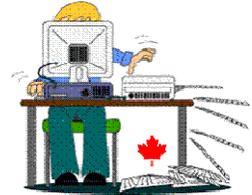


Media Watch...

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

Best practice: Scroll down to [Specialist Publications](#) and 'Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany, and the U.S.' (p.12), in *Palliative Medicine*.

Canada

Rare agreement in Ontario on need for end-of-life discussions

ONTARIO | *The Toronto Star* (OpEd) – 24 June 2013 – It's a rare moment when all three political parties ... find themselves in agreement. But the complex issues behind end-of-life care are clearly resonating with enough Ontarians ... that normally divisive Members of Provincial Parliament agree that it's time to take action. The issue got a boost ... when Premier Kathleen Wynne told reporters that it needed a good "discussion." Wynne was clearly inspired by the compassionate motives behind Québec's Bill 52, An Act Respecting End-of-Life Care, even if the legislation risks conflict with ... [Canada's] ... Criminal Code by allowing physicians to administer lethal medication at a patient's request.¹ While Ontario isn't ready for that bold move, new doors are opening. In the days following Wynne's comments, Progressive Conservative Leader Tim Hudak suggested a government committee look into the issue. New Democratic Party health critic France Gélinas agreed. They are right to ask for a committee ... one with good researchers and the opportunity to discuss the circumstances surrounding death with Ontarians from all walks of life. http://www.thestar.com/opinion/editorials/2013/06/24/rare_agreement_in_ontario_on_need_for_endoflife_discussions_editorial.html

1. QUÉBEC | CTV News (Montréal) – 12 June 2013 – '**Québec government tables assisted suicide bill.**' The controversial Bill 52 outlines the conditions necessary for someone to get medical assistance to die and spells out the requirements necessary before a doctor can accept. Social Services Minister Véronique Hivon is forming a commission on end-of-life care that will be mandated to ensure the legislation is being applied correctly. [Noted in Media Watch, 17 June 2013, #310 (p.3)] <http://montreal.ctvnews.ca/quebec-government-tables-assisted-suicide-bill-1.1322449>

N.B. See 'Assisted suicide: Québec has found a flexible approach to euthanasia law' next page.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUÉBEC | *The Globe & Mail* (OpEd) – 27 June 2013 – '**Assisted suicide: Québec has found a flexible approach to euthanasia law.**' By framing euthanasia as a medical, not criminal, matter, Québec brings the debate into provincial jurisdiction. This is a smart move, given that waiting for the federal government to pass a similar bill is an act of futility. Canada has proven itself to be entirely unable to regulate abortion, a similarly controversial act that intersects criminal and medical law (federal and provincial jurisdiction). Abortion, like euthanasia, is too divisive for the federal government. And so, Canada has inconsistent abortion policies because guidelines are set by individual hospitals. The lack of regulation also means lost opportunities for oversight and data collection. [Québec's] Bill-52 sets the law for physicians and institutions across Québec and demands high standards for care and oversight. <http://www.theglobeandmail.com/commentary/assisted-suicide-quebec-has-found-a-flexible-approach-to-euthanasia-law/article12853839/>

U.S.A.

"nodding at once unspeakable events"

The American way of death

THE ECONOMIST | Online – 29 June 2013 – Over an abstract watercolour that hints at a setting sun, a Hallmark card expresses gladness that "our paths came together in this life" and vows: "You're in some of the best memories I have and you always will be." The card, a 2014 addition to the company's "sympathy" range, will be for sending to people who know they are dying. After decades of euphemism and denial, America is rediscovering death. The greetings-card industry, which studies social trends carefully, is a useful window on changing manners. Editors and art directors at Hallmark's headquarters in Missouri say that customers now want candour, even about terminal illness. On shelf-sections marked "tough times" or "extended illness," there are messages about Alzheimer's (or, in card-speak, "the twilight that fell on your loved one's mind"). The word cancer, long shunned, now appears on mass-market cards. Such frankness was last seen a century ago, when lives were short, health precarious, and loved ones routinely expired in the family home. <http://www.economist.com/news/united-states/21580157-hallmark-cards-show-new-candour-about-terminal-sickness-american-way-death>

Senate Special Committee on Aging

Advanced Care Planning

ASSOCIATION OF MATURE AMERICAN CITIZENS | Online – 27 June 2013 – In a hearing entitled 'Renewing the Conversation: Respecting Patient's Wishes and Advanced Care Planning,' Senators and experts who specialize in end-of-life care testified to current trends among older Americans and shared their recommendations for responsible health care planning. A common theme emerged: patients and physicians are not discussing death and are not routinely making plans for their end-of-life care. This conversation is not happening frequently

enough within families either, leaving spouses or a proxy with the pressure of making important medical decisions quickly in times of need and emotional distress. <http://amac.us/advanced-care-planning>

Specialist Publications

'Advance directives are often not honoured' (p.8), posted on *BioEdge*.

Many cancer patients expect palliative care to cure

REUTERS | Online – 26 June 2013 – In a survey of patients with terminal lung cancer, nearly two-thirds did not understand that radiation treatments intended only to ease their symptoms would not cure their disease.¹ Among the nationwide sample of patients with advanced lung cancers, four out of five thought the radiation would help them live longer and two in five believed it might cure their cancers. "Radiation therapy can be used to relieve symptoms caused by metastatic lung cancer, such as pain from bony metastases, shortness of breath from lung tumors, or neurologic symptoms, such as weakness, from brain metastases," said the study's lead author, Dr. Aileen Chen of the Dana-Farber Cancer Institute in Boston. Patients with metastatic lung cancer usually live less than a year, she told Reuters, and their radiation treatments are intended to improve quality of life for the time that remains, so Chen was surprised that so many patients believed they would cure them. The study included 384 ... diagnosed with incurable lung cancer ... and were receiving radiation therapy. The patients answered questions about their expectations of the therapy. Overall, 64% did not understand that radiation was not at all likely to cure them. <http://www.reuters.com/article/2013/06/26/us-cancer-cure-idUSBRE95P15320130626>

1. 'Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer,' *Journal of Clinical Oncology*, 17 June 2013. Although patients receiving radiation therapy for incurable lung cancer believe it will help them, most do not understand that it is not at all likely to cure their disease. This indicates a need to improve communication... <http://jco.ascopubs.org/content/early/2013/06/17/JCO.2012.48.5748.abstract?sid=a92bb3e9-e3a5-4219-95bf-994b47b91811>

Brothers' keepers: End-of-life care in the Maine State Prison [Part 1]

MAINE PUBLIC BROADCASTING NETWORK | Online – 24 June 2013 – Kandyce Powell of the Maine Hospice Council has been coming into the prison about once a week for the past 13 years, as part of the council's mission of bringing hospice care training into underserved populations. With quiet persistence, Powell has outlasted three wardens and two corrections commissioners, but eventually convinced prison officials to let her undertake a training program for inmates on how to care for the dying. Powell is fond of saying that a prisoner should not be solely defined by his worst crimes. "You know how society feels about men and women who are incarcerated, and we don't try to get below the surface of who they really are as individuals," Powell says. "And that's what we're trying to do with this program." The intensive ... seminar proved

so successful that when it came time to begin a second class, several dozen inmates applied for a few select spots. Her message to these inmates was that they would learn about life by helping others through death. <http://www.mpbnet.com/News/MaineNewsArchive/tabid/181/ctl/ViewItem/mid/3475/ItemId/28650/Default.aspx>

[Prison hospice](#)

Articles on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a regular basis. A compilation of these articles in a single document is available on request. Contact information at the foot of p.15.

N.B. Part 2: <http://www.mpbnet.com/Home/tabid/36/ctl/ViewItem/mid/5347/ItemId/28668/Default.aspx>
Part 3: <http://www.mpbnet.com/Home/tabid/36/ctl/ViewItem/mid/5347/ItemId/28694/Default.aspx>

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.13.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | *The Houston Chronicle* (Texas) – 24 June 2013 – **'Vermont's smallest hospital opts out of aid-in-dying.'** Grace Cottage Hospital ... has become the latest to opt out of the state's new aid-in-dying law, but hospital officials expect to revisit the issue soon. "Opting out doesn't mean that we are not going to implement the law," said Dr. Maurice Geurts, the hospital's medical staff president. "We just need to take time to make sure that our employees, medical staff, board and patients understand all aspects of this law," he said. "We want to have a clear plan for education and communication as we develop policies and procedures for how to handle these situations." Most hospitals are expected, at least for the time being, to opt out of implementing it. Vermont's largest hospital, Fletcher Allen, also has opted out for now to give administrators a chance to "develop a thoughtful, compassionate policy that will respect our patients and providers." <http://www.chron.com/news/article/Vt-s-smallest-hospital-opts-out-of-aid-in-dying-4618272.php>

International

The Liverpool Care Pathway

Number of Sunderland patients placed on controversial end-of-life treatment doubles

U.K. (ENGLAND) | *The Sunderland Echo* – 29 June 2013 – The Liverpool Care Pathway (LCP) ... was implemented in hospitals three years ago to promote quality end-of-life care. Half of all patients who die in hospital are placed on it. In Sunderland, 229 patients were put on the scheme between 2010 and 2011. That has since almost doubled to 446 between 2012 to 2013. While other North East [National Health Service] trusts have received six-figure sums from the Department of Health to use the pathway under Commissioning for Quality & Innovation, Sunderland Royal Hospital has not received any direct payments. A spokesman for the hospital said LCP is being used to enable

staff to focus on care in the last hours or days of life, and tailor it to their needs. <http://www.sunderlandecho.com/news/health/number-of-sunderland-patients-placed-on-controversial-end-of-life-treatment-doubles-1-5808707>

Specialist Publications

'The media critique of The Liverpool Care Pathway: Some implications for nursing education' (p.9), in *International Journal of Palliative Nursing*.

Of related interest:

- U.K. | *The Daily Telegraph* – 26 June 2013 – **'Doctors warn Liverpool Care Pathway seen as "one-way ticket to death."**' Doctors have expressed concern about the misuse of the LCP, saying some patients have been denied life-extending treatment for weeks on end. Medics at the British Medical Association's conference ... called for changes in the way end-of-life care is delivered and warned that too often the pathway is being mistaken for a "one-way ticket" to death. The majority supported the principle of the LCP, which is supposed to mean treatment, food and drink can be withdrawn when a patient is close to death, if it will make them more comfortable. <http://www.telegraph.co.uk/health/healthnews/10143650/Doctors-warn-Liverpool-Care-Pathway-seen-as-one-way-ticket-to-death.html>

N.B. A representative sample of recent articles on The Liverpool Care Pathway noted in Media Watch are listed in the 10 June 2013 (#309) issue of the weekly report (pp.11-12).

End-of-life Care in Africa

Perils of operating palliative care

NIGERIA | Spy Ghana – 27 June 2013 – A country of about 160 million people, 36 States and 774 Local Government Areas, palliative care in Nigeria is disheartening, given that in 1996, a small amount of Nigerians initiated a crusade for palliative care. This promotion included opioids, which was aimed to manage pain. After that palliative care sponsorship there are only two centres across the country, where services to victims of chronic ailments like cancer and HIV/AIDS, renal failures, are being rendered. These centres are the Palliative Care Initiative (Ibadan), and Hospice Nigeria (Lagos). The management of victims in these centres is not unconnected without manmade discomfitures, unalloyed to what victims are suffering from. Harangues are that Nigeria is too far to redeeming the burdens of this sector, incomparable to what obtain in other African countries and the U.K. Six years after the few Nigerians made that move to introduce palliative care in Nigeria, it was finally made public in 2003, through the Palliative Care Initiative of Nigeria, now known as Centre for Palliative Care, Nigeria. The year 2003 was when palliative care was properly established to the Nigerian government, policymakers and general public. On-the-other-hand, palliative care is still novel to the country owing to the fact that it is not included as an area of acquisition for health professionals across the country. <http://www.spyghana.com/perils-of-operating-palliative-care/>

With Mandela, end-of-life care dilemmas magnified

THE ASSOCIATED PRESS | Online – 28 June 2013 – The emotional pain and practical demands facing Nelson Mandela's family are universal: confronting the final days of an elderly loved one. There are no rules for how or when the end may arrive. Some choose to let go with little medical interference; others seek aggressive treatment. Mandela's status as a respected global figure only complicates the situation, doctors and end-of-life experts say. Mandela "is not only revered, he is loved and profoundly admired by people all over the world, and the sense of letting go must be difficult for everyone involved," said Dr. William Schaffner, an infectious disease specialist at Vanderbilt University [Nashville, Tennessee]. In much of Africa, people are considered fortunate to live past age 60. For those who reach old age, death is still seen as sad, but friends and family typically celebrate with big parties to honor a life well-lived. Taking extraordinary measures to keep that person alive would be considered dishonorable, said Dr. Sola Olopade, the Nigerian-born clinical director for the University of Chicago's Center for Global Health. If such measures are being used for Mandela, many could consider it "quite painful," Olopade said, "because those are not the last memories you want to have for someone with such an exemplary life." <http://www.usatoday.com/story/news/world/2013/06/28/mandela-end-of-life-dilemmas/2473619/>

Noted in Media Watch, 17 October 2011, #223 (p.3):

- NIGERIA | *The Tribune* (Ibadan) – 14 October 2011 – **'Experts identify lapses in health care delivery in Nigeria.'** Dr. Israel Kolawole [of the University of Ilorin Teaching Hospital] has criticised the nation's health care system, saying the relief of suffering as a goal of medical care has been subjugated or lost ... adding that "our healthcare package does not fully address the emotional, spiritual and psychology suffering faced by patients with life-threatening illnesses." <http://www.tribune.com.ng/index.php/community-news/29644-experts-identify-lapses-in-health-care-delivery-in-nigeria>
- NIGERIA | *The Tribune* (Ibadan) – 12 October 2011 – **'Experts canvass support for people living with life-threatening diseases.'** Hospice & Palliative Care Association of Nigeria has decried the unavailability of oral morphine and other opioid analgesic, the mainstay drug for pain control in people living with life-limiting or life-threatening illnesses conditions... <http://www.tribune.com.ng/index.php/community-news/29523-experts-canvass-support-for-people-living-with-life-threatening-diseases>

End-of-life care in Ireland

2,500 patients a year are denied access to hospice services

IRELAND | *The Journal* (Dublin) – 26 June 2013 – Areas with limited access to hospice care have more cancer deaths in hospitals. According to the Irish Hospice Foundation, around 2,500 patients each year are denied access to the hospice care they need because of a lack of hospice services nationwide.¹ This is in spite of a national policy since 2001 that promised to provide one hospice bed for every 10,000 people. Going by current population figures, there should be 450 hospice beds in the country. Today, there are only 155 hospice beds available. There is a significant reduction in the number of deaths in acute hospitals in the areas where hospice beds are available. <http://www.thejournal.ie/hospice-care-ireland-966952-Jun2013/>

Unfairness in death

IRELAND | *The Irish Times* (Dublin) – 27 June 2013 – Dying patients need a special type of care and comfort. These words encapsulate the philosophical thrust behind a forceful report from the Irish Hospice Foundation which highlights stark inequities in specialist palliative care services throughout the State. Where a person lives can decide whether they have a "good death," whether there is a positive approach to the quality of their life at end of life, and whether suffering is relieved and families are supported through bereavement. Unfairness in Irish health service provision may be endemic but it becomes particularly poignant when death approaches. <http://www.irishtimes.com/news/health/unfairness-in-death-1.1443469>

1. *Access to Specialist Palliative Care Services and Place of Death in Ireland...*, Irish Hospice Foundation, May 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

Noted in Media Watch, 15 April 2013, #301 (p.8):

- IRELAND | *The Irish Examiner* (Lapps Quay, Cork) – 10 April 2013 – **'Dignity, when it's needed most.'** 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 Foundation to develop the Hospice Friendly Hospitals programme... <http://www.irishexaminer.com/lifestyle/features/dignity-when-its-needed-most-227884.html>

N.B. The IHF 'Competence & Compassion: End-of-Life Care' map provides practical advice and prompts along the end-of-life journey and a set of key considerations for staff in end-of-life care. http://www.hospicefriendlyhospitals.net/media/k2/attachments/End_of_Life_Care_Map_Print_friendly_version_1.pdf

Noted in Media Watch, 21 January 2013, #289 (p.4):

- IRELAND | The Atlantic Philanthropies – 17 January 2013 – **'Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report.'** This report presents the findings of a five-phased evaluation of the programme, which assessed the progress and impact of the programme to date, and the strategic learning for the field. http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf

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>

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

Report highlights growing need to improve end-of-life care for minority ethnic groups

U.K. | NATIONAL END OF LIFE CARE INTELLIGENCE NETWORK – 25 June 2013 – With Black, Asian and minority ethnic (BAME) groups aged 65 and over set to treble in the next 25 years, there is a growing need to rethink how accessible and appropriate end of life care is to people from diverse communities and their families, say palliative care experts. A report commissioned by Marie Curie Cancer Care and Public Health England ... highlights that the end of life care needs of BAME communities are varied, growing and, despite examples of good practice, overall not adequately met.¹ A systematic review found that lack of knowledge about services, misunderstandings and mistrust (due to previous experiences of discrimination), and a lack of cultural sensitivity on the part of service providers are identified as some of the reasons for low uptake of end of life care by BAME communities. The report authors say these issues can in part be addressed by improving communication with the patient and their family. The report recommends that service providers and commissioners recognise the growing need for improved end of life care for BAME communities and that they learn from examples of best practice...
<http://www.endoflifecare-intelligence.org.uk/news/>

1. *Palliative and end-of-life care for Black, Asian and Minority Ethnic groups in the U.K.* [Demographic profile and the current state of palliative and end-of-life care provision], Cicely Saunders Institute at King's College, June 2013. <http://www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf>

End-of-life care in South Africa

AIDS: Orphanage closes its hospice, babies no longer dying

SOUTH AFRICA | *The Christian Science Monitor* – 23 June 2013 – It was common, at Cotlands child-care facility, for one baby to die every week, in the small AIDS hospice opened there in 1996. In 2002, 89 babies died, almost two a week. Then, in 2008, babies at Cotlands stopped dying. There were no deaths in 2009 or 2010, either. The center realized this wasn't a fluke: Its HIV-positive children appeared to benefit from antiretroviral drugs, known as ARVs. Children were still being abandoned, or given up for adoption, but not – for the most part – because they were born with HIV. Last December, Cotlands closed its AIDS hospice. The Cotlands nursery is symbolic of a much bigger story. <http://www.csmonitor.com/World/Africa/2013/0623/AIDS-Orphanage-closes-its-hospice-babies-no-longer-dying>

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

British Columbia Council on Health Promotion

End-stage dementia and palliative care

BC MEDICAL JOURNAL, 2013;55(6):287,291. Although patients newly diagnosed with an early dementia may have years of quality life to come, it is also true that dementia is eventually a fatal illness. Patients with advanced dementia develop difficulties with mobility, lose the ability to communicate, and do not always recognize family or friends. At that point in the illness, prognosis for prolonged survival is poor, no matter how aggressively the patient is managed. This fact can come as quite a surprise to caregivers, including medical staff. Consequently, patients at the end stages of their illness can be subject to distressing and uncomfortable investigations and treatments that will not change the outcome significantly, but could adversely impact patient quality of life. http://www.bcmj.org/sites/default/files/BCMJ_55_Vol6_cohp.pdf

N.B. Several articles on end-of-life care for people living with dementia are noted in Media Watch, 14 January 2013, #288 (pp.8-9).

Advance directives are often not honoured

BIOEDGE | Online – 29 June 2013 – Advance directives give peace of mind to patients and their loved ones because they can be sure that their health care wishes will be followed even if they are not able to communicate. At least that's the theory. In practice, the situation is different, according to Susan P. Shapiro, a sociologist with the American Bar Association [ABA]. After observing a thousand interviews of doctors with families in two intensive care units, she found that what happens is far more complicated. Only about 36% of patients or their spokespersons claimed to have an advance directive. And in only about 10% of cases was the directive read. Sometimes it could not be found. In about one-third of patients with an advance directive, neither the doctor nor the families mentioned it. In about 25% of cases, the advance directive worked according to plan, giving peace of mind and a clear plan of action. But in 45% of cases, "there was no discernible evidence that the directive made any difference," she said. It was either never mentioned, "or if somebody tried to talk about it, it fell on deaf ears; the family didn't want to have anything to say about it." Sometimes the preferences were "simply flouted or ignored or disregarded." Sometimes patients changed their minds about the treatment they wanted, but they did not change the advance directive or tell their families. "And so what is written in stone are wishes that no longer apply to the patient." http://www.bioedge.org/index.php/bioethics/bioethics_article/10579

Of related interest:

- *JOURNAL OF CLINICAL ETHICS*, 2013;24(2): "'He got his last wishes": Ways of knowing a loved one's end-of-life preferences and whether those preferences were honored.' Advance care directives may provide information for families and surrogate decision makers; however, less than one-third of Americans have completed such documents. As the U.S. population continues to age, many surrogate decision makers likely will rely on other means to discern or interpret a loved one's preferences. While many surrogates indicate that they have some knowledge of their loved one's preferences, how surrogates obtain such knowledge is not well understood. Additionally, although research indicates that the emotional burden of end-of-life decision making is diminished when surrogates have knowledge that a loved one's preferences are honored, it remains unclear how surrogates come to know these preferences were carried out. <http://www.clinicalethics.com/>

Palliative care psychiatry: Update on an emerging dimension of psychiatric practice

CURRENT PSYCHIATRY REPORTS | Online – 22 June 2013 – Palliative care psychiatry is an emerging sub-specialty field... The discipline brings expertise in understanding the psychosocial dimensions of human experience to the care of dying patients and support of their families. The goals of this review are 1) to briefly define palliative care and summarize the evidence for its benefits; 2) to describe the roles for psychiatry within palliative care; 3) to review recent advances in the research and practice of palliative care psychiatry; and, 4) to delineate some steps ahead as this sub-field continues to develop, in terms of research, education, and systems-based practice. <http://link.springer.com/article/10.1007/s11920-013-0374-3>

[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>

The media critique of The Liverpool Care Pathway: Some implications for nursing education

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2013;19(6):275-280. This paper examines recent negative media discourse in the U.K. about The Liverpool Care Pathway for the dying patient. This media coverage may have had damaging effects, but it has also served to highlight inappropriate and even suboptimal end-of-life care. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=99433;article=IJPN_19_6_275_280

Noted in Media Watch, 17 June 2013, #310 (p.12):

- *BRITISH MEDICAL JOURNAL* | Online – 11 June 2013 – **'We need an alternative to The Liverpool Care Pathway for patients who might recover.'** Having a pathway for all situations is an obsession of today's medicine. Sometimes this has led to a pathway that was designed for one situation being adapted or used in another – and not always to good effect. <http://www.bmj.com/content/346/bmj.f3702>

N.B. A representative sample of recent articles on The Liverpool Care Pathway noted in Media Watch are listed in the 10 June 2013 (#309) issue of the weekly report (pp.11-12).

Reviving brain death: A functionalist view

JOURNAL OF BIOETHICAL INQUIRY | Online – Accessed 25 June 2013 – Recently both whole brain death and higher brain death have come under attack. These attacks, the authors argue, are successful, leaving supporters of both views without a firm foundation. This state of affairs has been described as "the death of brain death." Returning to a cardiopulmonary definition presents problems they also find unacceptable. Instead, the authors attempt to revive brain death by offering a novel and more coherent standard of death based on the permanent cessation of mental processing. <http://link.springer.com/article/10.1007/s11673-013-9450-y>

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2013;67(1):155-160. **'Improving incidence of referrals for psychosocial and spiritual transdisciplinary care in a palliative care service: Focus on brain death.'** The goal ... was to examine the uniformity of the hospital's delivery of psychosocial and spiritual care for the families of patients being evaluated for brain death. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,18,30;journal,1,264;linkingpublicationresults,1:300329,1>

Caring for elder parents: A comparative evaluation of family leave laws

JOURNAL OF LAW, MEDICINE & ETHICS | Online – 26 June 2013 – This paper reviews the national family leave laws of nine major OECD [Organisation for Economic Co-operation & Development] countries (Canada, Denmark, France, Germany, Italy, Japan, Netherlands, Spain, and the United Kingdom) and provides a state-by-state analysis within the U.S. The authors find that the U.S. has the least generous family leave laws among the nine OECD countries. With the exception of two states (California and New Jersey), the U.S. federal Family Medical Leave Act of 1993 provides no right to paid family leave for eldercare. They survey the current evidence from the literature on how paid leave can impact family caregivers' employment and health outcomes, gender equality, and economic arguments for and against such laws. The authors argue a generous and flexible family leave law, financed through social insurance, would not only be equitable, but also financially sustainable. <http://onlinelibrary.wiley.com/doi/10.1111/jlme.12058/abstract>

The meanings of red envelopes: Promises and lies at a Singaporean Chinese funeral

JOURNAL OF MATERIAL CULTURE, 2013;18(2):155-169. Why do red envelopes appear at Singaporean Chinese funerals? Specifically, why are payments to corpse-handlers, coffin-carriers and gravediggers wrapped in red, when the work they do is described as being "white through and through"? Conventionally, red is the colour of auspicious occasions, hence it is the colour of a traditional wedding dress, while white is the colour of death, of the shroud and of mourning wreaths. The author suggests that the meanings of colours might actually be more complex than previous scholarship has suggested. By following this exchange of red envelopes, paying careful attention to the shifting meanings given to red, she reveals the complex, otherwise unarticulated, nature of the relationships made visible via their transfer. The author follows Keane's suggestion that attaching meaning to material takes considerable social work in order to clarify the meanings an object in exchange should carry. <http://mcu.sagepub.com/content/18/2/155.short>

Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care" and "transition of care": A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 June 2013 – The terms "actively dying," "end of life," "terminally ill," "terminal care" and "transition of care" are commonly used but rarely and inconsistently defined. One of 16, three of 134, three of 44, two of 93, and four of 17 articles defined or conceptualized actively dying, end of life, terminally ill, terminal care, and transition of care, respectively. Actively dying was defined as "hours or days of survival." The authors identified two key defining features for end of life, terminally ill, and terminal care: life-limiting disease with irreversible decline and expected survival in terms of months or less. Transition of care was discussed in relation to changes in: 1) place of care (e.g., hospital to home); 2) level of professions providing the care (e.g., acute care to hospice); and, 3) goals of care (e.g., curative to palliative). Definitions for these five terms were rarely found in dictionaries, textbooks, and organizational web sites. However, when available, the definitions were generally consistent with the concepts discussed previously. The authors identified unifying concepts for five commonly used terms in palliative care and developed a preliminary conceptual framework toward building standardized definitions. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00243-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00243-1/abstract)

Learning palliative care in India: Two personal perspectives

JOURNAL OF PALLIATIVE CARE, 2013;29(2):107-112. Higher-level learning processes should incorporate a phenomenographical approach as a means of benefiting others – this is a recognized research methodology. Although the authors do not follow a strict phenomenographical line, they do describe the different ways in which the two of them undertook their palliative care learning. Despite their professional career difference of over 20 years, the authors have each experienced gaps in their medical practices, prompting them for this "on-the-job" learning process. This learning has helped them to understand the progress of palliative care in India in their time *vis-à-vis* the global scenario.

N.B. Access to this journal is by subscription only. No link, therefore, is available to individual articles or abstracts of same. Journal contents page: <http://www.criugm.qc.ca/journalofpalliativecare/>

Noted in Media Watch, 14 January 2013, #288 (p.10):

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2012;18(3):149-154. '**Palliative care in India: Current progress and future needs.**' Despite its limited coverage, palliative care has been present in India for about twenty years. <http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2012;volume=18;issue=3;spage=149;epage=154;aulast=Khosla:type=0>
- *INDIAN JOURNAL OF PSYCHIATRY*, 2013;55(6):293-298. '**End-of-life care: Indian perspective.**' This article studies the core issues of developing palliative care ... keeping in mind the ethical, spiritual and legal issues. <http://www.indianjpsychiatry.org/article.asp?issn=0019-5545;year=2013;volume=55;issue=6;spage=293;epage=298;aulast=Sharma>

"To be a phenomenal doctor you have to be the whole package": Physicians' interpersonal behaviors during difficult conversations in pediatrics

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 June 2013 – Eleven interpersonal behaviors were identified as important by parents [i.e., study participants]. The majority identified empathy in physicians as critical. Availability, treating the child as an individual, and respecting the parent's knowledge of the child were mentioned by almost half of parents. Themes also considered important but by a smaller number of parents were allowing room for hope, the importance of body language, thoroughness, going beyond the call of duty, accountability, willingness to accept being questioned, and attention to the suffering of the child. To increase parental satisfaction and enhance the parent-physician therapeutic partnership, the authors recommend that physicians consider attending to the 11 interpersonal behaviors described in this manuscript, and that educational programs pay particular attention to these behaviors when training health care providers in the communication of bad news. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0103>

Costs and implications of discarded medication in hospice

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 June 2013 – While the Medicare requirement for hospice is a prognosis of six months or less, accurately predicting prognosis is very difficult. Because of this, medications for symptom control will often have to be prescribed and refilled without knowing exactly how much the hospice patient may require. The objective of the current study was to determine the amount of medication discarded at death. Additionally the authors wanted to estimate the cost related to discarded medication. The most frequent medication unused at the time of death was morphine solution followed by lorazepam. The cost of discarded morphine including tablets as well as solution totaled over \$6,000 for the study period. The next highest medication cost was lorazepam for both solution and tablets, which came to over \$1,600. The total estimated cost for all medications for the study period amounted to \$14,980. The results of this study indicate that hospice patients have variable amounts of discarded medication at the time of death and that the cost involved of these unused medications can be significant. Hospice organizations should investigate creative ways to reduce the amount of discarded medications. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0095>

Uncertainty – the other side of prognosis

NEW ENGLAND JOURNAL OF MEDICINE, 2013;26(368):2448-2450. Prognoses will always have inherent uncertainty, which is often difficult for patients, their families, and even physicians to deal with. But there are ways that clinicians can communicate more effectively to help patients and families manage uncertainty. <http://www.nejm.org/doi/full/10.1056/NEJMp1303295>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 June 2013 – **'The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: A communication guide.'** Early, integrated palliative care delivered in the ambulatory setting has been associated with improved quality of life, lower rates of depression, and even prolonged survival. The authors outline an expert practice that provides a step-wise approach to cultivating prognostic awareness in patients cared for by a palliative care clinician early in the course of the patient's disease. This approach can be used by both novice and more experienced ... clinicians. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0547>
- *PSYCHO-ONCOLOGY* | Online – 26 June 2013 – **'Do we get it right? Radiation oncology outpatients' perceptions of the patient centredness of life expectancy disclosure.'** The authors' findings of a majority preference for, and experience of, a self-determined approach to life expectancy disclosure amongst radiation oncology patients are encouraging. However, poor agreement between preferences and experiences highlights that additional effort from clinicians is required in order to achieve a truly patient-centred approach to life expectancy disclosure. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3337/abstract>

Home hospice care and the arts: Arts @ the Bedside

OMEGA – JOURNAL OF DEATH & DYING, 2013;67(1-2):241-246. An initiative of the Visiting Nurse Service of New York Hospice Care sought to train hospice volunteers with an art background, or interest, to safely and confidently introduce the arts in a variety of mediums to hospice patients and families. The number of volunteer art visits, session reports, and the impact on volunteers ... [and] ... suggest patients, staff and volunteers gain from ... arts in home hospice care. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,30,30;journal,1,264;linkingpublicationresults,1:300329,1>

Noted in Media Watch, 13 May 2013, #305 (p.16):

- *PROGRESS IN PALLIATIVE CARE*, 2013;21(2):83-88. 'Engage, empower, and enlighten: Art therapy and image making in hospice care.' When art therapy exists as part of an interdisciplinary hospice team, it can enhance the holistic continuum of end of life comfort care. <http://www.ingentaconnect.com/content/maney/ppc/2013/00000021/00000002/art00004>

Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany, and the U.S.

PALLIATIVE MEDICINE | Online – 24 June 2013 – While similar with regard to leading causes of death, patient needs, and potential avenues to care, different models of service provision were employed in the four countries studied. Although hospice and palliative care services were generally offered with standard care along the disease continuum and in various settings, and featured common elements such as physical, psycho-social, and spiritual care, outcomes (access, utilization, etc.) varied across jurisdictions. Barriers to best practice service provision included legislative (including jurisdictional), regulatory (e.g., education and training), and financial issues as well as public knowledge and perception ("giving up hope") challenges. Advance care planning, dedicated and stable funding toward hospice and palliative care, including caregiver benefits, population aging, and standards of practice and guidelines to hospice and palliative care, were identified as facilitators. Successful implementation of effective and efficient best practice approaches to care for the terminally ill, such as shared care, requires concerted action to align these system-level characteristics; many factors were identified as being essential but not sufficient. <http://pmj.sagepub.com/content/early/2013/06/24/0269216313493342.abstract>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 June 2013 – 'Quality indicators for palliative care: Update of a systematic review.' Recent developments in measuring quality of palliative care using quality indicators are mainly quantitative in nature, with a substantial number of new indicators being found. However, the quality of the development process varies considerably between sets. More consistent and detailed methodological descriptions are needed for the further development of these indicators and improved quality measurement of palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00143-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00143-7/abstract)

Promises to keep

Phenomenological study of ICU nurses' experiences caring for dying patients

WESTERN JOURNAL OF NURSING RESEARCH | Online – 24 June 2-13 – An encompassing theme of Promises to Keep emerged, with five sub-themes, including the following: a) promise to be truthful: "nurses are in the game of reality"; b) promise to provide comfort: "I'll make him comfortable"; c) promise to be an advocate: "just one more day"; d) "promise that couldn't be kept"; and, e) "promise to remain connected." Nurses accept the reality of death and express strong commitment to making it as comfortable, peaceful, and dignified as possible, despite critical care unit environments that foster a "paradigm of curing" rather than a "paradigm of caring." <http://wjn.sagepub.com/content/early/2013/06/23/0193945913492571.abstract>

Cont.

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 June 2013 – '**When a desired home death does not occur: The consequences of broken promises.**' Family care givers' [FCGs] despair about not being able to keep their promise for a home death was related to complicated bereavement. Prospective studies of the experiences of FCGs who are aiming for home deaths are needed to identify both short- and long-term interventions to effectively support death at home. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0541>

Media Watch Online

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/?S=MEDIA+WATCH>

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

Australia

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

Canada

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

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/uncategorized/media-watch-309-june-10-2013>

Europe

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

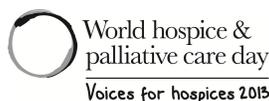
U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

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)



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

12 October 2013

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 26 June 2013 – '**Advance directives, dementia, and physician-assisted death.**' Many people are more concerned about the loss of autonomy and independence in years of severe dementia than about pain and suffering in their last months. To address this concern, people could write advance directives for physician-assisted death in dementia. Should such directives be implemented even though, at the time, the person is no longer competent and would not be either terminally ill or suffering unbearably? <http://onlinelibrary.wiley.com/doi/10.1111/jlme.12057/abstract>
- *NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE*, 2013;157(25):A6372. '**Ending life at the patient's request: Who sets the standards?**' Under the Dutch Termination of Life on Request & Assisted Suicide Act, independent review committees assess all reported cases of euthanasia and assisted suicide. They apply and conceptualise the criteria mentioned in the Act. Recently, the Royal Dutch Medical Association questioned a number of decisions made by the committees. This is a confusing situation for physicians: should they follow the "jurisprudence" of the committees or the standards as defined by their professional organisation? <http://europepmc.org/abstract/MED/23777969/reload=0;jsessionid=aGnyYuVlcBgzHO42kRJs.6>

Of related interest:

- *NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE*, 2013;157(25):A6472. '**Why the Royal Dutch Medical Association does not blindly follow the euthanasia review committees.**' The provisions of the Dutch Termination of Life on Request & Assisted Suicide Act are not always as clear as were originally hoped for. This also holds true with respect to the provision on the role of an advance directive in a case where the patient is no longer able to express his or her will. Euthanasia Review Committees now tend to interpret this provision broadly, although not always in a consistent way. The Royal Dutch Medical Association has its own responsibility in interpreting this provision in a way consistent with the professional standard. <http://europepmc.org/abstract/MED/23777972>

Media Watch: Editorial Practice

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

Distribution

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

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Worth Repeating

End-of-life care content in 50 textbooks from multiple specialties

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2000;283(6):771-778. Top-selling textbooks generally offered little helpful information on caring for patients at the end of life. Most disease-oriented chapters had no or minimal end-of-life care content. Specialty textbooks with information about particular diseases often did not contain helpful information on caring for patients dying from those diseases. Many patients in the U.S. currently receive sub-optimal care at the end of life. Inadequate physician training likely contributes to both deficient care for dying patients and increased anxiety for caring physicians. Medical education typically provides little training in care of the dying. Most medical schools, residencies, and fellowships offer almost no formal training in palliative care, the information taught is not well integrated into the curricula, and the few courses available are generally elective. National medical licensing examinations have

relatively few questions assessing students' end-of-life care competence. In general, students and physicians feel ill prepared to provide end-of-life care. Research suggests that the end-of-life content in internal medicine, pediatrics, and nursing textbooks is limited. <http://jama.jamanetwork.com/article.aspx?articleid=192380>

Extract from *Journal of the American Medical Association* article:

Textbooks serve as a cornerstone in the training of medical students and residents, as authoritative references and reviews for more experienced clinicians, and as an important feature of professional orthodoxy and culture. Textbooks are central to clinical medicine, not only describing the expected best practices but also codifying the principles and standards of clinical care.

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