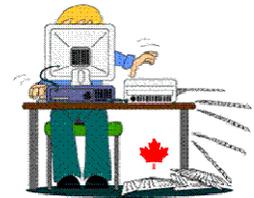


Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

Difficult and uncomfortable conversations in end-of-life care: Scroll down to [Specialist Publications](#) and 'Demand of words' (p.12), in *JAMA Internal Medicine*.

Canada

Community and home care

Deb Matthews' dirty little secret in health care

ONTARIO | *The Toronto Star* (OpEd) – 11 April 2013 – On the first anniversary of introducing her Action Plan for Health Care, Ontario Health Minister Deb Matthews bragged about the progress the Liberal government is making toward modernizing health-care delivery in the province. The secret is that the "progress" Matthews touts in her year-old action plan, which focuses on restoring access to primary care and care at home, health promotion and evidence-based services, is being made at the expense of critical health sectors that are being silently squeezed for money. The result is that tens of thousands of Ontario patients are going without the treatments or services they need to function as best they can at home or in their communities. Matthews ... has watched over her ministry as it quietly allowed vital

services and funding in rehabilitation services – physiotherapy, occupational therapy, speech-language therapy, dietitians and social work – to be slashed across the province. http://www.thestar.com/opinion/commentary/2013/04/11/deb_matthews_dirty_little_secret_in_health_care_hepburn.html

Extract from *The Toronto Star* OpEd

Between 2007 and 2012, the number of community-based visits to patients by physiotherapists plunged by 22%, or 130,000 visits, according to the government's own most recently published figures. Visits by occupational therapists fell by 30%, speech-language pathologists 47%, social workers 22% and dietitians 20%.

Noted in Media Watch, 8 April 2013:

- CTV NEWS | Online – 4 April 2013 – **'Provinces need to follow through on home care funding commitments: Report.'** Canada's provinces and territories talk a good game when it comes to funding in-home health care, but a new report is urging all orders of government to put their money where their mouths are.¹ <http://www.ctvnews.ca/canada/provinces-need-to-follow-through-on-home-care-funding-commitments-report-1.1223641>

1. 'Portraits of Home Care,' Canadian Home Care Association, April 2013. <http://www.cdnhomecare.ca/media.php?mid=3394>

Funding end-of-life care

Perram House hospice closing... – staff got two days' notice

ONTARIO | *The Toronto Star* – 10 April 2013 – Staff at Perram House Hospice say they are shocked they were given just two days' notice the home was closing. Perram House – one of the few hospices in the city providing end-of-life care to marginalized, homeless and drug-addicted people – will close Wednesday. The recently unionized staff learned Monday their jobs had been terminated and the hospice would close. "We were in shock," said Prapti Giri, chair of the union bargaining team. "The lack of notice has prevented us from doing any campaigning and has given us no time to take any action." But Frank McCrea, president of IT staffing company Procom and chair of the hospice's board, called the closure an inescapable "tragedy" caused by dwindling donations and the union's refusal to accept wage cuts. Perram House, a brick heritage home, has eight beds often used by Toronto's neediest citizens. Of the five residents at the hospice, two have been transferred home and the other three will go to Toronto Grace Hospital. The staff of 33 people, including five full-time employees, voted to join the Ontario Public Service Employees' Union in September after six years without a wage increase. The union was warned on 21 March that the hospice would close in 30 to 60 days if members did not accept either a wage cut of up to 10% or a staff cut of registered practical nurses. The union voted 88% against the cuts 4 April. http://www.thestar.com/life/health_wellness/2013/04/10/perram_house_hospice_closing_wednesday_staff_got_two_days_notice.html

N.B. Perram House website: http://www.perramhouse.ca/notification/PH_Message.htm

Of related interest:

- BRITISH COLUMBIA | *Campbell River Mirror* – 9 April 2013 – '**Hospice struggles while others get millions.**' Lower Mainland hospice societies receive millions in funding from the Ministry of Health. Meanwhile, in Campbell River, the city's small hospice gets stiffed \$5,000 by the Vancouver Island Health Authority. "It's very, very frustrating," says Valery Puetz, board chair for the Campbell River Hospice Society. On 25 March, the Ministry of Health handed over \$8 million for four hospice societies in the Greater Vancouver area...¹ In contrast, the Campbell River hospice, and two other Island societies, each receive \$5,700 in annual funding from the health authority. <http://www.campbellrivermirror.com/news/202180901.html>

1. 'Province introduces plan to improve end-of-life care,' 1130 News (Vancouver), 25 March 2013. Dying-with-dignity is the goal of a new plan by the province to improve end-of-life care. [Noted in Media Watch, 1 April 2013] <http://www.news1130.com/2013/03/25/bc-introduces-plan-to-improve-end-of-life-care/>

Noted in Media Watch, 1 April 2013:

- BRITISH COLUMBIA | *Comox Valley Record* (Courtenay) – 27 March 2013 – '**Comox Valley wonders where its end-of-life funding is.**' Residents have been advocating for residential hospice beds for over six years, yet there are still zero dedicated hospice palliative care beds. <http://www.comoxvalleyrecord.com/news/200335711.html>



Barry R. Ashpole

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

Nationwide patient survey

A more humane hospital

CBC NEWS | Online – 9 April 2013 – While cleanliness was a major cause for concern for those who answered *the fifth estate* patient survey, many respondents also talked about feeling alienated by the hospital system and getting the brush-off when they tried to raise issues of concern with staff. Most respondents said they sympathized with nurses and doctors who seemed rushed and overworked but wished these professionals would communicate more openly and sympathetically with patients and family members. "She lost her quality of life in hospital," wrote one respondent about her 91-year-old mother, who was blind and who died in a Kingston, Ontario, hospital. "I think she lost her dignity as well because everyone talked about her but not with her." Many people said they left the hospital feeling demoralized and disillusioned with the health-care system. <http://www.cbc.ca/news/health/story/2013/04/08/hospitals-patient-survey.html>

N.B. The above was a sidebar to a report on a national patient survey conducted by the CBC program *the fifth estate*, 'Dirty hospital rooms a top concern for Canadians' (scroll down to 'A more humane hospital'). Link to *the fifth estate* episode, 'Rate my hospital,' broadcast 14 April 2013: <http://www.cbc.ca/fifth/2012-2013/2013/04/rate-my-hospital.html>

Noted in Media Watch (under 'Worth Repeating'), 11 February 2013:

- *JOURNAL OF PALLIATIVE MEDICINE*, 2012;15(4):457-462. **"Tu souffres, cela suffit": The compassionate hospital.** Modern health care facilities attract staff members who are able to exercise varying degrees of compassion in their busy daily routines. However, little discussion has taken place on how health care organizations might best harness and integrate aspects of individual compassion to create an organization with compassion as a core value. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0378?prevSearch=opera&searchHistoryKey=>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) – 9 April 2013 – **Winnipeg woman urges MPs to reopen assisted suicide debate.** Canada's justice minister has rejected Susan Griffiths's plea to allow assisted suicides in this country. The Winnipeg grandmother, who is in Europe to access an assisted suicide, says she will fight until her dying days to have the practice legalized in Canada. A spokesman for federal Justice Minister Rob Nicholson said a majority of MPs voted in 2010 against amending the Criminal Code to permit assisted suicide in Canada... The federal government does not intend to reopen that debate, the spokesman added. <http://www.cbc.ca/news/canada/manitoba/story/2013/04/08/mb-assisted-suicide-griffiths-susan-europe-letters-mps.html>

Interview with Balfour Mount

Die softer: How we can give life a better ending

THE GLOBE & MAIL | Online – 13 April 2013 – ...for the second time in 20 years, the law against assisted suicide is before the courts, in a challenge that will probably go to the Supreme Court. But a group of notable Canadians, including actor Gordon Pinsent, actor Sheila McCarthy and Senator Sharon Carstairs, are trying to call attention to this aspect of death and dying: they've collaborated with visual artists to create "legacy blankets" to raise awareness of Advanced Care Planning Day 16 April. Balfour Mount, who coined the term palliative care, offers a perspective on how his influential idea has been implemented and how to think about the end of life. <http://www.theglobeandmail.com/life/health-and-fitness/health/die-softer-how-we-can-give-life-a-better-ending/article11173497/>

U.S.A.

Do not resuscitate law expanded

MICHIGAN | WIN 98.5 News (Battle Creek) – 12 April 2013 – Legislation that would require that do-not-resuscitate orders be recognized in Michigan nursing homes gained the support of a House committee. The House Judiciary Committee voted unanimously for the three-bill package...The legislation specifically allows do-not-resuscitate orders to cover areas outside of hospitals. Under current law, the orders are not in effect in nursing homes or mental health facilities. The package would also allow a qualified guardian to sign off on a do-not resuscitate order on behalf of a patient and would ban a guardian from signing off on a do-not-resuscitate order without visiting the patient within 14 days of executing the order. In addition, the bills would bring certain protections for guardians. <http://wincountry.com/news/articles/2013/apr/12/do-not-resuscitate-law-expanded/>

Noted in Media Watch, 1 April 2013:

- TEXAS | *The New York Times* – 30 March 2013 – '**A Texas Senate bill would revise the State's end-of-life procedure.**' If a physician's decision to end treatment contradicts the patient's advance directive or the judgment of the patient's surrogates, [the existing] State law gives patients or their families ten days to find another provider and appeal the doctor's decision to a hospital ethics committee. http://www.nytimes.com/2013/03/31/health/state-senate-bill-would-revise-end-of-life-procedure.html?_r=0

Noted in Media Watch, 27 August 2012:

- *HEALTHCARE ETHICS COMMITTEE FORUM* | Online – 19 August 2012 – '**Institutional futility policies are inherently unfair.**' For many years a debate has raged over what constitutes futile medical care, if patients have a right to demand what doctors label as futile, and whether physicians should be obliged to provide treatments that they think are inappropriate. <http://www.springerlink.com/content/q033k26474v2m877/>

Puzzling budget cuts for hospices

FLORIDA | *Herald-Tribune* (Sarasota) – 11 April 2013 – Despite evidence that hospice reduces Medicare spending hospices across the country are facing reimbursement cuts that could put some in jeopardy. The Centers for Medicare & Medicaid Services initiated a seven-year phase-out of the Budget Neutrality Adjustment Factor in 2009. This will ultimately result in a reduction in hospice reimbursement rates of approximately 4%. The Patient Protection & Affordable Care Act imposed an additional change to the Medicare hospice rate formula that will further cut hospice payments by nearly 12% over the next decade. These cuts will impact all hospices and could be particularly devastating for small hospices, which make up the majority of hospices in the U.S. In 2011, 46% of America's 5,300 hospices admitted fewer than 150 patients annually, and 79% admitted fewer than 500 patients. So while hospice continues to prove itself as a health care model that not only scores high in patient and family satisfaction, but also in cost-effectiveness, hospices are having to carefully examine how they do their work in order to ensure that they can continue to provide high-quality services with fewer available dollars. A second contradiction involves the nature of hospice usage. One continuing theme that hospice providers hear from patients and their loved ones is that they wished they had entered hospice care earlier, but didn't because it hadn't been recommended by their physician, or they were unaware of its benefits, or they were frightened by the implications of what it means to be a hospice patient. <http://www.heraldtribune.com/article/20130412/COLUMNIST/304129996/-1/sports?Title=Gerry-Radford-Puzzling-budget-cuts-for-hospices>

Cont.

Of related interest:

- INDIANA | *South Bend Tribune* – 8 April 2013 – **'Facing the end sooner.'** Because they believe hospice care means giving up at the very end of life, recent studies say, the average length of time patients enroll in a hospice program is only three days – not nearly long enough to fully benefit from what such care has to offer.¹ Researchers noted that more than 28% of dying patients received hospice care for three days or less.¹ Although the numbers of those enrolled in hospice has risen slightly since 2009, the National Hospice & Palliative Care Organization says "concerns about the increasing number of people receiving hospice for three days or less is a call for action." <http://www.southbendtribune.com/news/sbt-facing-the-end-sooner-20130408,0,121957.story>

1. 'Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions..' *Journal of the American Medical Association*, 2013;309(5):470-477. [Noted in Media Watch, 11 February 2013] <http://jama.jamanetwork.com/article.aspx?articleid=1568250>

Specialist Publications

'How and when to discuss hospice?' (p.14), in *Neurology Today*.

Hospice interior design

Making space for hospice in the care continuum

HEALTHCARE DESIGN | Online – 11 April 2013 – Designing for the continuum of care – both architecturally and clinically – is all the rage right now, but some designers and care organizations feel that hospice and palliative care have been tucked in the back corner of eldercare for too long. The [recent] 2013 Environments for Aging Conference in New Orleans gave providers, architects and designers a chance to show how elder-living spaces, hospitals and end-of-life care teams can exist in a symbiotic relationship. One prime example is the Community Hospice of Northeast Florida (CHNF), which teamed up with Gresham Smith & Partners to integrate a hospice building right on an active hospital campus. CHNF, one of the largest non-profit hospices in the country, receives a whopping 65% of its intake directly from the local hospital, compared to the national average of 33%, thanks to a local partnership. In conceiving its new hospice in St. Augustine, Florida, CHNF's design challenges included creating a facility that didn't feel like a facility. <http://www.healthcaredesignmagazine.com/article/efa-2013-making-space-hospice-care-continuum>

Noted in Media Watch, 25 March 2013:

- *QJM* | Online – 13 March 2013 – **'Patient dying in hospital: An honoured guest in an honoured place?'** [In *Modern Hospice Design: The Architecture of Palliative Care* (London: Routledge, 2009)] Ken Worpole reviewed the architecture and design of hospital spaces in which the dying find themselves. The idea of hospital being an honoured place with dying patients as honoured guests opens a new window into our daily reality of working in hospitals. <http://qjmed.oxfordjournals.org/content/early/2013/03/13/qjmed.hct064.extract>

Noted in Media Watch, 6 September 2010:

- *DESIGN & HEALTH* | Online – Accessed 2 September 2010 – **'Palliative care unit design: Patient and family preferences.'** The primary purpose of this qualitative study was to identify what palliative care patients and their families perceive to be important elements in the design of a palliative care unit for end-of-life care. Secondary objectives included exploring whether differences in preferences and perceptions exist between patients and family members. <http://www.worldhealthdesign.com/Palliative-Care-Unit-Design.aspx>

Living wills often 'not worth the paper they're written on'

INVESTMENT NEWS | Online – 10 April 2013 – Very often, the instructions in living wills are "not worth the paper they're written on," says Charlie Sabatino, of the American Bar Association Commission on Law & Aging. Even if a copy of your living will ends up at the hospital with you – that's hardly guaranteed – doctors routinely don't know how to interpret them. They may still leave friends and family confused about what you want. Leading experts in the field known as "advance care planning" are pushing for a change. Their goal: Keep the lawyers away from advance care planning. Yes, many of these experts are, like Sabatino, attorneys themselves, but they say an overly legalistic approach may be why so many living wills are proving useless, and why so few people ever sign them in the first place. Not surprisingly, people are unwilling to (quite literally) sign their lives away with forms they barely understand. The alternative is more time consuming, but ultimately more likely to mean your true wishes are followed when you end up sick or injured and unable to speak for yourself. It starts with appointing someone you trust to make decisions on your behalf, a step that does require the correct form depending on the state you live in. Then ... you must talk with your designated "health care agent" about your wishes – what sort of life you'd like to live if you get sick and under what circumstances you'd like to die. Then, and only then, it might make sense to formalize your wishes in a

legal document like a living will. Too many people flip this process around. They start by quickly filling out some legal forms at their lawyer's office. Then, they never look at them again nor discuss them with relatives. <http://www.investmentnews.com/article/20130410/FREE/130419998#>

Extracts from *Investment News* article

Doctors and nurses speak a different language from the one used by lawyers in many living wills. A typical living will directs physicians to stop treatment in the event of a "terminal" illness. This mystifies health care workers, who can define "terminal" as meaning a patient has anything from an hour to six months or more to live.

Many living wills are drawn up years before they're relied upon. That's a problem because, as people age, they tend to change their views on what they can tolerate when facing a serious illness.

[Specialist Publications](#)

'The impact of advance care planning of place of death, a hospice retrospective cohort study' (p.10), in *BMJ Supportive & Palliative Care*.

When discussing end-of-life plans, language should not be an issue

ABC NEWS | Online – 9 April 2013 – Spanish ... is the second most-common language spoken in households in the U.S. I don't know how other couples manage two languages, but there are times when either Spanish or English is better suited for a particular activity – arguing, for example. When I talk about death – in general or my own – it's just easier for me to do in English. I imagine that's a common phenomenon because it's all in the details ... the nuances of each word. I know from direct observation and experience that even with the best-intentioned health care providers and interpreters navigating the U.S. health care system when English is not your first language is deeply challenging. It's hard enough to talk about illnesses and treatments. That difficulty multiplies when thinking and communicating about more deeply personal topics. Spanish – and hundreds of other languages in the U.S. – are spoken by individuals who may not be familiar with the amount of personal input welcomed (sometimes demanded) by the health care system, particularly when it comes to end-of-life care. <http://abcnews.go.com/blogs/health/2013/04/09/when-discussing-end-of-life-plans-language-should-not-be-an-issue/>

Cont.

Noted in Media Watch, 16 July 2012:

- *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>

Noted in Media Watch (under 'Worth Repeating'), 18 February 2012:

- *PALLIATIVE MEDICINE*, 2010;24(4):427-434. "**The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with U.S.-born White, non-Latino cancer caregivers.**" This study identifies a significant dilemma: how to discuss hospice with a patient and family who prefer not to discuss a terminal prognosis. <http://pmj.sagepub.com/content/24/4/427.short>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | ABC News – 12 April 2013 – '**Montana doctors could face jail time for assisted suicide.**' In 2009, the state Supreme Court ruled narrowly in *Baxter v. Montana* that state law protects doctors from prosecution when helping terminally ill patients die, but it fell short of addressing the larger question of whether physician-assisted suicide was a guaranteed right under the state constitution. But on Thursday, the Montana Senate gave a preliminary nod to a House-passed bill that would criminalize physician-assisted suicide. <http://abcnews.go.com/Health/montana-doctors-face-jail-time-assisted-suicide/story?id=18935792>
- WASHINGTON STATE | *U.S. News & World Report* – 10 April 2013 – '**Physician-assisted suicide program rarely used, study finds.**' Physician-assisted suicide laws can raise controversy and concern with their passage, but a new study from Washington State suggests many of those fears may be unfounded.¹ Washington's Death With Dignity Act hasn't lead to scores of terminally ill people seeking lethal prescriptions, the researchers report: Almost three years after the law was enacted, just 255 people had obtained a lethal prescription from a physician. <http://health.usnews.com/health-news/news/articles/2013/04/10/physician-assisted-suicide-program-rarely-used-study-finds>
 1. 'Implementing a death with dignity program at a comprehensive cancer center,' *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;368(15):1417-1424. As more states consider legislation regarding physician-assisted death, the experience of a comprehensive cancer center may be informative. <http://www.nejm.org/doi/full/10.1056/NEJMsa1213398>

International

End of life care in Cyprus

Paphos hospice forced to downsize

CYPRUS MAIL (Nicosia) | Online – 11 April 2013 – The Friends Hospice in Paphos has been forced to scale down its operation due to the deepening economic crisis. The hospice is currently the only operational hospice in Paphos and is situated in a dedicated wing of the Evangelismos hospital. Since opening in 2006, the facility has expanded and now consists of a seven-bed unit which is solely run by donations, money raised by the shops and fundraising events. According to a hospice spokesman, running a multi-bed facility is no longer an option. He said: "We can't continue as we are as we just can't bring in the €500,000 which is needed to operate the hospice every year." <http://www.cyprus-mail.com/cyprus/paphos-hospice-forced-downsize/20130410>

N.B. Friends Hospice in Paphos website: <http://www.paphoshospice.org/>

End-of-life care in Ireland

Dignity, when it's needed most

IRELAND | *The Irish Examiner* (Lapps Quay, Cork) – 10 April 2013 – According to Irish Hospice Foundation (IHF) research, 43% of us die in acute hospital settings. Seven in 10 want to die at home but – for many of us – that wish is not fulfilled. This prompted the IHF to develop the Hospice Friendly Hospitals (HFH) programme, to bring hospice principles into hospital practice. "We set up the HFH programme to ensure that end-of-life care becomes central to the everyday business of hospitals," says Jackie Crinion, HFH programme manager [see sidebar]. The initiative raises awareness among hospital staff about end-of-life care and teaches them how to talk to patients and family. "For many staff, that's scary. It can be awkward and off-putting to face these poignant and difficult conversations," says Crinion. <http://www.irishexaminer.com/lifestyle/features/dignity-when-its-needed-most-227884.html>

Ireland's end-of-life care map

Doctors and other healthcare staff in hospitals are being encouraged to use the 'Competence & Compassion: End-of-Life Care' map. Developed by the IHF, the map provides practical advice and prompts along the end-of-life journey ...and, provides a set of key considerations for staff in end-of-life care: how doctors can recognise a progressive deterioration in health; diagnosing dying; communicating in difficult circumstances; planning end of life care with patients; communicating CPR decisions; and, caring for a deceased patient. http://www.hospicefriendlyhospitals.net/media/k2/attachments/End_of_Life_Care_Map_Print_friendly_version_1.pdf

London hospices receive share of £60million from government

U.K. | London 24 – 10 April 2013 – 14 London hospices which provide end of life care for children and adults have been given a share of £60million to improve care environments and settings.¹ The hospices will benefit from £4,872,237, which will be used to create new spaces for patients, their families and carers, whilst also supporting the care hospices provide to people in their own homes. http://www.london24.com/news/london_hospices_receive_share_of_60million_from_government_1_2013673

1. 'Hospices Funding Breakdown' provides details of funding given to individual hospices as part of the Capital Grant Scheme. <https://www.gov.uk/government/publications/hospices-funding-breakdown>

Obituaries celebrate lives of loved ones

SINGAPORE | *The Straits Times* – 9 April 2013 – The Lien Foundation wants to change the way people view newspaper advertisements about death. It thinks obituaries and death anniversary advertisements can be more cheerful and celebrate the lives of those who have passed on, instead of just listing the names of those left behind. The philanthropic group has launched an Obitcheery campaign with a series of ads ... that combine pictures with interesting details about the people featured. It is also inviting people to nominate their loved ones for such tributes to be published. This is the latest effort by the foundation, which has been working to remove the taboo over talking about death and dying. Foundation chief executive Lee Poh Wah said the aim of the campaign is to "capture the essence" of those who have died. So, the ads feature interesting and fun pictures of those who have died, not the usual head-and-shoulder shots seen in obituaries. <http://www.asiaone.com/News/Latest%2BNews/Singapore/Story/A1Story20130408-414263.html>

N.B. Obitcheery campaign homepage: <http://obitcheery.com/>

Cont.

Noted in Media Watch, 8 April 2013:

- CANADA | *The Globe & Mail* (Toronto) – 5 April 2013 – **'Why obituaries seduce us: They're a door on a world that's vanishing.'** The good that men do may be interred with their bones, as Shakespeare wrote – but the best bits live on after them, thanks to the obituary pages. <http://www.theglobeandmail.com/commentary/why-obituaries-seduce-us-theyre-a-door-on-a-world-thats-vanishing/article10823791/>

Of related interest:

- TAIWAN | BBC World Service (Taipei) – 23 February 2013 – **'Taiwan's most famous professional mourner.'** Crying on command isn't easy, but Liu Jun-Lin is hired to do it every day, at funerals for people she never knew. She's Taiwan's best-known professional mourner – a time honoured tradition in her country that may be dying out. Crying for a living is controversial, seen by some as the commercialisation of grief, but mourners like Liu say their profession has a long history in Taiwan, where according to tradition the deceased needs a big, loud send-off to cross smoothly into the afterlife. <http://www.bbc.co.uk/news/magazine-21479399>

[Specialist Publications](#)

'Hog heaven: Funeral and mourning rituals of an independent motorcycle club' (p.11), in *International Journal of Motorcycle Studies*.

[Media Watch: Editorial Practice](#)

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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.

[Media Watch posted on Palliative Care Network-e Website](#)

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

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

The impact of advance care planning of place of death, a hospice retrospective cohort study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 April 2013 – There is limited evidence of the impact of advance care planning (ACP) on outcomes. 969 patients were included [in this retrospective cohort study]. 550 (57%) people completed ACP. 414 (75%) achieved their choice of place of death. For those who chose home, 34 (11.3%) died in hospital; a care home 2 (1.7%) died in hospital; a hospice 14 (11.2%) died in hospital and 6 (86%) who chose to die in hospital did so. 112 (26.5%) of people without ACP died in hospital. Mean number of days in hospital in the last year of life was 18.1 in the ACP group and 26.5 in the non-ACP group. Mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730. Mean number of emergency admissions for those who died in hospital was 2.2 and who died elsewhere was 1.7. ACP is associated with a reduction in the number of days in hospital in the last year of life with less hospital costs, supporting the assumptions made in the End of Life Care Strategy 2008. <http://spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.abstract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 14 April 2013 – '**Development and evaluation of an aged care specific advance care plan.**' Documentation in use at facilities prior to the advance care planning intervention most commonly recorded preferences regarding hospital transfer, life prolonging treatment and personal/cultural/religious wishes. 7 of 12 document sets failed to adequately and clearly specify the resident's preferences as regards life prolonging medical treatment. <http://spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000392.abstract>

The use of touch in counseling: An ethical decision-making model

COUNSELING & VALUES, 2013;58(1):59-68. Although some counselors have advocated for the limited use of touch in counseling, others have argued that touch has no place within the counseling relationship. Despite the controversy, the use of touch has been shown to have a number of therapeutic benefits; however, there are few ethical decision-making models that are appropriate for considering the use of touch in counseling. The authors discuss the controversy surrounding the use of touch and the benefits/contraindications of touch. The ethical principles of counseling are also examined. <http://onlinelibrary.wiley.com/doi/10.1002/j.2161-007X.2013.00025.x/abstract>

Navigating bereavement with spirituality-based interventions: Implications for non-faith-based counselors

COUNSELING & VALUES, 2013;58(1):69-84. The authors explore how spirituality is often avoided in secular counseling settings, discuss adverse effects of unresolved grief on clients' functioning, and propose the concept that spirituality can be used to help clients through the bereavement process. Finally, the authors offer research and clinically based interventions that counselors, particularly those who do not identify as faith-based, can use to incorporate spirituality into their work with bereaved clients. <http://onlinelibrary.wiley.com/doi/10.1002/j.2161-007X.2013.00026.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Of related interest:

- *SUPPORTIVE CARE IN CANCER*, 2013;21(5):1445-1451. **""To cherish each day as it comes": A qualitative study of spirituality among persons receiving palliative care.**' Thematic analysis found that the spiritual dimension was of significance for the [study] participants who understood it as a vital element connected to seeking meaning, purpose and transcendence in life. Religious and non-religious aspects of spirituality were expressed. <http://link.springer.com/article/10.1007/s00520-012-1690-6>

Encouraging/supporting dying parents to talk to their children

END OF LIFE JOURNAL, 2013;3(2). Communicating with children about the anticipated death of a parent can be very challenging, even for experienced palliative care professionals. It can be particularly difficult for dying parents to discuss the fact that they are dying with their children. Consequently, they may adopt an overly positive stance in order to shield their children from the truth. When unable to understand what is happening within their family, children can blame themselves for the parent's illness. Open and honest communication, even with very young children, can lead to beneficial outcomes in terms of bereavement. As parents know their children best, it is preferable for the parents to explain the situation themselves; however, dying parents often require support from healthcare professionals in order to begin this difficult process. This article provides an overview of the main factors for nurses and other health professionals to consider when supporting dying parents to communicate with their children. It aims to improve the confidence of practitioners in relation to encouraging dying parents to undertake such difficult conversations. <http://endoflifejournal.stchristophers.org.uk/clinical-skills/encouraging-supporting-dying-parents-to-talk-to-their-children>

Noted in Media Watch, 17 September 2012:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 September 2012 – '**How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients.**' Families with young children often struggle to talk about and cope with a parent's life-threatening illness and potential death. Adult interdisciplinary palliative medicine teams often feel unprepared to facilitate the open communication with these children that has been shown to reduce anxiety, depression, and other behavioral problems. In pediatric settings, child life specialists routinely provide this support to hospitalized children as well as their siblings and parents. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0019>

Evidence-based practice in hospice: Is qualitative more appropriate than quantitative?

HOME HEALTHCARE NURSE, 2013;31(4):184-188. Evidence-based practice has become the accepted phrase relative to healthcare quality and outcomes. Hospice providers have begun to express an interest in applying evidence to practice ... with its tiers of evidence, ranks quantitative research methods at the top. However, there is concern that applying evidence-based practice to a subjective concept like pain and suffering may be problematic. A more balanced approach to quality outcomes in hospice care may need to involve patient experience and qualitative research. http://journals.lww.com/homehealthcareonline/Abstract/2013/04000/Evidence_Base_d_Practice_in_Hospice_Is_Qualitative.3.aspx

Hog heaven: Funeral and mourning rituals of an independent motorcycle club

INTERNATIONAL JOURNAL OF MOTORCYCLE STUDIES, 2013;9(1). How we grieve and mourn is influenced not only by our dominant culture, but also by our membership in sub-cultural groups. This study considers how being a member of a motorcycling sub-culture manifests itself in the rituals associated with loss. Members of independent motorcycle clubs were asked directly about the rituals they feel important to themselves and the families of loved ones. Results show that the love of a common social subculture – motorcycling – has led club members to develop a distinctive philosophy on the meaning of life and death. Members of the motorcycle clubs articulated a shared set of mourning rituals they believe essential to themselves, their club members and the families of lost friends. http://ijms.nova.edu/Spring2013/IJMS_Artcl.Shabanowitz.html

Nurses' preferred end-of-life treatment choices in five countries

INTERNATIONAL NURSING REVIEW | Online – 8 April 2013 – Previous research has focused on physician's perspectives of end-of-life (EOL) decision making... There is a lack of research pertaining to the EOL treatment preferences of nurses and especially nurses working in a variety of care settings. Nurses in the countries surveyed – Hong Kong, Ireland, Israel, Italy and the U.S. – consistently chose a more aggressive option for patients than for themselves or for a parent. Treatment preferences of nurses varied from country to country. Lack of knowledge of patients' wishes and duty of care were the main influencing factors on treatment preferences. <http://onlinelibrary.wiley.com/doi/10.1111/inr.12024/abstract;jsessionid=BB230B036D8127FBF9F9062A7DCBD67.d01t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 4 March 2013:

- *THE MEDICAL POST* (Canada) | Online – 26 February 2013 – '**Doctors aren't like others at the end of life.**' Researchers found that when doctors were asked about their treatment preferences in the hypothetical event of an irreversible brain injury, 90% said they would decline CPR, more than 85% reported they would say no to ventilation and dialysis, and around 80% would opt out of surgery and a feeding tube. The only treatment most wanted: pain medication. <http://www.canadianhealthcarenetwork.ca/physicians/news/doctors-arent-like-others-at-the-end-of-life-26828>

N.B. Footnoted are other articles on the same subject noted in past issues of Media Watch

Difficult and uncomfortable conversations

Demand of words

JAMA INTERNAL MEDICINE | Online – 1 April 2013 – In medicine, there is a brittle demand of words – once spoken, they cannot be called back, for their footprint is forever – particularly at the end of life. They embed themselves in the hearts of patients and families and hold dominion over understanding or uncertainty, acceptance or denial. They can also hurt or heal, or harm or help, and bear witness to the suffering of disease – and the manner of the physician. Patients and families are often distressed, in shock, and grieving, and frequently waiting to hear the words they don't want to hear. And physicians don't want to say the words – it's disheartening and stressful. Moreover, the emotional content of words and the asymmetrical and oftentimes paternalistic relationship between physician and patient can become overwhelming and unbearable, exaggerating vulnerability and fear, and further contributing to difficult and uncomfortable conversations. Unfortunately, many physicians have a "dis-ease" caring for certain ailments and may be adversely affected by a clinical impotence to cure a life-threatening illness. This clinical impotence can bring about an unintentional detached remoteness, and far-too-often, time away from the bedside. <http://archinte.jamanetwork.com/article.aspx?articleID=1673752>

Of related interest:

- *JOURNAL OF HEALTH COMMUNICATION* | Online – 11 April 2013 – '**Physicians' use of clear verbal communication.**' This study found that medical residents used clear communication techniques infrequently and tended to over estimate the clarity with which they communicate. <http://www.tandfonline.com/doi/abs/10.1080/10810730.2012.757398>
- *QJM*, 2013;106(4):385-388. '**Being better clinicians: An acronym for excellence.**' Five main characteristics were derived [from this literature review] – maintaining a systematic method; employing observation and listening; accessing databases; emphasizing a personal empathic attitude and sharing information and decisions with the patient and family. <http://qjmed.oxfordjournals.org/content/106/4/385.abstract>

Depictions of "brain death" in the media: Medical and ethical implications

JOURNAL OF MEDICAL ETHICS | Online – 12 April 2013 – Debates and controversies have shaped the understanding and the practices related to death determined by neurological criterion (DNC). Confusion about DNC in the public domain could undermine this notion. This confusion could further jeopardise confidence in rigorous death determination procedures, and raise questions about the integrity, sustainability, and legitimacy of modern organ donation practices. The authors examined the depictions of "brain death" in major American and Canadian print media to gain insights into possible common sources of confusion about DNC and the relationship between expert and lay views on this crucial concept. Results showed problematic aspects in American and Canadian media, with some salient differences. DNC was used colloquially in 39% of the articles and its medical meaning infrequently defined. The neurological criterion for determination of death was mentioned in less than 10% of the articles, and life support in about 20% of the articles. Organ donation issues related to DNC were raised more often in Canadian articles than in American articles. <http://jme.bmj.com/content/early/2013/04/11/medethics-2012-101260.abstract>

Noted in Media Watch, 3 September 2012:

- *McGill Journal of Law & Health*, 2012;6(1):41-136. **'A death-defying leap: Section 7 Charter implications of the Canadian Council for Donation & Transplantation's guidelines for the neurological determination of death.'** These brain death guidelines, adopted in some parts of Canada by both policy-makers and practitioners, with possible effects on organ and tissue supplies, substantially redefine the point at which physicians may declare neurological death. Aspects of this redefinition raise patient safety concerns because they reveal a potential for physicians to declare death significantly earlier, and with greater chance of error, than previous brain death guidelines. <http://mjlh.mcgill.ca/pdfs/vol6-1/MJLH%20Vol.%206.%20No.%201%20-%20Shaw.pdf>

Noted in Media Watch, 27 August 2012:

- *CLINICAL ETHICS*, 2012;7(3):128-132. **'Brain death: Justifications and critiques.'** The authors review the historical development of brain death, and then evaluate the various attempts to justify the claim that patients who are diagnosed as brain dead can be considered dead for all legal and social purposes, and especially with regard to procuring their vital organs for transplantation. <http://ce.rsmjournals.com/content/7/3/128.abstract>

From sedation to continuous sedation until death: How has the conceptual basis of sedation in end-of-life care changed over time?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 April 2013 – Numerous attempts have been made to describe and define sedation in end-of-life care over time. However, confusion and inconsistency in the use of terms and definitions persevere in the literature, making interpretation, comparison, and extrapolation of many studies and case analyses problematic. This review shows that terminology has evolved from simple to complex terms with definitions varying in length, comprising different aspects of sedation such as indications for use, pharmacology, patient symptomatology, target population, time of initiation, and ethical considerations, in combinations of a minimum of two or more of these aspects. There is a pressing need to resolve the conceptual confusion that currently exists in the literature to bring clarity to the dialogue and build a base of commonality on which to design research and enhance practice of sedation in end-of-life care. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00141-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00141-3/abstract)

Transitioning from caregiving to widowhood

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 April 2013 – Older women caregivers [i.e., study participants] described their caregiver role as taxing, particularly in light of their own chronic conditions that they failed to prioritize and address. They did not ask for help in managing their roles and health problems, but quietly endured. Hence, they did not communicate their needs or strains explicitly. The degree of perceived adequacy of communication and interaction with health professionals were important factors impacting on their bereavement. It is imperative for health professionals to appreciate that older women caregivers may need more supportive interaction and information during the end-of-life caregiving, they may have expectations of communication, and they may deny or fail to focus on their own health issues. A patient/family/carer-centered approach could negate this oversight and improve the outcomes for these women as they transition into widowhood. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00139-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00139-5/abstract)

Noted in Media Watch, 18 March 2013:

- *ILLNESS, CRISIS & LOSS*, 2013;21(1):3-13. 'I'm not the man I was: Reflections on becoming a widower.' The author of this article focuses on the intertwined questions of profound loss, the search for meaning, and the impact of that search on the reshaping of identities. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,10;journal,1,73;linkingpublicationresults,1:103734,1>

How and when to discuss hospice?

NEUROLOGY TODAY, 2013;13(7):18-20. In an analysis of sites of death in 2000, 2005, and 2009, investigators reported that only 24% of people over 65 died at home.¹ That's an increase from 15% in 1989 and parallels a decreased number of deaths in acute care hospitals. But experts say the statistics would be better if clinicians involved patients with chronic neurodegenerative disease and their families early on in discussions about planning for hospice care. http://journals.lww.com/neurotodayonline/Fulltext/2013/04040/How_and_When_to_Discuss_Hospice__8.aspx

1. 'Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions..' *Journal of the American Medical Association*, 2013;309(5):470-477. [Noted in Media Watch, 11 February 2013] <http://jama.jamanetwork.com/article.aspx?articleid=1568250>

What's in a name: Is the moniker 'palliative care' too loaded?

THE ONCOLOGY REPORT | Online – 10 April 2013 – That which we call a rose by any other name would smell as sweet. Perhaps not, if the conversation turns to palliative care. A telephone survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. In contrast, there was no significant difference in outcomes when patients heard either a "patient-centered" or "traditional" description of palliative/supportive care services, Rachael Maciasz said at the recent annual meeting of the American Association of Hospice & Palliative Medicine. "It may be that 'palliative care' is so loaded with advanced cancer patients because of family members' or friends' experiences with this in the past (they think) their family member is going to die," she said. "Perhaps what comes after that, no matter how you describe it, you can't change that impression." [Most common cancer diagnoses of study participants were breast (32%), lung (18%), and gastrointestinal (13%).] <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>

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Noted in Media Watch, 14 January 2013:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 January 2013 – '**Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.**' Although most [study participants] claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral, as well as with the supportive care team after the referral was made. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685>

Noted in Media Watch, 3 September 2012:

- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – '**Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.**' Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. The authors conducted a systematic review of the literature to further identify concepts and definitions on these terms. <http://link.springer.com/article/10.1007/s00520-012-1564-y>

Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care

PEDIATRICS | Online – 8 April 2013 – Forgoing artificial nutrition and hydration (FANH) in children at the end of life (EOL) is a medically, legally, and ethically acceptable practice under specific circumstances. However, most of the evidence involves dying adults. All parents [i.e., study participants] were satisfied with their decision to FANH and believed that their child's death was generally peaceful and comfortable. Despite overall satisfaction, all parents had doubts and questions about the decision and benefited from ongoing assurances from the clinical team. <http://pediatrics.aappublications.org/content/early/2013/04/03/peds.2012-1916.abstract>

Of related interest:

- *PEDIATRICS* | Online – 8 April 2013 – '**Forgoing artificial nutrition and hydration: What to make of parents' views.**' No abstract available. <http://pediatrics.aappublications.org/content/early/2013/04/03/peds.2013-0380.full.pdf+html>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *INTERNATIONAL JOURNAL OF PUBLIC HEALTH* | Online – Accessed 9 April 2013 – '**Public acceptance of euthanasia in Europe: A survey study in 47 countries.**' Relatively high acceptance was found in a small cluster of Western European countries, including the three countries that have legalized euthanasia and Denmark, France, Sweden and Spain. In a large part of Europe public acceptance was relatively low to moderate. Comparison with the results of the previous European Values Survey wave (1999) suggests a tendency towards a polarization in Europe, with most of Western Europe becoming more permissive and most of Eastern Europe becoming less permissive. There is roughly a West-East division in euthanasia acceptance among the European public, making a pan-European policy approach to the issue difficult. <http://link.springer.com/article/10.1007/s00038-013-0461-6#>

Noted in Media Watch, 7 January 2013:

- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 29 December 2012 – '**Different trends in euthanasia acceptance across Europe. A study of 13 western and 10 central and eastern European countries, 1981-2008.**' Euthanasia acceptance increased each decade up until 2008 in 11 of 13 western European countries; in central and east European countries, it decreased or did not increase between 1999-2008 in 8 of 10 countries. <http://eurpub.oxfordjournals.org/content/early/2012/12/28/eurpub.cks186.abstract>

Cont.

- *JOURNAL OF LOSS & TRAUMA*, 2013;18(2):539-555. **'Physician-assisted death and its relationship to the human services professions.'** The history, current status, opinions and attitudes, and ethical issues related to physician-assisted death are examined. Implications for physician-assisted death and its interface with the human services professions are described with respect to multiculturalism; identity; perceptions of disease, illness, and pain; attitudes towards therapy; family decision making; ethics; and professional roles. <http://www.tandfonline.com/doi/abs/10.1080/15325024.2012.719345>

Media Watch Online

Asia

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

Australia

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

Canada

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

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

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

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

Europe

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

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

International

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

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

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

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