Media Watch...

is intended as an advocacy, research and teaching 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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Social disadvantage at end of life: Scroll down to <u>Specialist Publications</u> and 'Palliative care and vulnerability: An impossible equation? A study of social sheltering in palliative care units' (p.10), in *Médecine Palliative*.

Canada

End-of-life care in Ontario

Another sad tale of incompetence

ONTARIO | The Windsor Star - 20 February 2015 - In Windsor, about 200 people per year spend their final days at the Hospice of Windsor under their care. Slightly more pass away in the 20 palliative care beds in the hospitals. Far more of us – between 500 and 600 people each year - get to spend our final moments at home. Until 2006 one lonely doc, Dr. Charmaine Jones, handled every Windsor case herself. She retired and left town a burnout. Now a team does her work because more and more of us are asking to die at home or in a hospice with our loved ones near, rather than in a hospital bed in ER or ICU. So you'd think there would be a plan to have these people trained, organized and available to all who need them. But there wasn't - not until 2011, when Windsor physician Dr. Darren Cargill helped set up a province-wide palliative care plan under the auspices of the Ontario Medical Association [OMA]. Cargill's OMA committee lined up about 40 teams of about 200 other palliative care docs all across the province so that most Ontario residents could have similar access to their services 24/7. By 2012, 30 teams agreed to a deal with the province to pay them \$63 per week to cover each patient, or about \$172,000 per team per year. That's about \$5 million for the entire province. The government agreed, and the teams went to work. But two years later, not one of the docs - or the nurses - has been paid a nickel for their work yet. They've been doing the extra hours, on call at night and on weekends and holidays, paying staff and incurring office expenses and missing family events. But no cheques arrive in the mail. The OMA has written repeatedly to the ministry to ask what's up with the 2012 agreement, and get form letter responses. Why is that? The doctors' efforts have spared thousands of people from unwanted final hours in hospital. Instead, the palliative teams either made house calls or dispatched nurses to administer the drugs which made it possible for them to pass away in their own beds, family at their sides. http://blogs.windsorstar.com/opinion/chrisvander-doelen-another-sad-tale-of-incompetence

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE TORONTO STAR (OpEd) | Online 27 February 2015 'Ottawa should start drafting new law on assisted suicide.' When Canadians go to the polls later this year they aren't likely to reward Prime Minister Stephen Harper and his Conservative government for dragging out the process of crafting a new law on physician-assisted suicide. The country needs an updated law, and soon. After debating the issue for a generation most Canadians, 80%, have come around to the view that desperately suffering people should be entitled to get help ending their lives, within strict limits. And the Supreme Court agrees. It's now up to Parliament to craft a new law with some dispatch. Yet Harper continues to play for time, telling Parliament he intends to consult "widely and very comprehensively" with Canadians "of all backgrounds" before responding to the Supreme Court ruling. That doesn't sound like a politician who's in a hurry to grasp the nettle. http://www.thestar.com/opinion/editorials/2015/02/26/ottawa-should-start-drafting-new-law-on-assisted-suicide-editorial.html
- THE NATIONAL POST | Online 26 February 2015 'No need for Harper government to enact new assisted-suicide legislation: Professor.' As pressure mounts on the Harper government to enact new doctor-assisted death legislation, a provocative school of thought is emerging: why not leave the field unregulated? "We don't legislate to regulate how doctors withdraw life-saving treatment. Why must we legislate to regulate how they administer suicide?" said Amir Attaran, a prominent University of Ottawa law professor who holds the Canada Research Chair in law, population health and global development policy. It is illogical, he said, to believe "we must legislate or else" in the wake of the Supreme Court of Canada ruling legalizing assisted suicide. Mr. Attaran said this ... decision favoured "a carefully designed and monitored system of safeguards," but did not say they needed to be legislated safeguards. http://news.nationalpost.com/2015/02/26/no-need-for-harper-government-to-enact-new-assisted-suicide-legislation-professor/
- THE NATIONAL POST | Online 23 February 2015 'How far should a doctor go? MDs say they need clarity on Supreme Court's assisted suicide ruling.' Canada's doctors are seeking clarity from the federal government on what the Supreme Court of Canada intended in its landmark ruling on assisted dying, including the question of how far a doctor is permitted to go in contributing to a patient's death. "We've got a few key questions that we think need clarity and this is one of them: Is it euthanasia or is it assisted dying?" said the Canadian Medical Association's director of ethics and professional affairs, Dr. Jeff Blackmer. The powerful doctors' lobby said it is not clear whether the high court has opened the door not just to assisted suicide where a doctor writes a prescription for a lethal overdose of drugs the patient takes herself but also to something many physicians find profoundly more uneasy: pushing the syringe themselves. Its own internal polling has found 26.7% of doctors would be willing to participate in assisted suicide if requested to by a patient, compared with 20.9% for voluntary euthanasia. http://news.nationalpost.com/2015/02/23/how-far-should-a-doctor-go-mds-say-they-need-clarity-on-supreme-courts-assisted-suicide-ruling/

<u>U.S.A.</u>

Palliative care bill approved by House

OKLAHOMA | *The Edmond Sun* – 26 February 2015 – An advisory panel that helps set state health policies would have more input from experts on the coordinated care of patients with chronic conditions under a measure approved unanimously in the Oklahoma House of Representatives. House Bill 1085 ... modifies the Home Care & Hospice Advisory Council to include palliative care and specifies membership of the Home Care, Hospice & Palliative Care Advisory Council. The measure directs the council to identify ways to improve the quality and delivery of palliative care. The legislation, which will increase the panel's membership from seven to nine members, was approved by a vote of 90-0. It now proceeds to the Oklahoma Senate for consideration. http://www.edmondsun.com/news/state_news/palliative-care-bill-approved-by-house/article_23dd5468-be0c-11e4-9638-fb8ee6c52043.html

Medicare toughens standards on nursing homes

THE NEW YORK TIMES | Online - 20 February 2015 – The star ratings of nearly a third of the nation's nursing homes were lowered on Friday, as federal officials readjusted quality standards in the face of criticism that the ratings were inaccurate and artificially inflated. Federal officials said they hoped the changes would make it easier for consumers to differentiate between facilities, as well as spur nursing homes to make improvements. The changes ... were mainly aimed at one of three major criteria used to rate the homes on the Nursing Home Compare website, which ranks more than 15,000 nursing homes on a one- tofive-star scale. Officials essentially adjusted the curve for the quality-measures rating, which is based on information collected about every patient. Representatives for the nursing home industry said that rather than helping consumers, the changes could frustrate them. http://www.nytimes.com/2015/02/21/business/ nursing-home-ratings-fall-as-tougherstandards-take-effect.html?ref=health& r=0

Specialist Publications

'American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement' (p.6), in *Journal of the American Geriatrics Society.*

'The role of palliative care in population management and Accountable Care Organizations' (p.9), in *Journal of Palliative Medicine*.

'Being discharged from hospice alive: The lived experience of patients and families' (p.9), in *Journal of Palliative Medicine.*

'How well do emergency physicians understand Physicians Orders for Life Sustaining Treatment (POLST) forms?' (p.9), in *Journal of Patient Safety.*

Noted in Media Watch, 1 September 2014, #373 (p.4):

 THE NEW YORK TIMES | Online – 24 August 2014 – 'Medicare star ratings allow nursing homes to game the system.' Only one of the three criteria used to determine the star ratings – the results of annual health inspections – relies on assessments from independent reviewers. <u>http://www.nytimes.com/2014/08/25/business/medicare-star-ratings-allow-nursing-homesto-game-the-system.html</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

STATE OF WASHINGTON | Seattle Weekly – 24 February 2015 – 'Are patients considering death with dignity getting all the information they need?' An Oregon cancer doctor named Kenneth Stevens told a legislative committee in Olympia about a former patient name Jeanette Hall. As he recalled it, Hall had been told she had inoperable cancer and resolved to make use of Oregon's Death With Dignity Act. "This was very much a settled decision," Stevens told the state Senate's Law & Justice Committee. "I informed her, however, that her cancer was treatable and that her prospects were good," he continued. As a result, she underwent treatment. The cancer disappeared. "Today, 15 years later, she's thrilled to be alive," Stevens said. It's for the Halls of the world, or rather of Washington state, that Stevens said he was supporting Senate Bill 5919, which would require doctors treating patients who want to avail themselves of our state's Death With Dignity Act to inform them about possible cures and treatments. http://www.seattleweekly.com/news/957078-129/are-patients-considering-death-with-dignity

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.12.

International

Helping Mexico's terminally ill to "live well"

MEXICO | BBC News (U.K.) – 28 February 2015 – Human Rights Watch estimates that in Mexico tens of thousands of terminally ill patients are suffering because they don't have access to proper end-of-life care. Pain-relieving drugs such as morphine are often difficult to access, and many doctors are unaware of how to navigate the complicated system of prescription. But now the Mexican government is making changes to help the terminally ill to live and die in the best way possible. <u>http://www.bbc.com/news/health-31647273</u>

End-of-life care in England

Patients should have right to choose where they die, says care inquiry

U.K. (England) | The Guardian – 26 February 2015 – People nearing the end of their lives should have the right to choose where they die included in the National Health Service (NHS) constitution, says a report commissioned by ministers in England.¹ The Choice in End-of-Life Care review board recommends that dying patients' choices and preferences on care and treatment be recorded in personal plans that are easily accessible electronically by health and social care professionals. A nominated senior clinician should also be responsible for a dying patient's care. The review board said 24/7 end of life care for people opting to die out of hospital must be available to everyone in the last year of their lives within five years. Despite some "great strides forward," far too many dying people still received inadequate or ill-suited care. Claire Henry, the review board's chair, said they had taken a "pragmatic" approach, sticking to realistic state funding increases of £130 million a year from the next government's first funding review after the election. Almost half a million people die in hospital each year. To help reduce that number by a fifth, older people who have to contribute to their own care will have to pay more, while charities will also have to find more money. The review board's would like to see a 40% reduction in the number of people who die in hospital but takes the view that insisting on extra state funding of more than £800 million a year is not an option in the current financial climate. http://www.theguardian.com/uknews/2015/feb/26/patients-should-have-right-to-choose-where-they-die-says-care-inquiry

 'What's Important to Me: A Review of Choice in End-of-Life Care,' Choice in End-of-Life Care Programme, February 2015. <u>https://www.gov.uk/government/publications/choice-in-end-of-lifecare</u>

Of related interest:

U.K. (England) | *The Basingstoke Gazette* – 22 February 2015 – 'Hospice launches scheme for terminally ill to be cared for at home.' A Basingstoke hospice is introducing an innovative scheme which will allow terminally ill people to be cared for in their own homes. St Michael's Hospice will, over the next five years, introduce four community hubs ... across its referral area of North Hampshire. Each hub will be managed by a senior nurse, who will coordinate a team of palliative care doctors, nurses, therapists and social workers. The teams will work closely with GPs, community nurses, carers and other health-care professionals. http://www.basingstokegazette.co.uk/news/health/11807934.Hospice_launches_scheme_for_t_erminally_ill to be cared for at home/

Back Issues of Media Watch

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: http://www.ipcrc.net/archive-global-palliative-care-news.php

Elder care in Wales

Care home scandals and the fallout from Mid Staffs provides impetus for planned new Welsh social care law

U.K. (Wales) | Wales Online – 23 February 2015 – The Welsh Government is hoping to take on board lessons from a raft of care scandals with a new Assembly law that could give regulators powers to shut all care homes run by operators who do not meet standards. The new Regulation & Inspection of Social Care (Wales) Bill, introduced to the Assembly, aims to shake-up the regulation regime in a bid to make care home owners and operators of other social care services more accountable. <u>http://www.walesonline.co.uk/news/wales-news/care-home-scandals-fallout-mid-8704669</u>

N.B. 'Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013, #292 (p.5)] <u>http://www.midstaffspublicinquiry.com/report</u>

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

Conscientious objection and the standard of care

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS | Online – 25 February 2015 – Recently the scope of protections afforded those healthcare professionals and institutions that refuse to provide certain interventions on the grounds of conscience have expanded, in some instances insulating providers (institutional and individual) from any liability or sanction for harms that patients experience as a result. With the exponential increase in the penetration of Catholic-affiliated healthcare across the country, physicians and nurses who are not practicing Catholics are nevertheless required to execute documents pledging to conform their patient care to the *Ethical & Religious Directives for Health Care Services* as a condition of employment or medical staff privileges. In some instances, doing so may result in patient morbidity or mortality or violate professional standards for respecting advance directives or surrogate decision making. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9572319&fulltextType =RA&fileId=S0963180114000528

Noted in Media Watch, 21 March 2011, #189 (p.9):

 THE HASTINGS REPORT, 2011;41(2):28-29. 'Making sense of the Roman Catholic directive to extend life indefinitely.' In November 2009, the U.S. Conference of Catholic Bishops issued Ethical & Religious Directives for Catholic Health Care Services, requiring that all patients ... be provided with artificial hydration and nutrition if such care could extend life indefinitely. <u>http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5164</u>

Middle East experience as a model for global palliative care

CLINICS IN GERIATRIC MEDICINE | Online – 17 February 2015 – Care for elderly people with life-limiting illness cannot be delivered primarily by geriatricians or palliative care practitioners. The role of these clinicians is to help carers become adept in palliative care medicine. In a culture in which family ties run deep, the offer of palliative care from an outsider may be met with suspicion. The family bond in the Middle East is strong, but the emotional response to terminal illness may push families to request futile treatments, and physicians to comply. When palliative care is well developed and well understood, it provides a viable alternative to such extreme terminal measures. http://www.geriatric.theclinics.com/article/S0749-0690(14)00132-3/abstract

Noted in Media Watch, 19 June 2015, #393 (p.5):

UNITED ARAB EMIRATES | Zawya (Dubai) – 13 January 2015 – 'Healthcare experts in the region call for further development of palliative care for severely ill patients in the Middle East.' Palliative care remains underdeveloped in the Middle East. A few Arab countries such as Lebanon, Kuwait, Saudi Arabia, Sudan, Egypt, and Jordan have limited palliative care services, but most Middle Eastern countries do not have any palliative care at all. https://www.zawya.com/story/Healthcare experts in the region call for further development of palliative care for severely ill patients in the Middle East-ZAWYA20150113065352/

N.B. Noted in this issue of Media Watch are selected articles on palliative care in Middle Eastern countries noted in past issues of the weekly report.

Patient perception of physician compassion after a more optimistic vs. a less optimistic message: A randomized clinical trial

JAMA ONCOLOGY | Online – 26 February 2015 – One hundred patients were randomized to observe two standardized, 4-minute videos depicting a physician discussing treatment information (more optimistic message vs. less optimistic message) with a patient with advanced cancer. Both physicians made an identical number of empathetic statements and displayed identical posture. Patients perceived a higher level of compassion and preferred physicians who provided a more optimistic message. <u>http://oncology.jamanetwork.com/article.aspx?articleid=2120917</u>

American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 26 February 2015 – There is ample evidence lesbian, gay, bisexual, and transgender (LGBT) individuals face discrimination in the healthcare setting. Providing high-quality health care for older LGBT adults will require active steps by organizations, institutions, advocacy groups, and health professionals that create an environment that is free from discrimination. This position statement addresses the vision of the Society for the care of LGBT older adults and specific steps that can be taken to ensure they receive the care that they need. http://onlinelibrary.wiley.com/doi/10.1111/jgs.13297/abstract

Noted in Media Watch, 30 December 2013, #338 (p.2):

- U.S. (New York State) | Advocate 27 December 2013 'End-of-life care for an aging LGBT population.' With the number of self-identified LGBT adults age 65 or older expected to double by 2030 from 1.5 million to 3 million, according to the National Resource Center on LGBT Aging the time has never been more urgent to discuss this silent challenge: How do we meet the unique end-of-life care needs for an aging LGBT population? LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care...¹ notes http://www.advocate.com/health/2013/12/27/end-life-care-aging-lgbt-population
 - 1. The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults, National Resource Center on LGBT Aging, November 2011. <u>http://www.lgbtagingcenter.org/resources/resource.cfm?r=419</u>

N.B. Selected articles on the provision and delivery of end-of-life care for LGBT individuals noted in past issues of Media Watch are listed in the 21 May 2012, #254 (p.9) issue of the weekly report.

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

Hospice in the nursing homes: Perspectives of a medical director

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 21 February 2015 – For more than 3 decades I have practiced and taught geriatric medicine, mostly in the nursing home setting. For those not familiar with nursing home care in the early 1980s, it was almost entirely long-term palliative care, as rehab was carried out in the hospital setting. There were no do-not-resuscitate regulations, as it seemed clearly futile to try to resuscitate nursing home patients. When a patient appeared to failing, usually from multiple co-morbid cognitive and physical issues, measures were put in place to ensure a comfortable and dignified death. http://www.jamda.com/article/S1525-8610(15)00098-5/abstract

Evaluation of an interdisciplinary curriculum teaching team-based palliative care integration in oncology

JOURNAL OF CANCER EDUCATION | Online – 25 February 2015 – This article reports the success of one university's effort to design and implement an interdisciplinary curriculum teaching team-based palliative care in oncology which was mandatory for medical, nursing, social work, and chaplaincy students. Quantitative evaluation indicated students made significant improvements related to palliative care knowledge and skills and readiness for inter-professional education. Feedback revealed that students appreciated the experiential aspects of the curriculum most, especially the opportunity to observe palliative teams at work and practice team-based skills with other learners. While there exist many obstacles to inter-professional education and hands-on learning, the value of such experiences to the learners justifies efforts to initiate and continue similar programs in the health sciences. http://www.ncbi.nlm.nih.gov/pubmed/25708910

Of related interest:

BMC MEDICAL ETHICS | Online – 26 February 2015 – 'New frontiers in the future of palliative care: Real-world bioethical dilemmas and axiology of clinical practice.' In our time there is growing interest in developing a systematic approach to oncologic patients and end-oflife care. An important goal within this domain is to identify the values and ethical norms that guide physicians' decisions and their recourse to technological aids to preserve life. http://www.biomedcentral.com/content/pdf/s12910-015-0003-2.pdf

Noted in Media Watch, 23 February 2015, #398 (p.10):

SUPPORTIVE CARE IN CANCER | Online – 14 February 2015 – 'How well is palliative care integrated into cancer care? A MASCC, ESMO, and EAPC Project.' One hundred eighty-three different institutions completed this survey, 28 % of ESMO designated centers. Most institutions had palliative care programs and most programs consisted of an inpatient consult service and outpatient clinics. A minority had inpatient palliative care beds and institution supported hospice services. http://link.springer.com/article/10.1007/s00520-015-2630-z

N.B. MASCC: Multinational Association of Supportive Care in Cancer; ESMO: European Society for Medical Oncology; EAPC: European Association for Palliative Care.



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

Dignity-conserving care in palliative care settings: An integrative review

JOURNAL OF CLINICAL NURSING | Online – 23 February 2015 – Thirty-one articles were included. Nine dignity model themes were used to classify care actions: 1) level of Independence; 2) symptom distress; 3) dignity-conserving perspectives; 4) dignity-conserving practices; 5) privacy boundaries; 6) social Support; 7) care tenor; 8) burden to others; and, 9) aftermath concerns. Reported care actions included listening, conveying empathy, communication and involving patients in care. Care actions could be classified under most of dignity model themes. However, there were less reported care actions related to level of independence and aftermath concerns, which meant that these had to be formulated independently. Synthesising the available evidence of dignity-conserving care identifies evidence-based care actions and provides guidance to nurses in clinical practice caring for patients with palliative care needs. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12791/abstract

Noted in Media Watch, 7 April 2014, #352 (p.13):

PALLIATIVE MEDICINE | Online – 31 March 2014 –'An integrative review of dignity in endof-life care.' Dying with dignity is regarded as a goal of quality end-of-life care. However, the meaning of dying with dignity is ambiguous, and no comprehensive synthesis of the existing literature has been published. Themes of dying with dignity are as follows: a human right, autonomy and independence, relieved symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential satisfaction, privacy, and calm environment. Factors influencing dignity include demographic, illness-related, and treatment-/care-related factors, as well as communication. Models of dignity in end-of-life care and instruments to measure dignity were reported. Interventions to support dignity stressed physical, psychological, and spiritual supports not only to dying patients but also to family members. http://pmi.sagepub.com/content/early/2014/03/31/0269216314528399.abstract

Do advance directives direct?

JOURNAL OF HEALTH POLITICS. POLICY & LAW | Online – 19 February 2015 – Resolution of long-standing debates about the role and impact of advance directives ... has been hampered by a dearth of appropriate data, in particular data that compare the process and outcomes of end-of-life decision making on behalf of patients with and without advance directives. Drawing on a large ethnographic study of patients in two intensive care units in a large urban teaching hospital, this article compares aspects of the medical decisionmaking process and outcomes by advancedirective status. The study finds few significant differences between patients without advance directives and those who claim to have them. Surprisingly, these few differences hold only for those whose directives are in their hospital chart. There are no significant differences between those with no directive and those claiming to have a copy at home or elsewhere. The article considers the implications if directives seemingly must be in hand even to show modest effects. Do advance directives direct? http://jhppl.dukejournals.org/content/early/201 5/02/12/03616878-2888424.abstract

Challenges in Choosing Wisely's international future

JAMA INTERNAL MEDICINE | Online – 25 February 2015 – Since its 2012 launch by the American Board of Internal Medicine Foundation, the Choosing Wisely campaign has affected more than 60 U.S. specialty societies. The campaign is becoming an international phenomenon, This rapid expansion is a heartening sign that there is increasing international sentiment against wasteful medical practices. However, actually decreasing wasteful and harmful health care will require patient and physician commitment as well as objective evidence of effectiveness.<u>http://archinte.jamanetwork.com/article.aspx?a</u> rticleid=2130720

Of related interest:

 JOURNAL OF PATIENT SAFETY, 2015;11(1):1-8. 'How well do emergency physicians understand Physicians Orders for Life Sustaining Treatment (POLST) forms?' Significant confusion exists among members of the Pennsylvania chapter of the American College of Emergency Physicians [i.e., survey respondents] regarding the use of POLST in critically ill patients. This confusion poses risk to patient safety. Prior POLST education had no impact. http://journals.lww.com/journalpatientsafety/Abstract/2015/03000/TRIAD VI How Well Do Emergency Physicians.1.aspx

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

The role of palliative care in population management and Accountable Care Organizations

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 February 2015 – By 2021, health care spending [in the U.S.] is projected to grow to 19.6% of the GDP [Gross Domestic Product], likely crowding out spending in other areas. The 2010 Affordable Care Act (ACA) attempts to curb health care spending by incentivizing high-value care through the creation of Accountable Care Organizations (ACOs), which assume financial risk for patient outcomes. With this financial risk, health systems creating ACOs will be motivated to pursue innovative care models that maximize the value of care. Palliative care, as an emerging field with a growing evidence base, is positioned to improve value in ACOs by increasing high-quality care and decreasing costs for the sickest patients. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0231

Being discharged from hospice alive: The lived experience of patients and families

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 February 2015 – Approximately 259,000 patients were discharged alive from U.S. hospices in 2010. The study explored the experiences of adults discharged ... due to decertification related to ineligibility or extended prognosis ... Findings included two primary themes: 1) suffering "AS"; and, 2) the paradox of hospice discharge. These ... were supported by 12 sub-themes: 1) abandonment; 2) unanswered questions; 3) loss of security; 4) loneliness; 5) uncertainty; 6) anger and frustration; 7) physical decline; 8) bearing exhaustive witness; 9) having and needing support; 10) mixed feelings; 11) not dying fast enough; and, 12) hospice equals life. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0228

Promoting resiliency among palliative care clinicians: Stressors, coping strategies, and training needs

JOURNAL OF PALLIATIVE MEDICINE | Online - 25 February 2015 - Palliative care clinicians (PCCs) are susceptible to burnout, as they regularly witness immense patient and family suffering: however, little is known about their specific challenges and training needs to enhance their long-term sustainability. The purpose of this qualitative study was to explore common stressors, coping strategies, and training needs among PCCs in efforts to inform the development of a targeted resiliency program. Content analysis highlighted three main areas of stressors: 1) systematic challenges related to managing large, emotionally demanding caseloads within time constraints; 2) patient factors, such as addressing patients' mutable needs, managing family dynamics, and meeting patient and family demands and expectations; and, 3) personal challenges of delineating emotional and professional boundaries. Engaging in healthy behaviors and hobbies and seeking emotional support from colleagues and friends were among the most common methods of coping with stressors. In terms of programmatic topics, PCCs desired training in mind-body skills (e.g., breathing, yoga, meditation), health education about the effects of stress, and cognitive strategies to help reduce ruminative thoughts and negative self-talk. A majority of clinicians stressed the need for brief strategies that could be readily integrated in the workplace. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0221

Noted in Media Watch, 17 November 2014, #384 (p.7):

ClÊNCIA & SAÚDE COLETIVA, 2014;19(12):4829-4878. 'Resilience and death: The nursing professional in the care of children and adolescents with life-limiting illnesses.' The care given to children and adolescents with life-limiting illnesses triggered resilience-related answers [among the study participants] concerning alternatives that oscillate between individual reactions ... and the search for a ... collective support based on personal relationships. http://www.scielo.br/pdf/csc/v19n12/1413-8123-csc-19-12-04869.pdf

Noted in Media Watch, 19 May 2014, #358 (p.7):

 JOURNAL OF ALTERNATIVE & COMPLEMENTARY MEDICINE | Online – 7 May 2014 – 'Promoting resiliency among palliative care clinicians: A pilot intervention.' No intervention has been reported in looking at resilience within an interdisciplinary group of palliative care team members. <u>http://online.liebertpub.com/doi/full/10.1089/acm.2014.5270.abstract</u>

Palliative care and vulnerability: An impossible equation? A study of social sheltering in palliative care units

MÉDECINE PALLIATIVE | Online – 27 February 2015 – At a time when care is being rationalized, the question arises: is there adequacy between the provision of palliative care and the needs generated by social disadvantage in end-of-life? The objective of this study was to assess the actual status of social sheltering in pallative care units and determines the causal factors. Social sheltering was defined as the period during which a patient remains in hospital between the day of being deemed medically fit for discharge and the actual day of discharge. The authors identified the factors that impede a patient's discharge, within three categories: family, financial, and structural. Of the 44 identified stays, 16 were extended for purely social reasons, equating to 10.3 % of nights being social sheltering. Social sheltering appeared to be the result of at least two factors of vulnerability from amongst poverty, isolation, and poor accommodation, which – in the absence of any alternative to hospitalization – prevented the return at home. Social sheltering is a reality whether the responsibility is assumed by palliative care units or passed downstream. http://www.sciencedirect.com/science/article/pii/S1636652215000021

N.B. French language article

Tracey and respect for autonomy: Will the promise be delivered?

MEDICAL LAW REVIEW | Online – 25 February 2015 – The central issue of the Court of Appeal decision in *R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors* ... concerned whether competent adults should be involved in the decision-making process for do not attempt cardio-pulmonary resuscitation (DNACPR) decisions. These are sensitive decisions made on the basis that cardio-pulmonary resuscitation would be futile, or that efforts to resuscitate would not be in the best clinical interests of the person concerned. The Court held that patient involvement in DNACPR decisions should be the presumption, even if clinicians sincerely believed that resuscitation would be futile, unless that involvement would cause actual psychological or physical harm. This case commentary explores the potential implications of this decision... <u>http://medlaw.oxfordjournals.org/content/early/2015/02/24/medlaw.fwv003.abstract</u>

Noted in Media Watch, 23 June 2014, #363 (p.6):

U.K. (England) | BBC News – 17 June 2014 – 'Legal duty over resuscitation orders.' Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate order on medical notes, the Court of Appeal in England ruled. The issue was raised by a landmark judgement that found doctors at Addenbrooke's Hospital, in Cambridge, had acted unlawfully. http://www.bbc.com/news/health-27886265

Of related interest:

PSYCHO-ONCOLOGY | Online – 23 February 2015 – "'We have to discuss it": Cancer patients' advance care planning impressions following educational information about cardiopulmonary resuscitation.' Of 54 study participants, 26 ... articulated questions, comments, or both. Reviewer analyses demonstrated thematic consensus and resulted in seven distinct themes listed in decreasing order of prevalence: 1) Advance care planning (ACP) should be started early; 2) educational information about CPR affirmed participants' existing beliefs/knowledge/values about advanced illness; 3) participants were apprehensive about ACP but wanted to discuss it; 4) gaps in knowledge about ACP emerged; 5) CPR information was helpful/acceptable; 6) physicians should be involved in ACP; and, 7) medical questions about critical illness arose. http://onlinelibrary.wiley.com/doi/10.1002/pon.3786/abstract

When a child dies: Pediatric oncologists' follow-up practices with families after the death of their child

PSYCHO-ONCOLOGY | Online - 23 February 2015 – Pediatric oncologists [i.e., study participants] actively engage in follow-up practices that include making phone calls, sending an email or condolence card, attending funerals or visitations, having longterm and short-term meetings with parents, and attending hospital or departmental memorials for the deceased child. Attending funerals or visitations was less frequent and varied widely across pediatric oncologists. Reasons for not participating in bereavement follow-up practices included logistical, emotional, and practical considerations. While the majority of pediatric oncologists at two Canadian centers engage in some follow-up practices with bereaved families, these practices are complex and challenging because of the emotional nature of these interactions. Medical institutions should provide both structured time for this follow-up work with families, as well as medical education and financial and emotional support to pediatric oncologists who continue caring for these families long after their child has died. http://onlinelibrary.wiley.com/doi/10.1002/po n.3770/abstract

Bereavement and loss: Developing a memory box to support a young woman with profound learning disabilities

BRITISH JOURNAL OF LEARNING DISABILI-TIES | Online – 17 February 2015 – Supporting bereaved people with profound learning disabilities still remains an under-researched area. Moreover, the barriers of communication and disenfranchised grief mean that they often do not receive the support they require, leading to emotional and behavioural difficulties. This article describes research ... which explored how memory box work was used to support the bereavement process with one young woman, Claire, and the outcomes for Claire and her family. Exploring the history of the relationship between Claire and her brother, the work also benefitted her mother... http://onlinelibrary.wiley.com/doi/10.1111/bld.121 29/abstract;jsessionid=514C1C39662EAB74BCF 73DB45611BFFE.f01t04?deniedAccessCustomis edMessage=&userIsAuthenticated=false

Of related interest:

 AUSTRALIAN CRITICAL CARE | Online – 21 February 2015 – 'What is "normal" in grief?' Research conducted over the past two decades has revealed that grief ... is rarely experienced as a steady progression from high acuity (intensity) to eventual resolution. Instead of this single "traditional" path, four distinct trajectories are supported by empirical data: resilience, chronic grief, depressed-improved, and chronic depression. Furthermore, a small subset of individuals never fully integrate the loss into their life, and continue to experience severe disruption in daily life many years after the loss event, a phenomenon known as Complicated Grief. http://www.australiancriticalcare.com/article/S1036-7314(15)00006-5/abstract

Gravesites and websites: A comparison of memorialisation

VISUAL STUDIES, 2015;30(1):37-53. For centuries, gravesites have been utilised for memorialisation, and in recent time, websites are also used as memorials, and in this article, the authors compare these two different groups of artefacts. Through a careful consideration of the form, composition and content of physical and online memorial sites for the dead, they suggest contrasting modes of relations across these two groups in terms of collectives, time and space and the relationships with the deceased themselves. On the one hand, the gravesite memorial uses its carved stone, inscriptions and position in place to imply a mode of relations that is modern, structured, objectified, formal and intransient: the dead remain spatially sequestered, socially dead and bureaucratised. On the other hand, the Web memorial implies a mode of relations that is subtly different – a mode of relations that is neo-modern, networked, subjective, personal and fluid. <u>http://www.tandfonline.com/doi/abs/10.1080/1472586X.2015.996395#.VOzNhXzF_YR</u>

N.B. This issue of *Visual Studies* includes a section on the aesthetic of death and after-death in an Internet age. Journal contents page: <u>http://www.tandfonline.com/toc/rvst20/30/1#.VOzPFHzF_YQ</u>

Media Watch Online
International
INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2015/02/media-watch/#CHINESE</u>
INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <u>http://www.ipcrc.net/archive-global-palliative-care-news.php</u>
PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch
PALLIMED (Hospice & Palliative Medicine Blog): <u>http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</u> [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): <u>http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</u>
Australia
WESTERN AUSTRALIA Palliative Care WA Inc: <u>http://palliativecarewa.asn.au/site/helpful-resources/</u> [Scroll down to 'International Websites' and <u>www.ipcrc.net/archive-global-palliative-care-news.php</u> to access the weekly report]
Canada
ONTARIO HPC Consultation Services (Waterloo Region/Wellington County): <u>http://hpcconnection.ca/general-resources/in-the-news/</u>
ONTARIO Palliative Care Consultation Program (Oakville): <u>http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</u> [Scroll down to 'Additional Resources']
Europe
EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://www.eapcnet.eu/Themes/Organization/Links.aspx</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]
HUNGARY Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes
U.K. Omega, the National Association for End-of-Life Care: <u>http://www.omega.uk.net/media-watch-hospice-palliative-</u> care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Assisted (or facilitated) death

Representative sample of recent news media coverage:

DER SCHMERZ | Online – 22 February 2015 – 'Tötung auf verlangen und assistierter suizid.' The current debate about end-of-life decisions in Germany focuses on physician-assisted suicide (PAS). However, there is only limited information available on physicians' attitudes towards euthanasia or PAS, and no data on nurses' attitudes. The [survey] questions focused on two scenarios: 1) a patient with an incurable fatal illness, and 2) a patient with an incurable but non-fatal illness. The question was: "Should euthanasia or physician-assisted suicide (PAS) be allowed." In addition, the participants were asked what they wanted for themselves if they were the patient concerned. The general support for euthanasia and PAS was high: 40.5 % supported euthanasia in case of a fatal illness ("definitely...," "probably should be allowed"), 53.5 % supported PAS. The support decreased in case of a non-fatal illness; however, it increased when the participants were asked about their attitudes if they were the patient concerned. http://link.springer.com/article/10.1007/s00482-015-1513-z#

N.B. German language article.

EUROPEAN JOURNAL OF COMPARATIVE LAW & GOVERNANCE, 2015;2(1):37-91. 'Comparing the law and governance of assisted dying in four European nations.' This article provides a comparative law and governance insight to assisted dying in England, France, Switzerland and the Netherlands, bringing together empirical studies of regulation and normative thinking about the role of the state. It follows the "new governance" scholarly effort to challenge the conventional wisdom that regulation, especially in regard to controversial and sensitive public policy issues, must be determined by top-down, command and control rules. http://booksandjournals.brillonline.com/content/journals/10.1163/22134514-00201003

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.

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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.

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