

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.

2 June 2014 Edition | Issue #360



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

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Professional development and education: Scroll down to [Specialist Publications](#) and 'Bedside teaching rounds reconsidered' (p.8), in *Journal of the American Medical Association*.

Canada

Palliative care strategy call backed by House of Commons

CBC NEWS | Online – 28 May 2014 – In a rare show of near all-party unity, the House of Commons has endorsed New Democrat MP Charlie Angus's call for a cross-country strategy on palliative and end-of-life care. The non-binding motion calls on the government to work with the provinces and territories to ensure access to "high-quality, home-based and hospice palliative care," provide more support to caregivers, and encourage Canadians to "discuss and plan for end-of-life care." Angus described his proposal as "the common sense solution staring Canada's political parties in the face," and it appears he was right. The motion passed the House with just one dissenting vote: Bloc Québécois MP Jean-Francois Fortin, whose party has historically objected to any proposal that involves a national strategy. It had already earned public backing of Conservative MPs Harold Albrecht and Maurice Vella-

cott, as well as Liberal MP Francis Scarpaleggia, who signed on as co-sponsors. <http://www.cbc.ca/news/politics/palliative-care-strategy-call-backed-by-house-of-commons-1.2657151>

New Democratic Party palliative-care motion gets through Commons, now up to Tories to respond

THE GLOBE & MAIL | Online – 28 May 2014 – The House of Commons passed an Opposition motion that calls on the federal government to come up with a national strategy on palliative care. And while not promising to launch a formal effort to create such a strategy, Health Minister Rona Ambrose says she supports the call. <http://www.theglobeandmail.com/news/politics/ndp-palliative-care-motion-gets-through-commons-now-up-to-tories-to-respond/article18902276/>

Noted in Media Watch, 12 May 2014, #357 (p.9):

- CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 2 May 2014 – 'Canadian Medical Association call for palliative care strategy gets federal backing.' The Canadian Medical Association (CMA) and a Parliamentary All-Party Committee have joined forces to advocate for the development of a national strategy on palliative care. CMA President-elect Dr. Chris Simpson noted that as few as 16% of Canadians will have access to any palliative care services this year. <http://www.cma.ca/cmacallforpalliativecarestrategygetsfederalbacking>

Cont.

1. 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

Of related interest:

- ONTARIO | *The Toronto Star* – 26 May 2014 – '**Getting the death you want.**' Currently, about 30% of Canadians live in areas with good access to such care. But even as end-of-life issues receive more public debate, those who care for patients and families facing death say the more personal discussions about dying are not happening as often as they should. http://www.thestar.com/news/death_and_dying/2014/05/26/getting_the_death_you_want.html#

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Montreal Gazette* – 27 May 2014 – '**Motion filed in court to quash Quebec's proposed assisted death legislation.**' The Quebec government's assisted death legislation is illegal and should be quashed, says a motion filed in Quebec Superior Court... Under Bill 52, which was reintroduced in the National Assembly last week and would be the first of its kind in Canada, a doctor who receives the repeated consent of a patient could administer medication to cause death. But Paul Saba, the family physician who filed the motion with Lisa D'Amico, a 48-year-old with cerebral palsy, said euthanasia can't be considered a medical treatment and therefore does not fall within provincial jurisdiction. The bill, the motion says, violates both the Quebec and Canadian Charter of Rights and Freedoms, Quebec's Civil Code, the Quebec Code of medical practice, medical ethics, the Criminal Code and the Constitution. <http://www.montrealgazette.com/news/Motion+filed+court+quash+Quebec+proposed+assisted+death+legislation/9882501/story.html>

Noted in Media Watch, 26 May 2014, #359 (p.2):

- QUEBEC | CBC News – 22 May 2014 – '**Dying with dignity bill restored by new Quebec government.**' Quebec's new Liberal government reintroduced the end-of-life care bill as it was before the [provincial] election call in March – when it was only steps away from its adoption. <http://www.cbc.ca/news/canada/montreal/dying-with-dignity-bill-restored-by-new-quebec-government-1.2651286>

U.S.A.

Doctors say they would shun aggressive treatment when near death

CALIFORNIA | National Public Radio – 29 May 2014 – Everyone dies. But when doctors' time is up, they are different from the rest of us. They "go gently" rather than opt for aggressive end-of-life treatments... They have seen the suffering of their patients at the end of life and want no part of it. In fact, nearly 9 in 10 young physicians just finishing up their residencies or fellowships wouldn't want to receive life-prolonging CPR or cardiac life support if they were terminally ill and their heart or breathing stopped, a Stanford University School of Medicine survey finds.¹ The report ... notes the disconnect between the aggressive care the average person receives – an average of about \$7,000 worth for Medicare beneficiaries in their last month

of life – and what doctors would want for themselves. To be sure, non-doctors don't necessarily want that care. According to one survey, most people would prefer to die at home and want care to focus on comfort.² <http://www.npr.org/blogs/health/2014/05/29/316701155/doctors-say-they-would-shun-aggressive-treatment-when-near-death>

Specialist Publications

'Stability of end-of-life preferences: A systematic review of the evidence' (p.7), in *JAMA Internal Medicine*.

Cont.

1. Scroll down to [Specialist Publications](#) and 'Do unto others: Doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives' (p.11).
2. 'Final Chapter: Californians' Attitudes and Experiences with Death and Dying,' California Healthcare Foundation, February 2012. [Noted in Media Watch, 20 February 2012, #241 (p.3)] <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf>

Population trends

The silver tsunami: As state's population ages, groups raise awareness for end-of-life care

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 25 May 2014 – The oldest of America's baby boomers are still more than a decade away from needing hospice care in great numbers, but with 10,000 boomers turning 65 every day, hospices are already preparing for the oncoming "silver tsunami." The issue will be felt acutely in Pennsylvania, where seniors 85 and up are the fastest growing demographic block, and where more than 15% of the population is older than 65 – a percentage bested by only Florida and West Virginia. As a result, the number of U.S. hospice care services has been growing rapidly since 2000, and the number of people using such care is growing, too – in 2000, about 23% of Medicare beneficiaries who died in the same year used hospice care. By 2012, that figure was close to 45%, and the average length of stay is up to nearly three months. Yet despite increasing acceptance and use of hospice care ... there is room for growth. Over a quarter of people who died in hospice are only enrolled during their last week of life, according to a recent Medpac report.¹ Some physicians are reluctant to suggest hospice care until death is imminent. The patient's family also may find it hard to accept the prognosis and encourage intensive medical measures to save someone's life, even when it won't do any good. <http://www.post-gazette.com/healthypgh/2014/05/25/Silver-tsunami-As-Pennsylvanias-population-ages-groups-raise-awareness-for-end-of-life-care/stories/201405250010>

1. 'Report to the Congress: Medicare Payment Policy,' The Medicare Payment Advisory Commission, March 2014. http://www.medpac.gov/documents/mar14_entirereport.pdf

International

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

Health chiefs pledge to improve end of life care after phasing out controversial Liverpool Care Pathway

U.K. (England) | *The Norwich Evening News* – 30 May 2014 – Significant strides have been made in improving end-of-life care across Norfolk after the government scrapped the controversial Liverpool Care Pathway (LCP), health chiefs said.¹ Officials from the three acute hospitals in Norfolk said they were developing more personalised plans for dying patients after phasing out the "discredited" palliative care programme following an independent report into the practice. However, experts told members of the Norfolk Health Overview & Scrutiny Committee that there was uncertainty over the future of end-of-life care and National Health Trusts trusts were still awaiting official guidelines from a Leadership Alliance for the Centre of Dying People report.² LCP, which was developed in the 1990s, was intended to allow people with a terminal illness to die with dignity. http://www.eveningnews24.co.uk/news/health_chiefs_pledge_to_improve_end_of_life_care_after_phasing_out_controversial_liverpool_care_pathway_1_3621374

1. *More care, less pathway: Review of Liverpool Care Pathway for dying patients* [in England], Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Cont.

2. 'Care for people in the last days and hours of life, 'Leadership Alliance for the Care of Dying People, 20 March 2014. The Alliance's latest joint statement identifies five priorities in end-of-life care. [Noted in Media Watch, 31 March 2014, #351 (p.5)] <http://www.england.nhs.uk/wp-content/uploads/2014/03/lacdp-int-state-20mar14.pdf>

Elder care in the U.K.

Overall standard of home care improving, report says

U.K. (Scotland) | BBC News – 30 May 2014 – The standard of care delivered by home carers in Scotland has seen an overall improvement, says a new report.¹ The report looked at the results of three years of inspections of "home helps" and other homecare services. It says 80% of these were found to be of a good standard, and an increasing proportion got top marks. However, the body warned that the number of services judged to be performing badly has nearly doubled. The report also found that the highest standard of care was more likely to be delivered by voluntary services, while those provided by the private sector were most likely to be poor, and to have complaints about them upheld. <http://www.bbc.com/news/uk-scotland-27627602>

1. 'Caring for people at home: How care at home services operate in Scotland and how well they performed between 2010 and 2013,' The Care Inspectorate, Scotland, May 2014. http://www.careinspectorate.com/images/stories/documents/New%20and%20Events/news_items/Caring_for_people_at_home_report.pdf

End-of-life care in Australia

\$52 million to improve palliative care services and training

AUSTRALIA | National Department of Health – 29 May 2014 – The Australian Government will provide \$52 million over three years to improve palliative care services and training. Minister Fiona Nash said the State and Territory Governments were responsible for delivering palliative care services, while the Australian Government supports projects that enhance the overall quality of services. This funding is in addition to the support the Australian Government provides to state and territories to operate palliative care services, the subsidies for palliative care medicines under the Pharmaceutical Benefits Scheme, and palliative care consultations under the Medical Benefits Scheme. <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarelyr2014-nash022.htm>

Of related interest:

- AUSTRALIA | *The Herald Sun* (Melbourne) – 28 May 2014 – **'Federal cuts "could be devastating" for the terminally ill at Emerald hospice Fernlea House, which may close.'** Fernlea House chief executive Sharyn Turney said an overhaul in federal funding next year would mean at least half the patients at the respite centre would not be covered. The federal government has announced it will integrate the existing Commonwealth HACC [Home & Community Care] Program, the National Respite for Carers Program, and the Day Therapy Centres Program under a single streamlined Commonwealth Home Support Programme... <http://www.heraldsun.com.au/leader/east/federal-cuts-could-be-devastating-for-the-terminally-ill-at-emerald-hospice-fernlea-house-which-may-close/story-fngnvlxu-1226933218234>
- AUSTRALIA | *The Herald Sun* (Melbourne, Victoria) – 27 May 2014 – **'Lack of death plan causes anguish: Study.'** Most Australians are missing out on an opportunity to influence where and how they die, says a study that shows a serious lack of end-of-life planning.¹ <http://www.heraldsun.com.au/news/breaking-news/lack-of-death-plan-causes-anguish-study/story-fni0xqi4-1226932871211>

1. Palliative Care Australia, 27 May 2014: 'Australians aren't "prepared" to die – Survey,' <http://pallcare.org.au/Default.aspx?tabid=1114>; 'Australians turn to GPs for advice on preparing to die – Survey,' <http://pallcare.org.au/Default.aspx?tabid=1114>

Trust your doctor, not Wikipedia, say scientists

U.K. | BBC News – 27 May 2014 – Wikipedia, the online encyclopaedia, contains errors in nine out of 10 of its health entries, and should be treated with caution.¹ Scientists in the U.S. compared entries about conditions such as heart disease, lung cancer [etc.] with peer-reviewed medical research. They said most articles in Wikipedia contained "many errors." From a public health standpoint, patients should not use Wikipedia as a primary resource because those articles do not go through the same peer-review process as medical journals. The online encyclopaedia is a charity, and has 30 million articles in 285 languages. It can be edited by anybody, but many volunteers from the medical profession check the pages

for inaccuracies, said Wikimedia U.K. The open-access nature has "raised concern" among doctors about its reliability, as it is the sixth most popular site on the Internet. <http://www.bbc.com/news/health-27586356>

What Wikipedia says about...

End-of-life care: http://en.wikipedia.org/wiki/End-of-life_care

Hospice: <http://en.wikipedia.org/wiki/Hospice>

Palliative care: http://en.wikipedia.org/wiki/Palliative_care

1. 'Wikipedia vs peer-reviewed medical literature for information about the 10 most costly medical conditions,' *Journal of the American Osteopathic Association*, 2014;114(5):368-373. <http://www.jaoa.org/content/114/5/368.full>

Noted in Media Watch, 8 August 2011, #213 (p.7):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 4 August 2011 – '**Patient-oriented cancer information on the Internet: A comparison of Wikipedia and a professionally maintained database.**' Because of a lack of formal editorial control, the authors hypothesized that the content of Wikipedia would be less complete and accurate than that of a peer-reviewed web site. Although the Wikipedia resource had similar accuracy and depth as the professionally edited database, it was significantly less readable. <http://jop.ascopubs.org/site/er/JOP000209.pdf>

Leaving in peace

As China faces a rapidly aging society, the experiences of the nation's first hospice could offer solutions to some looming problems

CHINA | *The Beijing Review* – 26 May 2014 – Li Wei starts all of his college lectures with the same statement, "I have good news for you. You will die in less than 20,000 days." As the founder and president of China's first palliative care facility – the Songtang Hospice in Beijing – Li has worked in terminal care for almost 30 years. Death, a taboo subject in China, is something he comes face to face with on a daily basis. "Normally the students are shocked to hear this. It seems that they never thought about death at their age," Li said. Li's figure 20,000 comes from the average life span in China, which was 75 in 2013. "We place too much importance on birth but avoid talking about death," Li said. "This creates an illusion that

we have plenty of time." Tradition would have us keep family members at home, especially our elders," Li said. "If an old person is sent to a hospice, his or her children will be scolded as not being filial enough, which is a very serious accusation in China." http://www.bjreview.com.cn/nation/txt/2014-05/26/content_620758.htm

Specialist Publications

'Preferences on end-of-life decisions among older Chinese in Macau' (p.9), in *Journal of Transcultural Nursing*.

Cont.

Noted in Media Watch, 9 September 2013, #322 (p.6):

- *ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT*, 2013;8(1):9-13. **'Palliative care in Mainland China.'** Factors that have slowed the development of palliative care include cultural values that encourage efforts to cure ... over the alleviation of suffering, limited public policies and funding for palliative care, and poor education of healthcare professionals about end-of-life care. <http://search.informit.com.au/documentSummary?dn=489509343939048;res=IELHEA>

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

Posttraumatic growth in parents caring for a child with a life-limiting illness: A structural equation model

AMERICAN JOURNAL OF ORTHOPSYCHIATRY, 2014;84(2):123-133. Parents who have a child who is born or is later diagnosed with a life-limiting illness ... become caregivers in ways that parents of predominantly well children do not. While the circumstances are undisputedly stressful, for some parents benefits can co-occur... This article tests two structural equation models of possible factors that allow these parent caregivers to experience growth in the circumstances. Parents in this research demonstrated growth as measured by the Post Traumatic Growth Inventory. It appears that particular personal resources reflected in personal well-being are a precursor to the process of positive meaning making, which then, in turn, contributes to growth. <http://psycnet.apa.org/index.cfm?fa=search.displayRecord&id=4922F7DF-BB38-0728-4ED4-08F58736C15F&resultID=1&page=1&dbTab=pa&search=true>

Hospice and palliation in the English-speaking Caribbean

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS | Online – 27 May 2014 – This article presents empirical data on the limited availability of hospice and palliative care to the 6 million people of the English-speaking Caribbean. Ten of the 13 nations responded to a survey and reported employing a total of 6 hospice or palliative specialists, and having a total of 15 related facilities. The evolving socioeconomic and cultural context in these nations bears on the availability of such care, and on the willingness to report, assess, and prioritize pain, and to prescribe opiates for pain. Socioeconomics and culture also impinge on what medications and modalities of care are routinely available for pain or other conditions and can challenge professionalism, empathy, and responsiveness to patients' unrelieved pain. Although all respondents report having a protocol for pain management, hospice, or end-of-life care, their annual medical use of opiates is well below the global mean. The International Narcotics Control Board ... Caribbean and other low- and middle-income countries to increase their use of opiates to treat pain, and to overcome both unfounded fears of addiction and overly restrictive interpretation of related laws and regulations. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9272348&fulltextType=RA&fileId=S0963180113000959>



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Got volunteers? The selection, training, roles, and impact of hospice palliative care volunteers in Canada's community-based volunteer programs

HOME HEALTH CARE MANAGEMENT & PRACTICE – 20 May 2014 – This article provides a brief overview of the selection, training, roles, and impact on family caregivers of community-based hospice palliative care volunteers in Canada. In many Canadian communities, carefully selected and well-trained volunteers are available to provide emotional support, companionship, practical assistance, and other kinds of help and comfort to dying persons and their families, mostly at home. Unfortunately, these services are often underutilized. Anecdotal and empirical evidence suggests that lack of awareness and/or understanding of this beneficial community resource is a major reason for the underutilization of volunteers. Education is the key to promoting awareness. <http://hmc.sagepub.com/content/early/2014/05/20/1084822314535089.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 May 2014 – '**Motivations, death anxiety, and empathy in hospice volunteers in France.**' French hospice volunteers scored significantly lower on 3 categories of motives on the Inventory of Motivations for Hospice Palliative Care Volunteerism compared to a sample of Canadian hospice palliative care volunteers ... suggesting that cultural differences may be involved. <http://ajh.sagepub.com/content/early/2014/05/30/1049909114536978.abstract>

Conceptual development of "at-homeness" despite illness and disease: A review

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 26 May 2014 – "At-homeness" was found to be a contextually related meaning of wellness despite illness and disease embedded in the continuum of being metaphorically at-home and metaphorically homeless. This was characterized by three interrelated aspects and four processes: being safe through expanding/limiting experiences of illness and time, being connected through reunifying/detaching ways of relating, and being centred through recognition/non-recognition of oneself in the experience and others giving/withdrawing a place for oneself. This conceptualization is to be regarded as a step in conceptual clarification. Further empirical investigation and theoretical development of "at-homeness" are needed. The conceptualization will be a step of plausible significance for the evaluation of interventions aimed at enhancing wellness for people with severe long-term illness, such as the frail elderly, and people with chronic illness or palliative care needs. <http://www.ijqhw.net/index.php/qhw/article/view/23677>

Stability of end-of-life preferences: A systematic review of the evidence

JAMA INTERNAL MEDICINE | Online – 26 May 2014 – Policies and practices that promote advance care planning and advance directive completion implicitly assume that patients' choices for end-of-life care are stable over time, even with changes in health status. Considerable variability among studies in the methods of preference assessment, the time between assessments, and the definitions of stability preclude meta-analytic estimates of the stability of patients' preferences and the factors influencing these preferences. Although more seriously ill patients and those who engage in advance care planning most commonly have stable preferences for future treatments, further research in real-world settings is needed to confirm the utility of advance care plans for future decision making. <http://archinte.jamanetwork.com/article.aspx?articleid=1876674>

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[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

Commentary on 'Stability of end-of-life preferences: A systematic review of the evidence':

- *JAMA INTERNAL MEDICINE* | Online – 26 May 2014 – **'What should be the goal of advance care planning?'** <http://archinte.jamanetwork.com/article.aspx?articleid=1876673>

Of related interest:

- *HEALTH CARE ANALYSIS*, 2014;22(2):174-191. **'Autonomy and dignity: A discussion on contingency and dominance.'** With dying increasingly becoming a medicalised experience in old age, we are witnessing a shift from concern over death itself to an interest in dying "well." Fierce discussions about end-of-life decision making and the permissibility of medical intervention in dying, discursively structured around the notion of a "good" death, are evidence of this shift. This article focuses on "autonomy" and "dignity" as key signifiers in these discussions. <http://link.springer.com/article/10.1007/s10728-012-0217-0>
- *JOURNAL OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS*, 2014;27(6):28-31. **'When communication fails: Resolving end-of-life impasses.'** This scenario explores the roles and influences that complicated one patient's care and how the situation was resolved. http://journals.lww.com/jaapa/Abstract/2014/06000/When_communication_fails_Resolving_end_of_life.7.aspx

Bedside teaching rounds reconsidered

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;311(19):1971-1972. In his 1905 farewell address to the staff of Johns Hopkins Hospital, Sir William Osler reflected on 16 years of accomplishments in the field of medical education, concluding that his greatest achievement was "[teaching] medical students in the wards, as I regard this as by far the most useful and important work I have been called upon to do." Photographs of Osler examining patients and teaching others reveal his systematic approach and its command on his trainees' attention. Osler has become a model for modern teachers, although few of them currently regard bedside teaching as their greatest achievement. Most surveys today show that teachers spend less than 25% of their teaching time at the bedside, instead preferring conference rooms or the hallway outside patients' rooms as the place of instruction. Barriers to bedside teaching – mostly absent during Osler's time – are insufficient time to teach, dependence of diagnosis on technology, obstacles created by infection control, and distractions from clinical responsibilities at distant computer stations. Also, many teachers find bedside teaching inherently difficult: normal clinical activities frequently interrupt all but the shortest of prepared bedside lessons, and spontaneous questions from patients and learners at the bedside are often unanswerable, at least immediately, and may fall outside the teacher's expertise. <http://jama.jamanetwork.com/article.aspx?articleid=1872820>

Noted in Media Watch, 19 August 2013, #319 (p.19):

- *THE ATLANTIC* | Online – 12 August 2013 – **'Medicine's most important teachers.'** William Osler once said that medical education at its best "begins with the patient, continues with the patient, and ends with the patient." In other words, no matter how knowledgeable and skilled our medical school faculty members, medical education centers less on what the teachers seek to teach than on what patients need future physicians to learn. <http://www.theatlantic.com/health/archive/2013/08/medicines-most-important-teachers/278573/>

Noted in Media Watch, 25 February 2013, #294 (p.13, under 'Worth Repeating'):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2011;1(2):193-197. **'Overcoming the challenges of bedside teaching in the palliative care setting.'** Bedside teaching is the process of active learning in the presence of a patient and is one of the most traditional teaching techniques used in undergraduate medicine. Students and patients both appear to benefit from the ... bedside experience. However, bedside teaching with medical students and palliative care patients presents a number of challenges for the patient, the learner and the educator. <http://spcare.bmj.com/content/1/2/193.abstract?sid=68a10cdd-e64a-4b9a-b17e-947fe2be9bab>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 May 20 – '**Palliative care in the intensive care unit: Are residents well trained to provide optimal care to critically ill patients?**' The most common barrier identified by residents [i.e., study participants] was discrepancies in goals of care between the medical team and patients/families (18.7%). A palliative care consult was most commonly obtained when the patient was terminally ill (22.9%). <http://ajh.sagepub.com/content/early/2014/05/30/1049909114536979.abstract>
- *HEALTH AFFAIRS* | Online – 28 May 2014 – '**Palliative care: A new direction for education and training.**' The fundamental approach to decision-making for the older adult with serious illness needs to change from the standard approach to the palliative care approach. <http://healthaffairs.org/blog/2014/05/28/palliative-care-a-new-direction-for-education-and-training/>

Preferences on end-of-life decisions among older Chinese in Macau

JOURNAL OF TRANSCULTURAL NURSING | Online – 20 May 2014 – Four major themes were identified [in this study]: a) institutionalized care at the end of life was preferred as not to be a burden on family; b) life-prolonging measures were not preferred; c) funeral arrangement preferences were based on personal and religious beliefs; and, d) end-of-life decision making would be deferred to others. These themes provide an understanding of personal preferences of older Chinese on end-of-life issues, and personal preferences are always secondary to their respect toward family and medical doctors. This compliance with family and medical authority can be understood through Chinese cultural beliefs. Knowledge of cultural influences is needed for nursing professionals to deal effectively with older adults and families regarding end-of-life issues. <http://tcn.sagepub.com/content/early/2014/05/20/1043659614526758.abstract>

Disposal or dispersal? Environmentalism and final treatment of the British dead

MORTALITY | Online – 28 May 2014 – This article shows how this operates when the "waste" comprises human remains, specifically how innovative "dispersal" practices are now challenging the "disposal" discourse of nineteenth-century burial and twentieth-century cremation which contained the dead within special death spaces separated from everyday environments for living. Since the 1990s, disposal practices have been supplemented by practices with an entirely different rationale. Instead of containing the dead in safe, out of the way places, new practices disperse human remains back into environments that sustain the living, whether this be via natural burial, new cremation practices or new technologies currently being developed, namely alkaline-hydrolysis and freeze-drying. Promoters of all these innovations appeal to ecological usefulness, blurring the boundary between the living and the dead, thereby positioning the dead body as a gift to the living and/or to the planet. Thus, a new ecological mentality is increasingly framing the management of all the dead – not just those interred in natural burial grounds. In the light of this, we reconsider land use policy, and question death studies' use of the term "disposal." <http://www.tandfonline.com/doi/abs/10.1080/13576275.2014.920315?queryID=%24%7BresultBean.queryID%7D>

Noted in Media Watch, 26 May 2014, #359 (p.10):

- *THE GEOGRAPHICAL JOURNAL* | Online – 15 May 2014 – '**Sustainable deathstyles? The geography of green burials in Britain.**' The authors map the emergence of a new mode of burial and remembrance in Britain. Since a "green" burial ground was established in Carlisle in 1993, sites for so-called "green," "natural" or "woodland" funerals have proliferated. <http://onlinelibrary.wiley.com/doi/10.1111/geoj.12087/abstract;jsessionid=B9F94AECA4F2BA2E1207A9416C9CF8D8.f03t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: A systematic review

PALLIATIVE MEDICINE | Online – 27 May 2014 – The authors reviewed 78 studies examining end-of-life care in over 3.7 million cancer decedents; 33 were published since 2008. They observed exponential increases in service use and costs as death approached; hospital services being the main cost driver. Palliative services were relatively underutilized and associated with lower expenditures than hospital-based care. The 15 studies using quality indicators demonstrated that up to 38% of patients receive chemotherapy or life-sustaining treatments in the last month of life and up to 66% do not receive hospice/palliative services. Observational studies using health administrative data have the potential to drive evidence-based palliative care practice and policy. <http://pmj.sagepub.com/content/early/2014/05/24/0269216314533813.abstract>

End-of-life care in The Netherlands

Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: A national survey of the considerations and beliefs of GPs, intellectual disabilities physicians and care staff

PATIENT EDUCATION & COUNSELING | Online – 23 May 2014 – Professionals predominantly believed that considerations about quality of life are most important. Quality of life and wellbeing were also frequently considered in both decisions to start/continue an intervention and decisions to forgo/withdraw an intervention. Seventy per cent believed that people with ID [intellectual disabilities] should always be informed about interventions, and 61% would respect a refusal by the person. The family's wishes were explicitly considered more often than the wishes of the person with ID. Although respondents agree that the quality of life is highly important, the wishes of people with ID ... were often not considered in decisions about potentially burdensome medical interventions. [http://www.pec-journal.com/article/S0738-3991\(14\)00194-3/abstract](http://www.pec-journal.com/article/S0738-3991(14)00194-3/abstract)

Of related interest:

- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 27 May 2014 – **'To move or not to move': A national survey among professionals on beliefs and considerations about the place of end-of-life care for people with intellectual disabilities.** Professionals [i.e., study participants] agree that end-of-life care for people with intellectual disabilities should preferably take place in the client's home environment, even when nursing expertise, experience and adequate equipment are not (yet) in place. Nonetheless, a lack of expertise in end-of-life care is the foremost consideration in decisions to move a client. <http://onlinelibrary.wiley.com/doi/10.1111/jir.12130/abstract;jsessionid=75D2DD1B792FE97339AE179D38A0B710.f02t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 23 May 2014 – **'The challenges of providing culturally competent care within a disability focused team: A phenomenological exploration of staff experiences.'** Two superordinate themes emerged. The first concentrated on difficulties with language and communication and the challenges posed by the use of interpreters. The second included five subthemes that broadly described a five-stage process of dealing with barriers and engagement to service delivery, followed by reflections on the effort made to provide culturally competent care in the face of limited resources and training. <http://tcn.sagepub.com/content/early/2014/05/23/1043659614526454.abstract>

Noted in Media Watch, 11 November 2013, #331 (p.15):

- *PERSPECTIVES ON GERONTOLOGY*, 2013;18(3):380-387. **'Supporting adults with intellectual and developmental disabilities and communication disorders to express end-of-life wishes.'** This article addresses end-of-life communication issues faced by adults living with intellectual and developmental disabilities, their caregivers, and medical professionals. <http://div15perspectives.asha.org/content/18/3/80.abstract>

Cont.

Noted in Media Watch, 22 April 2013, #302 (p.9):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES*, 2013;26(3):215-230. **'The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities.'** This paper looks at the experiences of staff in dealing with issues of death and dying. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12024/abstract>

N.B. This issue of the journal focuses on dying and death, and people living with intellectual disabilities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>

Do unto others: Doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives

PLOS ONE | Online – 28 May 2014 – Data show there is accelerating fragmentation of care of seriously ill Americans at the end-of-life. Dying patients continue to be hospitalized and subjected to ineffective therapies that erode their quality of life and their personal dignity. Doctors' attitudes have hardly changed in the past 23 years despite the passage of the Patient Self Determination Act [1990]. The data show doctors have a striking personal preference to forego high-intensity care for themselves at the end-of-life and prefer to die gently and naturally. To the best of the authors' knowledge, this is the first study to analyze resuscitation preferences of a large and diverse cohort of younger doctors and to determine that they too predominantly opt for comfort care for themselves at the end of life. Current national data show very clearly that terminally ill Americans receive care from many subspecialists in the last six months of life and are subjected to ineffective high-intensity treatments only to die expected deaths from known chronic illnesses. An important question our study raises is why doctors choose to forego high-intensity treatments for themselves at the end-of-life but continue to provide such care to their terminally ill patients? In other words, why are doctors choosing care for themselves that is very different from what they provide to their patients? <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0098246>

Physician perspectives on end-of-life care

'How doctors die: Showing others the way,' *The New York Times*, 19 November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.5)] <http://www.nytimes.com/2013/11/20/your-money/how-doctors-die.html>

'How to die like a doctor,' *Forbes*, 7 March 2012. [Noted in Media Watch, 12 March 2012, #244 (p.3)] <http://www.forbes.com/sites/carolynmccclanahan/2012/03/07/how-to-die-like-a-doctor/>

'Doctors do die differently...,' *Forbes*, 2 March 2012. [Noted in Media Watch, 5 March 2012, #243 (p.2)] <http://www.forbes.com/sites/carolynmccclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/>

'How doctors choose to die,' *The Guardian* (U.K.), 19 February 2012. [Noted in Media Watch, 27 February 2012, #242, p.8] <http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors>

'Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo,' *The Daily Mail* (U.K.), 14 February 2012. [Noted in Media Watch, 27 February 2012, #242 (p.8)] <http://www.dailymail.co.uk/health/article-2100684/Why-doctors-like-die-endure-pain-treatment-advanced-cancer.html>

'What doctors know – and we can learn – about dying,' *Time Magazine* (U.S.), 16 January 2012. [Noted in Media Watch, 23 January 2012, #237 (p.2)] <http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit>

[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>

The challenge of dialysis at the end of life

RENAL & UROLOGY NEWS | Online – 1 June 2014 – Dialysis is now used as a maintenance treatment as frequently as for acute episodes, but a shift has occurred in the manner and frequency with which it is offered to different patient populations. "Many of these patients don't realize they are in the final phase of life because no one has talked forthrightly with them," said Mildred Z. Solomon, president of The Hastings Center, an independent, New York-based bioethics research institute. "Many people are being put on dialysis as a rite of passage before they die." There is a simmering movement by physicians and ethicists who are concerned with the role dialysis has played near the end of life. It is time ... to begin having difficult discussions, including advising patients about the likely trajectory of their illness and their prognosis, as well as discussing whether dialysis is something they want to start and letting them know it can be stopped. <http://www.renalandurologynews.com/the-challenge-of-dialysis-at-the-end-of-life/article/348877/>

Describing spirituality at the end of life

WESTERN JOURNAL OF NURSING RESEARCH | Online – 25 May 2014 – Spirituality is salient to persons nearing the end of life (EOL). Unfortunately, researchers have not been able to agree on a universal definition of spirituality reducing the effectiveness of spiritual research. A literature review was conducted to determine the common attributes that comprise the essence of spirituality, thereby creating a common ground on which to base spiritual research. Forty original research articles (2002 to 2012) focusing on EOL and including spiritual definitions/descriptions were reviewed. Analysis identified five attributes that most commonly described the essence of spirituality, including meaning, beliefs, connecting, self-transcendence, and value. <http://wjn.sagepub.com/content/early/2014/05/23/0193945914535509.abstract>

Representative sample of articles on spirituality and end-of-life care noted in recent issues of Media Watch:

- *JOURNAL OF PASTORAL CARE & COUNSELING*, 2014;68(1). **'In the shadow of death: Existential and spiritual concerns among persons receiving palliative care.'** This study explores existential and spiritual concerns from the perspective of people receiving palliative care. Findings reveal existential and spiritual aspects as interconnected and an integral part of the participants' everyday existence. [Noted in Media Watch, 31 March, 2024, #351 (p.9)] <http://journals.sfu.ca/jpcp/index.php/jpcp/article/view/691>
- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. **'Six understandings of the word 'spirituality' in a secular country.'** Spirituality is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>

N.B. This issue of the *Archive for the Psychology of Religion* focuses on spirituality. Contents page: <http://booksandjournals.brillonline.com/content/15736121>.
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3):111. **'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.'** This issue of the journal gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care. [Noted in Media Watch, 24 June 2013, #311 (p.12)] Contents page: <http://www.tandfonline.com/toc/wswe20/current>
- *ONCOLOGY NURSING FORUM*, 2014;41(1):33-39. **'Spirituality and uncertainty at the end of life.'** Health professionals must recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the need to frequently assess for spiritual uncertainty. Recommendations are provided in addressing spiritual uncertainty with patients. [Noted in Media Watch, 6 January 2014, #339 (p.13)] <http://ons.metapress.com/content/qu254t23r3126830/>

Worth Repeating

Strategies used by families to navigate uncharted territory when a child is dying

JOURNAL OF PALLIATIVE CARE, 2005;21(2):103-110. The eight families in this grounded theory study moved through a process of navigating uncharted territory as they lived with a child who was dying from a neurodegenerative, life-threatening illness. The process was characterized by four dimensions: 1) entering unfamiliar territory; 2) shifting priorities; 3) creating meaning; and, 4) holding the fort. Parents used strategies such as seeking and sharing information; going into slow motion and focusing on the child; taking one day at a time and reframing the experience; and living by the clock and promoting the child's health, to manage the physical, cognitive, and emotional work arising from the situation. This paper focuses on the strategies that families used. <http://dev.europepmc.org/abstract/MED/16114809/reload=0;jsessionid=HJEXBEkPeOXnFTzEQWfv.0>

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.



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

Home page: <http://www.worldday.org/>

Materials: <http://www.worldday.org/materials/>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/>

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]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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>

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