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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Compiled & Annotated by Barry R. Ashpole

Communicating in a sensitive and timely manner: Scroll down to <u>Specialist Publications</u> and 'What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key' (p.10), in *The Oncologist*.

Canada

Family caregiver job protection

Employment Standards Amendment Act came into effect 29 October

ONTARIO | *Northern Life* (Sudbury) – 31 October 2014 – New provincial legislation will allow Ontario caregivers to take extra time off work without the risk of losing their jobs. The Employment Standards Amendment Act allows family caregivers to apply for unpaid leave from their jobs under a number of different conditions. Family caregiver leave allows an individual [for example] to take up to eight weeks of unpaid, job-protected leave to care for a family member with a serious medical condition. <u>http://www.northernlife.ca/news/localNews/2014/10/31-caregiver-leave-of-</u> work-sudbury.aspx

Assisted (or facilitated) death

Representative sample of recent news media coverage:

ONTARIO | The Guelph Mercury – 1 November 2014 – 'Comprehensive palliative care reduces need for assisted suicide.' In mid-October, the Supreme Court of Canada heard an appeal by the B.C. Civil Liberties Association that could grant terminally ill Canadians the right to assisted suicide. With the court's impending ruling, which is not expected for several months, and the passing of Bill 52 in Quebec (Medical Aid in Dying) and rumblings from Parliament of another private member's bill on assisted suicide, Canada is at a crossroads. The court faces a daunting task. The arguments it heard are complex, diverse and impassioned, given our societal fear of death and the process leading to it. While some will try to reassure the court that many Canadians support physician hastened death, others will caution that popularity is hardly a trustworthy guide to constructive and just social policy reform. But first, the court must consider whether its decision will improve care for the terminally ill. http://www.guelphmercury.com/opinion-story/4955557-comprehensive-palliative-care-reduces-need-for-assisted-suicide/

- THE NATIONAL POST | Online 27 October 2014 'Margaret Somerville: Rejecting euthanasia and respecting the secular spirit.' Recently, [journalist] Jonathan Kay, [broad-caster] John Moore and I participated in a panel on CBC's The National [news program] discussing assisted suicide and euthanasia.¹ Kay supported extreme individual autonomy: Whatever their reason, competent adults should have the right to euthanasia. Moore proposed some conditions, such as terminal illness, on exercising that right. I argued that we should reject euthanasia, in part, because it's dangerous for vulnerable people and society. Subsequently, both Kay and Moore wrote articles ... supporting their views and decrying mine.^{2,3} http://fullcomment.nationalpost.com/2014/10/27/margaret-somerville-rejecting-euthanasia-and-respecting-the-secular-spirit/
 - 1. 'Assisted suicide: Where do Canada and other countries stand?' CBC's The National, 13 October 2014. [Noted in Media Watch, 20 October 2014, #380 (p.2)] <u>http://www.cbc.ca/news/canada/assisted-suicide-where-do-canada-and-other-countriesstand-1.2795041</u>
 - 2. 'Why my generation will be the one to enshrine the right to assisted suicide,' *The National Post*, 16 October 2014. <u>http://fullcomment.nationalpost.com/2014/10/16/jonathan-kay-why-my-generation-will-be-the-one-to-enshrine-the-right-to-assisted-suicide/</u>
 - 3. 'Don't tell me how to die,' *The National Post*, 17 October 2014. http://fullcomment.nationalpost.com/2014/10/17/john-moore-dont-tell-me-how-to-die/

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

Relief at the door: Palliative care improves lives and eases the cost of dying

CALIFORNIA | USA Today – 1 November 2014 – This seemingly straightforward, yet pioneering system – recognized as "outpatient palliative care" – is element of an experiment sponsored by the Palo Alto Medical Foundation, soon to expand all through much of the Bay Area. A comparable innovation will appear in San Jose in the fall with the opening of the Palliative Care Center Silicon Valley, the very first independent stand-alone facility of its type in California, run by Hospice of the Valley. Palliative care is not hospice, which also focuses on emotional assistance and relieving symptoms for persons in the final six months of a terminal illness. Palliative sufferers might have a number of years left. And it does not require providing up the chase for a remedy, as hospice does. In fact, palliative care can ease illnesses that aggressive treatments frequently trigger. But neither is it a hospital, exactly where aggressive care at every crisis can cost tens of thousands of dollars. http://www.usanews.net/breaking/relief-at-the-door-palliative-care-improves-lives-the-cost-of-dying-h36551.html

The ethical will, an ancient concept, is revamped for the tech age

THE NEW YORK TIMES | Online – 31 October 2014 – Originally an oral tradition, ethical wills have been used by Jewish people for centuries to pass on life lessons and ethics, such as the importance of charity. In the 11th century, ethical wills began to be written down, and some still exist in archives. These days, ethical wills are non-binding documents that are increasingly seen as important legacy-building ingredients, say experts, because they can convey a person's deep inner values and beliefs, even helping soothe ruffled feathers when dispensing family assets. http://www.nytimes.com/2014/11/01/your-money/the-ethical-will-an-ancient-concept-is-revamped-for-the-tech-age.html? r=0

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.15.

Medicare to consider covering end-of-life counseling

THE WALL STREET JOURNAL | Online – 31 October 2014 – Medicare said it will consider paying doctors to counsel patients about their options for end-of-life care, the same idea that spurred accusations of "death panels" and fanned a political furor around President Barack Obama's health-care law five years ago. Medicare will consider a change for 2016. Such counseling would be voluntary, aiming to make patients aware of their options so they can determine the type of care they want at the end of life. It is an idea that has wide support in the medical community... http://online.wsj.com/articles/medicare-to-consider-covering-end-of-life-counseling-1414793185

More evidence that we're bad at talking about death

NEW YORK MAGAZINE | Online – 28 October 2014 – It's not a mystery that Americans aren't always great at discussing end-of-life issues, or making sure our loved ones' last days are lived out in as much peace and comfort as possible. A study presented at the 2014 American College of Surgeons Clinical Congress adds a new element to the conversation, examining not older people who have suffered from long-term, potentially fatal illnesses, but rather those who have suffered from a traumatic injury. Half of older adults who sustain injuries severe enough that they could die in the hospital or become unable to function independently are not asked in the intensive care unit if they wish to speak with palliative care specialists about their preferences for end-of-life care, a new study finds. The study results suggest that many older trauma patients have unrecognized needs for palliative care, the authors said at the 2014 American College of Surgeons Clinical Congress. http://nymag.com/scienceofus/2014/10/more-evidence-were-bad-at-talking-about-death.html

Of related interest:

THE NEW YORK TIMES | Online – 30 October 2014 – 'Pronouncing the patient dead.' It
was only when I walked into the room and saw my patient still and utterly silent, his tired family
sitting around the bed, that I realized no one had ever told me precisely how to declare death. I
wished I could come back later, but it didn't seem right to leave him there, so I thumbed
through my pocket-sized intern survival guide. The manual was alphabetized, and the discussion about declaring death came somewhere before a section on diabetes management.
http://well.blogs.nytimes.com/2014/10/30/pronouncing-the-patient-dead/

Jahi McMath: New tests may not be enough to declare her alive, experts say

CALIFORNIA | *The Santa Cruz Sentinel* – 27 October 2014 – Her attorney calls her "Patient No. 1," a groundbreaking test of widely accepted standards defining brain death as a form of irreversible mortality. Indeed, as far as brain-dead patients go, Jahi McMath has entered uncharted territory. Most families, according to medical experts, come to terms with a medical diagnosis of brain death within days. Loved ones gather to say goodbye as machines are shut off, organ donation decisions are made, funeral services planned. Not so for Jahi, who would have celebrated her 14th birthday on Friday. Almost 11 months after she was first declared brain dead and became the subject of a national debate, the Oakland 13-year-old remains on machines – a case unlike any recorded in the U.S. since the medical establishment first recognized brain death as a form of death in the past century, experts said. Oddities and possible firsts abound in Jahi's case. http://www.santacruzsentinel.com/localnews/ci 26799085/jahi-mcmath-new-tests-may-not-be-enough

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Specialist Publications

'Cost of informal caregiving for U.S. elderly is \$522 billion annually, study finds' (p.14), in *Medical Xpress.*

Noted in Media Watch, 28 July 2014, #368 (p.6):

- AMERICAN JOURNAL OF BIOETHICS, 2014;14(8):3-8. 'Whither brain death?' The publicity surrounding the McMath and Muñoz cases^{1,2} has rekindled interest in brain death: the familiar term for human death determination by showing the irreversible cessation of clinical brain functions. The concept was developed to permit withdrawal of therapy in hopeless cases and permit organ donation. It is established medical practice and laws permit it in all U.S. jurisdictions. http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.925153?queryID=%24%7Bresult Bean.gueryID%7D
 - 'Jahi McMath, Ariel Sharon, and the Valley of Death,' *Time Magazine*, 9 January 2014. Today, more and more of us face the uncanny valley of the shadow of death. It's the domain of those, like Jahi [McMath] ... who suffer grievous injury and are kept on this side of life by elaborate and increasingly heroic medical procedures. [Noted in Media Watch, 13 January 2014, #340 (p.1)] <u>http://content.time.com/time/magazine/article/0,9171,2162277,00.html</u>
 - 'Case of Marlise Muñoz serves as launch pad for future rulings,' *The Daily Cougar* (Houston, Texas), 12 February 2014. Some of the Republican candidates running for Texas lieutenant governor have stated Judge Wallace was wrong [in the case of Marlise Muñoz] to have let Muñoz be taken off life support and promised, if elected, to "tighten state law" to not let something like this happen again. Is it prudent to make a fixed ruling in such matters to tie the hands of hospitals and families? [Noted in Media Watch, 17 February 2014, #345 (p.4)] http://thedailycougar.com/2014/02/12/case-marlise-munoz-serves-launchpad-future-rulings/

N.B. The focus of this issue of the *American Journal of Bioethics* is on brain death. Journal contents page: <u>http://www.tandfonline.com/toc/uajb20/current</u>

In the hospital, a bad translation can destroy a life

OREGON | National Public Radio – 27 October 2014 – Translating from one language to another is a tricky business, and when it comes to interpreting between a doctor and patient, the stakes are even higher. Thirteen years ago, the state of Oregon recognized the problem and required doctors and hospitals to start using professional interpreters. The Affordable Care Act also has expanded the kinds of materials that hospitals and insurers are required to translate for people who don't speak English. But more than a decade after its state law passed, Oregon still has trouble getting all patients the medical interpretation help they need. Oregon has about 3,500 medical interpreters ... [but] ... only about 100 of those have the right qualifications. A study by the American College of Emergency Physicians ... analyzed interpreter errors that had clinical consequences, and found that the error rate was significantly lower for professional interpreters than for *ad hoc* interpreters – 12% as opposed to 22%.¹ And, for professionals with more than 100 hours of training, errors dropped to 2%. http://www.npr.org/blogs/health/2014/10/27/358055673/in-the-hospital-a-bad-translation-can-destroy-a-life

 'Errors of medical interpretation and their potential clinical consequences: A comparison of professional versus *ad hoc* versus no interpreters,' *Annals of Emergency Medicine*, 2012;60(5): 545-553. <u>http://www.annemergmed.com/article/S0196-0644(12)00115-1/pdf</u>

Noted in Media Watch, 9 September 2013, #322 (p.13, under 'Worth Repeating'):

 JOURNAL OF PALLIATIVE MEDICINE, 2005;8(5):1016-1024. 'Communication about endof-life care between language-discordant patients and clinicians: Insights from medical interpreters.' The purpose of this study was to improve understanding of how to approach discussions between language-discordant patients and clinicians about terminal or lifethreatening illness. <u>http://online.liebertpub.com/doi/abs/10.1089/jpm.2005.8.1016</u>

Noted in Media Watch, 16 July 2012, #262 (p.8):

 JOURNAL OF PALLIATIVE MEDICINE | Online – 12 July 2012 – 'Interpretation for discussions about end-of-life issues: Results from a national survey of health care interpreters.' The majority of interpreters have experience with end-of-life discussions but, independent of interpreter training and experience, only half report that these discussions usually go well. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0032

Social skills and leadership in healthcare: The case for boosting doctors' EQ

FORBES | Online – 26 October 2014 – How emotionally intelligent is your doctor? Although answers to this question vary, it is not surprising that physicians' social skills or "EQ" [i.e., emotional quotient] are related to their job performance. After all, regardless of doctors' technical competence, their ability to deal with patients and influence their behavior will depend more on their personality and attitude than what they learned in medical school. But as James Stoller, the Institute Chair for Education at Cleveland Clinic, argues doctors have not been traditionally selected on their social skills. Given that medical training mostly rewards individual competitiveness and academic knowledge, most doctors are ill-equipped to cater to the human side of patient demands. http://www.forbes.com/sites/tomaspremuzic/2014/10/26/social-skills-leadership-in-healthcare-thecase-for-boosting-doctors-eg/

Quality of U.S. hospices varies, patients left in dark

THE WASHINGTON POST | Online - 26 October 2014 – More than a million times a year, a terminally ill patient in the U.S. is enrolled in hospice care. Each time, the family confronts a decision that, while critical, often must be made almost blindly: Which hospice to hire? A boom in the industry allows patients to choose from an array of hospice outfits, some of them excellent. More than a thousand new hospices have opened in the U.S. in the past decade. But the absence of public information about their quality, a void that is unusual even within the health-care industry, leaves consumers at a loss to distinguish the good from the bad. Though the federal government publishes consumer data about the quality of other health-care companies, including hospitals, nursing homes and home health agencies, it provides no such information about hospices. After years of public pressure, Congress in 2010 required that the government publish information about hospice quality. but the Medicare agency said in May that such consumer information would not be forthcoming until 2017 - at the earliest. Similarly, state records of hospice inspections are often unpublished, sparse, and, when ... available, difficult to find and understand. http://www.washingtonpost.com/business/ec onomy/guality-of-us-hospices-variespatients-left-in-dark/2014/10/26/aa07b844-085e-11e4-8a6a-19355c7e870a story.html

The business of dying

The Washington Post article is one in a series on the hospice industry in the U.S.:

Part 1: 'Terminal neglect? How some hospices treat dying patients,' 3 May 2014. [Noted in Media Watch, 5 May 2014, #356 (p.3)] http://www.washingtonpost.com/business/economy/ter minal-neglect-how-some-hospices-fail-thedying/2014/05/03/7d3ac8ce-b8ef-11e3-96aef2c36d2b1245_story.html

Part 2: 'Is that hospice safe? Infrequent inspections mean it may be impossible to know,' 26 June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.3)] http://www.washingtonpost.com/business/economy/isthat-hospice-safe-infrequent-inspections-means-it-maybe-impossible-to-know/2014/06/26/e258e880-eaa4-11e3-b98c-72cef4a00499_story.html

Part 3: 'Rising rates of hospice discharge in U.S. raise questions about quality of care,' 6 August 2014. [Noted in Media Watch, 11 August 2014, #370 (p.4)] http://www.washingtonpost.com/business/economy/leav ing-hospice-care-alive-rising-rates-of-live-discharge-inthe-us-raise-questions-about-quality-ofcare/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265 story.html

Part 4: 'As more hospices enroll patients who aren't dying, questions about lethal doses arise,' 25 August 2014, [Noted in Media Watch, 25 August 2014, #372 (p.3)] http://www.washingtonpost.com/news/storyline/wp/2014

/08/21/as-more-hospices-enroll-patients-who-arentdying-questions-about-lethal-doses-arise/?hpid=z5 Noted in Media Watch, 13 October 2014, #379 (p.4):

 THE NEW YORK TIMES | Online – 6 October 2014 – 'Extra scrutiny for hospices.' Bipartisan legislation will bring greater federal oversight to hospice programs across the country. <u>http://newoldage.blogs.nytimes.com/2014/10/06/extra-scrutiny-forhospices/? php=true& type=blogs&ref=health& r=0
</u>

Of related interest:

 NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online – 27 October 2014 – 'NHPCO's Facts & Figures: Hospice care in America.' An estimated 1.5 to 1.6 million patients were cared for by U.S. hospice programs in 2013. Of ongoing concern ... is the fact that 34.5% of patients died or were discharged within seven days of admission. http://www.nhpco.org/sites/default/files/public/Statistics Research/2014 Facts Figures.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

FORBES | Online – 27 October 2014 – 'Are we using the right language?' When accurate language is used, public opinion on physician-assisted suicide is basically split with 47% of U.S. adults approving and 49% disapproving of laws that would allow medical doctors to prescribe lethal doses of drugs for terminally ill patients. On one spectrum you have euthanasia opponents claiming that all life is precious no matter how short lived and pain-ridden. On the other end, euthanasia supporters argue for personal liberty, and the right to choose early death in cases of incredible suffering and terminal illness... However, when using euphemistic and dumbed-down language such as asking respondents whether they support the right to "end the [terminally ill] patient's life by some painless means," 70% of Americans were in favor of physician-assisted suicide. The same survey demonstrated "far fewer ... support it when the process is described as doctors helping a patient "commit suicide." The language used to describe physician-assisted suicide is directly correlated with support or opposition to the practice. http://www.forbes.com/sites/realspin/2014/10/27/physician-assisted-suicide-debate-are-we-using-the-right-language/

International

Elder and end-of-life care in the England

Dignity at last... Millions to get seven-day-a-week health care in their own homes

U.K. (England) | The Daily Express – 30 October 2014 – Millions of older people are today being promised seven-day-a-week health care in their own homes. A £5.3billion package aims to end visits to A&E [accident and emergency] departments and needless hospital stays. By ensuring National Health Service [NHS] and social care services work better together, older people will be able to live at home in comfort for as long as possible. Last year central government committed £3.8billion for 2015-2016 to the project but a joint announcement today by the Communities and Health Departments reveals the fund has now swollen to £5.3billion after councils and local NHS organisations put in an extra £1.5billion. NHS England's analysis of plans submitted by each local area shows the fund will support at least 18,000 carers, including social workers, occupational therapists and doctors and nurses working in the community. A new "national standard of sevenday health and social care" aims to save people having to resort to A&E departments for treatment or patients being kept in hospital when they are well enough to leave just because the help they need at home cannot be put in place at weekends. Patients will be jointly assessed in future by both health and social care professionals who can then design comprehensive care plans. http://www.express.co.uk/news/uk/529164/Millions-of-elderly-to-get-home-care-due-to-newpledge

Noted in Media Watch, 8 September 2014, #374 (p.3):

U.K. (England) | Commission on the Future of Health & Social Care in England – 4 September 2014 – 'A new settlement for health and social care.' The final report from the independent commission discusses the need for a new settlement for health and social care to provide a simpler pathway through the current maze of entitlements. It proposes an approach that redesigns care around individual needs regardless of diagnosis, and with a graduated increase in support as needs rise, particularly towards the end of life. The commission concludes this vision fit for the 21st century and is affordable and sustainable if a phased approach is taken and hard choices are taken about taxation. http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care

Of related interest:

U.K. (England) | National End-of-Life Care Intelligence Network – 23 October 2014 – 'Developing a new approach to palliative care funding: A first draft for discussion.' In the context of healthcare, a currency is made up of consistently identified units of care that can be used as the basis for payment between commissioners and providers. Palliative care has different challenges to much of acute care, so an approach based on procedures is not appropriate. http://www.england.nhs.uk/wp-content/uploads/2014/10/pall-care-fund-new-appr-fin.pdf

Mexico: Needless suffering at end of life

MEXICO | Human Rights Watch – 28 October 2014 - Tens of thousands of patients with terminal illnesses in Mexico suffer unnecessarily from severe pain and other symptoms because they cannot access adequate end-of-life care, Human Rights Watch said in a report.¹ 'Care When There Is No Cure: Ensuring the Right to Palliative Care in Mexico,' documents the lack of access for many patients to pain relief and other assistance known as palliative care. Although Mexico's health law explicitly grants people with terminal illness a right to palliative care, the service is offered almost exclusively at large specialist hospitals. Almost 600,000 people die every year in Mexico. Estimates by the World Health Organization and the Worldwide Hospice and Palliative Care Alliance suggest that more than half of these people require palliative care. http://www.hrw.org/node/130146

Palliative care in Latin America

Atlas de Cuidados Paliativos de Latinoamérica, Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)]

Spanish language edition:

http://cuidadospaliativos.org/uploads/2012/10/atlas/Atla s%20de%20Cuidados%20Paliativos%20en%20Latinoa merica.pdf;

Portuguese language edition:

http://cuidadospaliativos.org/uploads/2014/1/Atlas%20P ortugues.pdf;

English language edition:

http://cuidadospaliativos.org/uploads/2013/12/Atlas%20 of%20Palliative%20Care%20in%20Latin%20America.p df

Cont. next page



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

N.B. Palliative care in Mexico is provided mainly by hospital-based teams that operate as part of their organization's pain service. Interest was stimulated in 1990 by the Mexican Declaration on Cancer Pain Relief. During the early part of that decade, palliative care programs became operational at the Civil Hospital of Guadalajara and, in Mexico City, at the National Institute of Nutrition and the National Cancer Institute. Further impetus was provided in 1996 by the Declaration of Guadalajara, and in 2004, the Palia Institute opened, supported by government funding. That same year, 14 palliative care organizations were identified, which in total provided two hospices, four inpatient units, eight hospital teams, and three home care services; these latter services are financially constrained and unable to regularly cover items such as travel costs. Although intermittent training is offered by these organizations - and acknowledging that the principles of palliative care and pain control are taught to undergraduates at the Autonomous University of Guadalajara - accredited specialist training is not yet available in Mexico. Consequently, deep-seated beliefs regarding morphine and addiction are still to be found ... Source: 'Mapping levels of palliative care development: A global view,' Journal of Pain & Symptom Management, 2008;35(8):469-485: http://www.jpsmjournal.com/article/S0885-3924(07)00729-4/fulltext

Specialist Publications

'Assessing need for palliative care services for children in Mexico' (p.13), in *Journal of Palliative Medicine*.

End-of-life care in Wales

End-of-life care in Wales rated positively by patients and families in new report

U.K. (Wales) | Wales Online – 28 October 2014 – An annual report on end-of-life care in Wales says a survey of patients and their families has rated services positively.¹ The report said 94% of 1,834 responses to the iWantGreatCare survey were overwhelmingly positive, with 22.6% receiving perfect scores. However the annual report also outlined areas that need to be addressed over the next year. This included ensuring that systems are in place to supports more people to be cared for and to die in the place of their choice, and encouraging more people to make a will and share their final wishes with families and friends. http://www.walesonline.co.uk/news/wales-news/end-of-life-care-wales-rated-positively-8007191

1. 'Together for Health End-of-Life Care Delivery Plan: Annual Report 2014,' Health in Wales, Welsh Government. <u>http://wales.gov.uk/docs/dhss/publications/141024reporten.pdf</u>

Noted in Media Watch, 5 May 2014, #336 (p.5):

- U.K. (Wales) | BBC News 29 April 2014 'Dying patients' care survey plea by Marie Curie Cancer.' Patients who are dying need better opportunities to have their say about the standard of care they receive, says charity Marie Curie Cancer Care.¹ It wants the Welsh government to undertake an annual survey of bereaved families to see how they feel care services can be improved. <u>http://www.bbc.com/news/uk-wales-27213566</u>
 - 'Listening to Dying People in Wales: The case for improved patient experience data...,' Marie Curie Cancer Care, April 2014. <u>http://www.mariecurie.org.uk/Global/Policy/Listening-to-dying-people-in-Wales.pdf</u>

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>

High Court landmark ruling

Why I begged judge to end my sick daughter's life: "Nancy is no longer my girl, she's a shell"

U.K. (England & Wales) | *The Daily Mirror* – 25 October 2014 – They must have been the hardest words any mother could ever have to imagine about her child. But devoted Charlotte Fitzmaurice bravely wrote them down and handed them to a High Court judge to win for 12-year-old daughter Nancy what she believed she needed most. To put an end to her suffering – and finally to be at peace. Nancy was born blind with hydrocephalus, meningitis and septicaemia. It meant she could not walk, talk, eat or drink. Her quality of life was so poor she needed 24-hour hospital care and was fed, watered and medicated by tube. In a landmark decision, Justice Eleanor King immediately granted Charlotte's request. Nancy died 14 days later at London's Great Ormond Street [hospital] ... the first time a child breathing on her own, not on life support and not suffering a terminal illness, has been allowed to die. The judge's decision was fully supported by doctors at the world famous children's hospital... <u>http://www.mirror.co.uk/news/real-life-stories/begged-judge-end-sick-daughters-4509235</u>

End-of-life care in Northern Ireland

Woman received palliative care package the day her husband died

U.K. (Northern Ireland) | *The Fermanagh Herald* (Enniskillen) – 23 October 2014 – It was an opportunity for health service users to put their questions to the leaders who decide how our local health trust operates, where money is invested, and what area will face significant cuts. Caroline Kelly ... was one of 40 people who attended. Ms. Kelly raised issues surrounding palliative care in Fermanagh and what steps the trust is taking to secure localised services while a member of the audience also revealed that she received a care pack the day her husband died. While Dean Sullivan, director of commissioning for the trust, admitted palliative care hasn't had the same focus that other services have had, he revealed a major programme currently underway. "A programme is being taken forward with Marie Curie [Cancer Care] which will be coming at the end of the year or beginning of next year," he explained. <u>http://fermanaghherald.com/2014/10/woman-received-palliative-care-package-the-day-her-husband-died/</u>

N.B. See 'Working in Northern Ireland,' Marie Curie Cancer Care, March 2014. <u>http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/working-across-uk/NI-overview-March-2014.pdf</u>

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

Caregiver presence and patient completion of a transitional care intervention

AMERICAN JOURNAL OF MANAGED CARE, 2014;20(10):e439-e444. This study evaluated the association between family caregiver presence and patient completion of the Care Transitions Intervention, a patient activation model that provides care coaching for 30 days following hospital discharge. Family caregivers were more frequently present during recruitment for the intervention for patients who were in the older age group and less frequently present for white patients or patients who were dually eligible for Medicare and Medicaid. The presence of a family caregiver at recruitment was associated with a higher rate of patient acceptance to participate in the intervention and a higher rate of completion... <u>http://www.ajmc.com/publications/issue/2014/2014-vol20-n10/Caregiver-Presence-and-Patient-Completion-of-a-Transitional-Care-Intervention</u>

Of related interest:

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 19 October 2014 – 'Caregiving as a Canadian-Vietnamese tradition: "It's like eating, you just do it." The ways in which caregiving was perceived and expressed [by study participants] are reflected in three themes: 1) Natural: identity and care work; 2) Intentional: whole-person care; and, 3) Intensive: standards, struggle and the context of care. This research confirms the need for culturally-appropriate services and supports while illustrating that Vietnamese family caregivers not only value, but are also likely to use healthcare and social services if they are language-accessible, built on trust and demonstrate respect for their values as individuals, regardless of culture. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12126/full

End-of-life care in Germany

Dying in cancer centers: Do the circumstances allow for a dignified death?

CANCER, 2014;120(20):3254-3260. Prior research has shown that hospitals are often illprepared to provide care for dying patients. This study assessed whether the circumstances for dying on cancer center wards [in 16 hospitals belonging to 10 cancer centers in Baden-Wuerttemberg, Germany] allow for a dignified death. Half of the participants indicated that they rarely have enough time to care for dying patients, and 55% found the rooms available for dying patients unsatisfactory. Only 19% of respondents felt that they had been well-prepared to care for the dying... Palliative care staff reported much better conditions for the dying than staff from other wards (95% of palliative care staff indicated that patients die in dignity on their ward). Generally, physicians perceived the circumstances much more positively than nurses, especially regarding communication and life-prolonging measures. Overall, 57% of respondents believed that patients could die with dignity on their ward. http://onlinelibrary.wiley.com/doi/10.1002/cncr.28702/abstract

Of related interest:

- MEDICINE, HEALTH CARE & PHILOSOPHY | Online 26 October 2014 ""What the patient wants...": Lay attitudes towards end-of-life decisions in Germany and Israel.' National legislation, as well as arguments of experts, in Germany and Israel represent opposite regulatory approaches and positions in bioethical debates concerning end-of-life care. This study analyzes how these positions are mirrored in the attitudes of laypeople and influenced by the religious views and personal experiences of those affected. The authors analyzed eight focus groups in Germany and Israel in which laypeople (religious, secular, affected, and non-affected) were asked to discuss similar scenarios involving the withholding or withdrawing of treatment, physician-assisted suicide, and euthanasia. In both countries, respect for patient autonomy and patients' wishes to die with dignity found broad consent. Laypeople argued in favor of accepting such wishes when they were put down in an advance directive. http://link.springer.com/article/10.1007%2Fs11019-014-9606-5
- THE ONCOLOGIST | Online 31 October 2014 'What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key.' Oncologists [i.e., study participants] reported patients with unrealistic expectations to be a challenge for EOL [end-of-life] communication that is especially prominent in comprehensive cancer centers. They responded to this challenge quite differently by either proactively trying to facilitate advanced care planning or passively leaving the initiative to address preferences for care at the EOL to the patient. A major impediment to the proactive approach was uncertainty about the right timing for EOL discussions and about the balancing the medical evidence against the physician's own subjective emotional involvement and the patient's wishes. http://theoncologist.alphamedpress.org/content/early/2014/10/30/theoncologist.2014-0031.abstract

Choosing hospice or choosing dying: The cultural and medical meanings of "hospice" and the role of provider referrals in transition to hospice care

CLINICAL MEDICINE & RESEARCH, 2014;12(1-2):88. Hospice care is widely used at the end of life yet it remains stigmatized and feared. Current research on the transition to hospice overlooks the dimension of patient choice and the symbolic importance of hospice to patients and families. Understanding the transition from the point of view of patients and family members is critical in increasing use of hospice care and decreasing "late referrals." Examining narratives about transitioning to hospice reveals two insights. First, the referral is one highly variable element of a more complex process better conceptualized as a transition. Transitions may be 1) provider-driven or 2) patient/family-driven. Some patients and families play a very active role in this transition, including self-referring to hospice. Second, the style of provider referrals is commonly remembered as being very negative. Negative referrals tend to draw on a cultural meaning of hospice as "giving up" or "choosing dying," while positive referrals conceptualize hospice as a medical and psychosocial strategy that is advantageous for patients and families. Understanding referral as a discrete, but critical component of a longer strategy for transitioning to hospice care, should lead providers to carefully plan when and how they present hospice care to patients. Understanding the spectrum of patient and family perspectives can also improve providers' ability to customize their referrals and the likelihood that patients will transition to hospice care if and when it would benefit them. http://www.clinmedres.org/content/12/1-2/88.3.abstract

<u>Care planning</u>

Clarifying substituted judgement: The endorsed life approach

JOURNAL OF MEDICAL ETHICS | Online – 30 October 2014 – A primary goal of clinical practice is to respect patient autonomy. To promote this goal for patients who have lost the ability to make their own decisions, commentators recommend that surrogates make their treatment decisions based on the substituted judgment standard. This standard is commonly interpreted as directing surrogates to make the decision the patient would have made in the circumstances, if the patient were competent. However, recent commentators have argued that this approach – attempting to make the decision the patient would have made if competent – is theoretically problematic, practically infeasible, and ignores the interests of the patient's family and loved ones. These commentators conclude that the substituted judgment standard should be revised significantly, or abandoned altogether. While this response would avoid the cited problems, it also would require substantial changes to clinical practice and would raise significant problems of its own. The present paper thus considers the possibility that the criticisms do not point to problems with the substituted judgment standard itself; instead, they point to problems with the way it is most commonly interpreted. http://jme.bmj.com/content/early/2014/10/30/medethics-2013-101852.abstract

Of related interest:

CLINICAL MEDICINE & RESEARCH, 2014;12(1-2):105-106. 'Re-conceptualizing medical decisions: How home hospice care fosters patient and family engagement and decision-making.' Despite growing acceptance that patient engagement and shared decision-making should be goals of medicine, organizational attempts to support these ideals are limited and larger institutional structures often constrain patient autonomy. Home hospice care is a subset of medical care that has consciously developed a philosophical and practical approach to encouraging patient and family engagement. This research examines how home hospice care provides a different strategy for improving patient engagement and shared decision-making. http://www.clinmedres.org/content/12/1-2/105.4.abstract

- THE ONCOLOGY TIMES | Online 29 October 2014 'Patient-reported outcomes drive palliative care.' Patients may be selective about what they report to their caregivers, with reasons that may include the desire to be a "good" patient, willingness to exchange some discomfort or unpleasant symptoms for better disease control, a fear that their symptoms might halt or interrupt their treatment, limited time spent with their clinicians, the perception that nothing can be done to control symptoms, or sheer embarrassment. Physicians and nurses may have gaps in their knowledge and attitudes about symptoms, or may fail to ask because they are short on time and are concerned that having a discussion of symptoms will "open a can of worms" that they will then have to deal with. http://www.oncologypractice.com/the-oncology-care/e80d8282e4eb3b2582573e3f86a27d21.html
- PALLIATIVE & SUPPORTIVE CARE | Online 31 October 2014 'Examining family meetings at end of life: The model of practice in a hospice inpatient unit.' Provider communication with family members is particularly critical during advanced illness and end-of-life care. The National Consensus Project clinical practice guidelines for quality palliative care list regular family meetings among the recommended practices for excellent communication during end-of-life care, but do not provide specific guidance on how and when to provide such meetings. The authors' findings provide a theoretical model that can inform the design of a family meeting to address family members' needs for meaningful and contextualized information, validation of their important contributions to care, and preparation for the patient's death. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9398601&fulltextTy pe=RA&fileId=S1478951514001138
 - 'Clinical Practice Guidelines for Quality Palliative Care,' The [U.S.] National Consensus Project for Palliative Care' (3rd edition), 2009. <u>http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.p</u> <u>df</u>

Media Watch: Editorial Practice

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

Distribution

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

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Something Missed or Overlooked?

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

End-of-life care in Ireland

"My preference would be to be at home": Patients' experiences of their Hospice at Home Care

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online – 25 September 2014 – A specialist Hospice at Home (HaH) service commenced in 2006 in Mid-West Ireland whereby participants received palliative care from a specialist team in their own home. This paper presents the findings from the patients receiving the HaH service. Overall, participants' experiences of the service were positive with quality of care being highly rated. They regarded the service as supportive and responsive, particularly in relation to pain management and symptoms. Excellent communication and interpersonal skills from Hospice at Home staff members were highlighted. Overall, participants rated their own quality of life as high; although this cannot be attributed to the HaH service alone. Although not explicitly asked about, the possibility of being a burden to family remains an issue for those being cared for at home. The majority of participants were very satisfied with the service enabling them to be cared for at home. Areas for future improvements to the HaH service emerged, including discussions about advanced care directives, access and method of referral to the Hospice at Home service and patients' understanding of the service being delivered. http://omicsgroup.org/journals/my-preference-would-be-to-be-at-home-patients-experiences-oftheir-hospice-at-home-care-2165-7386.1000189.pdf

Assessing need for palliative care services for children in Mexico

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 October 2014 – Pediatric palliative care increasingly became integrated into health care institutions worldwide over the last decade. However, in Mexico and other developing countries with large populations of children, little is known regarding the need for palliative care services. The authors aimed to assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Secretaria de Salud [Ministry of Health] in Mexico. A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico, should be a topic of the national health care agenda. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0129

Of related interest:

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(10):502-508. 'Speaking to the deceased child: Australian health professional perspectives in paediatric end-of-life care.' An Australian study of parent and health-professional constructions of meanings around post-mortem care and communication revealed the practice of health professionals speaking to a child after death. Such findings illuminate an area of end-of-life-care practice that is not of-ten addressed. http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2014.20.10.502

Death on Facebook: Examining the roles of social media communication for the bereaved

JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS | Online – 21 October 2014 – This study examines the ways in which the social networking site Facebook was helpful and unhelpful to participants when someone they knew died. Analysis of 454 thought units revealed three themes describing participants' experiences with communication on Facebook during bereavement: news dissemination, preservation, and community. The results suggest that Facebook communication is both beneficial and challenging for bereaved users, which may produce a coping paradox. Implications of grief-related mediated communication and the coping paradox are explored. http://spr.sagepub.com/content/early/2014/10/21/0265407514555272.abstract

Noted in Media Watch, 10 March 2014, #348 (p.11):

 BULLETIN OF SCIENCE TECHNOLOGY SOCIETY | Online – Accessed 5 March 2014 – 'Virtual mourning and memory construction on Facebook: Here are the terms of use.' This article investigates the online information practices of persons grieving and mourning via Facebook. <u>http://bst.sagepub.com/content/early/2013/12/18/0270467613516753.abstract</u>

Noted in Media Watch, 5 March 2012, #243 (p.11):

 OMEGA – JOURNAL OF DEATH & DYING, 2012;64(4):275-302. 'Does the Internet change how we die and mourn?' The article outlines issues the Internet presents to death studies. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;j ournal,1,255;linkingpublicationresults,1:300329,1

Cost of informal caregiving for U.S. elderly is \$522 billion annually, study finds

MEDICAL XPRESS | Online – 27 October 2014 – The price tag for informal caregiving of elderly people by friends and relatives in the U.S. comes to \$522 billion a year, according to a new study.¹ Replacing that care with unskilled paid care at minimum wage would cost \$221 billion, while replacing it with skilled nursing care would cost \$642 billion annually. The study ... improves on earlier estimates about the value of informal caregiving by making use of the 2011 and 2012 American Time Use Survey, a new and unique database, to provide up-to-date cost estimates on informal caregiving. "Our findings provide a new and better estimate of the monetary value of the care that millions of relatives and friends provide to the nation's elderly," said Amalavoyal V. Chari, the study's lead author, a lecturer at the University of Sussex... "These numbers are huge and help put the enormity of this largely silent and unseen workforce into perspective." http://medicalxpress.com/news/2014-10-caregiving-elderly-billion-annually.html

1. 'The opportunity costs of informal elder-care in the U.S.: New Estimates from the American Time Use Survey,' *Health Services Research*, 7 October 2014. http://onlinelibrary.wiley.com/doi/10.1111/1475-6773.12238/abstract

Embedding of the spiritual dimension in palliative consultation services in The Netherlands: Inventory, evaluation, and recommendations

PROGRESS IN PALLIATIVE CARE | Online – 27 October 2014 – Caregivers in The Netherlands can ask for advisory support from Palliative Consultation Teams (PCTs). It is largely unclear, though, how consultants of these teams deal with spiritual questions. This article explores in what way the spiritual dimension of palliative care is embedded in the PCTs. Most [questionnaire] respondents are of the opinion that their team lacks expertise in spiritual care, the majority of the consultants do not receive regular training in dealing with the spiritual dimension, and many plans for education and training are in a preliminary stage. These limitations, however, go together with a clear desire for education and training in dealing with the spiritual dimension. Although most teams do not clearly distinguish between psychological, social and spiritual competences, the healthcare chaplain is most often mentioned as the expert in the field of spiritual care. http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000113

Of related interest:

ATLANTA MEDICINE, 2014;85(1):9-12. 'The history of afterlife.' Each of us comes to her or his own conclusions about afterlife; thoughts on this subject are natural for humans everywhere. Our ethnic culture, our specific faith tradition and our exposure to educational influences all affect our ultimate persuasion. No single opinion can be called "right" or "wrong." It is helpful, however, to appreciate the perceptions of others because the range of beliefs is broad. No matter what one's final conclusion, both past and present provide examples showing that others – somewhere, sometime – have come to similar convictions. No one is alone. http://www.mdatl.com/wp-content/uploads/2014/07/AM-February-March-2014.pdf#page=11

What do you say before you say good-bye? The psychotherapy of grief

TRANSACTIONAL ANALYSIS JOURNAL | Online – 27 October 2014 – Relational loss, death, and mourning are all part of life and human relationships. Protracted and compounded grief occurs when something interferes with the normal grieving process. The psychotherapy of grief is described and two primary relational approaches are emphasized: face-to-face psychotherapy and the use of internal imagery via the empty-chair technique. In both approaches, the aim is to provide a balanced expression of affect, including emotional pain, anger, resentment, appreciation, and love. http://tax.sagepub.com/content/early/2014/10/25/0362153714556622.abstract

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2014/10/media-watch/</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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: http://ahpca.ca/ (Scroll down to 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <u>http://hpcconnection.ca/general-resources/in-the-news/</u>

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

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-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRANIAN JOURNAL OF PUBLIC HEALTH, 2014;43(10):1316-1323. 'Euthanasia: Murder or not - a comparative approach.' Euthanasia is one of the most intriguing ethical, medical and law issues that marked whole XX century and beginning of the XXI century, sharply dividing scientific and unscientific public to its supporters and opponents. It also appears as one of the points where all three major religions (Catholic, Orthodox, and Islamic) have the same view. They are strongly against legalizing mercy killing, emphasizing the holiness of life as a primary criterion by which the countries should start in their considerations. Studying criminal justice systems in the world, the authors concluded that the issue of deprivation of life from compassion is solved on three ways. On the first place, we have countries where euthanasia is murder like any other murder from the criminal codes. Second, the most numerous are states where euthanasia is murder committed under privilege circumstances. On the third place, in the Western Europe we have countries where euthanasia is a legal medical procedure, under requirements prescribed by the law. In this paper, authors have made a brief comparison of the solutions that exist in some Islamic countries, where euthanasia is a murder, with Western where it represents completely decriminalized medical countries. procedure. http://iiph.tums.ac.ir/files/iournals/1/articles/7185/submission/original/7185-13150-1-SM.pdf
- JOURNAL OF PUBLIC HEALTH POLICY | Online 30 October 2014 'Will I stay or can I go? Assisted suicide in prison.' Assisted suicide (AS) is a controversial practice with which physicians and nurses are confronted more and more often. In Switzerland, it is available for Swiss residents and in certain cases for foreigners. Prisoners meet the same prerequisites for AS as the general population and should therefore be eligible for it. Ethical issues, such as informed choice and the autonomy of prisoners, and organizational questions need to be addressed. They must not lead to a denial of this practice. Even though prisons constitute a special area of work for medical staff, it is important to address the possibility of AS in prison openly. http://www.palgrave-journals.com/jphp/journal/vaop/ncurrent/abs/jphp201443a.html

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