, the changes in the following categories (each consisting of up to three phenomena) were considered highly relevant to clinicians in identifying and predicting a patient's last hours/days of life: "breathing," "general deterioration," "consciousness/cognition," "skin," "intake of fluid, food, others," "emotional state" and "non-observations/expressed opinions/other." http://link.springer.com/article/10.1007/s00520-012-1677-3

Worth Repeating

Lessons in life and death

Morbid fascination: Teaching the history of death

ACADEMIC EXCHANGE QUARTERLY | Online – 22 June 2005 – This article discusses the author's experience in designing and teaching a freshmen history course on death and dying. The article includes sample assignments and readings as well as samples of student evaluations and an explanation of the rather surprising results. The author concludes: "Talking about death is a widely held taboo in modern society, or so the theorists say. That taboo contributed to making this course initially popular but it also laid at the basis of its effectiveness as a vehicle for personal and intellectual development, both for the students and the instructor. This course has been one of the most satisfying teaching experiences that I have ever had. Some of my ideas worked better than others and much of its success can be attributed to the unintended consequences of allowing students to draw their own conclusions from historical examples in a supportive classroom environment – not necessarily my lectures. Still, this was the rare occasion where teaching goes well beyond the subject matter and reaches into places I never expected it to go." http://www.questia.com/library/1G1-136071090/morbid-fascination-teaching-the-history-of-death

Of related interest:

- U.S. | *Kansas State Collegian* – 14 April 2009 – **'Class offers historical perspective on death, cemeteries,'** It started with an effort to offer a different kind of reading for a history course. Albert Hamscher, professor of history, found what he was looking for in a book examining attitudes toward death and dying dating back to the Middle Ages. The book, written by French historian Philippe Aries, quickly became a favorite of students in Hamscher's history classes in the mid-1970s. In response to their requests, Hamscher created a course examining the subject matter in-depth. The History of Death & Dying (HIST 520) has been a mainstay in the department ever since. http://www.kstatecollegian.com/class-offers-historicalperspective-on-death-cemeteries-1.1713476
- U.S. | *Los Angeles Times* (California) – 3 September 2008 – **'College students study death to learn the meaning of life.'** Professor Norma Bowe has led her classes of 30 students into the refrigerated tombs of bodies stacked bunk-bed style in the morgue and into hospice bedrooms, glowing from television screens, occupied by the sickly and soon-to-die. http://www.latimes.com/news/printedition/front/la-na-deathclass3-2008sep03,0,1888119.story

Cont.

- THE NETHERLANDS | TheAge.com.au (Australia) – 14 February 2007 – **'Lesson in life and death: Pupils build dying teacher's coffin.'** Eri van den Biggelaar, a Dutch primary school teacher dying of cancer, is overseeing one last class project: her pupils are making her coffin. http://www.theage.com.au/news/world/lesson-in-lifeand-death-pupils-build-dyingteachers-coffin/2007/02/13/1171128974213.html

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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