Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice**, **palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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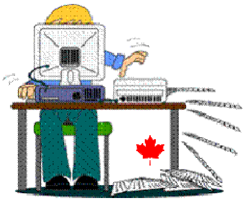


Compiled & Annotated by Barry R. Ashpole

Public voices opinions and shares experiences on dying and death: Scroll down to 'Give up chemo? No way. I owe it to my children to fight for every day of life' and 'The cost of dying: Lessons learned' (p.6 – U.S.A.) ...and, 'How doctors choose to die' (p.8 – International).

Canada

Family doctors are gatekeepers to palliative care

NOVA SCOTIA | *Chronicle Herald* (Halifax) – 26 February 2012 – With all the hand-wringing over health-care spending, not much discussion has been had about who provides access to a good, inexpensive death. An incredible amount of money is spent on providing support for people in their last weeks of life. The surprising thing is that the more money that is spent, the worse the quality of those last weeks. It really comes down to the gate-keepers of the providers of comfortable deaths – family physicians. It is these people who dispense the referrals to palliative care. http://thechronicleherald.ca/thenovascotian/67292-tale-two-deaths

Issues in pain management

Info in short supply on looming nationwide drug shortage

QUEBEC | Sun News Network (Montreal) – 25 February 2012 – The looming nationwide drug shortage has both the Quebec and national pharmacists' associations calling for a better system for monitoring the supply of drugs in Canada. Moreover, Health Canada told QMI [Press] Agency ... that it, too, didn't know what drugs would be affected by the production slowdown. Sandoz Canada, which supplies drugs to pharmacies and hospitals in the U.S. and Canada, announced in mid-February that it was stopping or slowing down the production of certain drugs in order to comply with an order from the U.S. Food & Drug Administration. The company confirmed that the drug production slowdown will affect the whole country.http://www.sunnewsnetwork.ca/sunnews/canada/archives/2012/02/20120225-091903.html

Extract from Sun News Network report

Diane Lamarre, president of Quebec's Order of Pharmacists, said the situation is "troubling" because Sandoz Canada is the main Canadian manufacturer of injectable medicines critical for palliative care and for surgeries.

Cont.

Of related interest:

- ALBERTA | *Edmonton Journal* – 22 February 2012 – **'Alberta won't limit funds or delist OxyContin substitute.'** Alberta has no plans to limit funding ... a move other provinces say they're taking to curb addictions to the narcotic painkiller. Saskatchewan, Ontario and the Atlantic provinces will no longer pay for the drug, except in cases of cancer or palliative care. Health Canada is doing the same, covering medication only for First Nations and Inuit patients who currently have prescriptions.http://www.edmontonjournal.com/news/Alberta+limit+funds+delist+OxyContin+substitute/6194309/story.html

Palliative care in the emergency department

Health report[1] revelations thump you right in heart

ALBERTA | *Calgary Herald* (OpEd) – 23 February 2012 – In a big report about something as emotional as health care, it's often the small things that thump you right in the heart. For me, one shocker was the Health Quality Council of Alberta's revelation that palliative care patients, when rushed to hospital in crisis, have been left to die on emergency ward gurneys. You can almost hear the rationalizing on the wards. They were going to die anyway. We need the bed for somebody who can live. Nobody planned for palliative cases in the ER zone. And so we have an Alberta version of the ice floe for dying elders. What a bitter, humiliating end for people who have already done their share of suffering. What a dreadful decision for medical professionals to be forced to make. What a brutal indictment of a system run into a moral swamp by political incompetence. The report, more than 400 pages, is worth sticking with for the many shafts of light it aims into dark corners of the system. http://www.calgaryherald.com/opinion/columnists/Braid+Health+report+revelations+thump+right+heart/6194550/story.html

Extract from Health Quality Council of Alberta report

There were many unfortunate cases of patients whose goals of care were clearly palliative who received care in the ED, some of whom died there. The needs of these patients, in the last few hours of their lives, had to be met in a setting that was never designed to provide this type of care. It diminished them and only further burdened the ED.

1. 'Review of the Quality of Care and Safety of Patients Requiring Access to Emergency Department Care and Cancer Surgery and the Role and Process of Physician Advocacy,' The Health Quality Council of Alberta, February 2012. http://www.hqca.ca/assets/files/FINAL%20REPORT.pdf

Representative sample of recent articles on palliative care in the emergency department:

- *EMERGENCY MEDICINE AUSTRALASIA*, 2012;24(1):4-6. **'Practically speaking: Emergency medicine and the palliative care movement'** (noted in Media Watch dated 20 February 2012). http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01531.x/full
- *EMERGENCY MEDICINE AUSTRALASIA*, 2012;24(1):102-104. **'Palliative care in the emergency department: An oxymoron or just good medicine?'** (noted in Media Watch dated 20 February 2012). http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01505.x/abstract
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;43(1):1-9. **'Does palliative care have a future in the emergency department? Discussions with attending emergency physicians'** (noted in Media Watch dated 9 January 2012). http://www.jpsmjournal.com/article/S0885-3924(11)00272-7/abstract
- CENTER TO ADVANCE PALLIATIVE CARE | Press release – 10 October 2011 – **'IPAL-EM launches to improve palliative care in emergency medicine'** (noted in Media Watch dated 14 November 2011). http://www.eurekalert.org/pub_releases/2011-11/tmsh-ilt110411.php
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 18 July 2011 – **'The palliative care model for emergency department patients with advanced illness'** (noted in Media Watch dated 25 July 2011). http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Vancouver Sun* – 25 February 2012 – **'Assisted suicide debate intensifies.'** Six "mobile euthanasia units" will become available in The Netherlands[1] ... to zip around this tiny and remarkably liberal country to help Dutch citizens facing an "unbearable" and "hopeless" medical situation die in their homes. A group of prominent citizens, meanwhile, has been lobbying since 2009 for a major expansion in the scope of Dutch assisted-death laws, allowing older people who are "tired of living" but have no serious medical problem to end it all without the involvement of a physician. To social conservatives ... including [those] in Canada where court challenges in B.C.[2] and Quebec[3,4] seek to declare the euthanasia ban unconstitutional, these are but two ... examples of a dangerous 'slippery slope' for any country that opens the door even a crack on this touchy matter. http://www.vancouversun.com/news/Assisted+suicide+debate+intensifies/6209384/story.html

    1. 'Go-ahead for world's first mobile euthanasia unit ...,' *Daily Mail* (U.K.), 10 February 2012 (noted in Media Watch dated 2 February 2012). http://www.dailymail.co.uk/news/article-2099089/Go-ahead-worlds-mobile-euthanasia-unit-allow-patients-die-home.html?ito=feeds-newsxml

    2. 'Right-to-die group begins court challenge of law prohibiting assisted suicide,' *Vancouver Sun* (B.C.), 2 August 2011 (noted in Media Watch dated 8 August 2012). http://www.vancouversun.com/news/Right+group+begins+court+challenge+prohibiting+assisted+suicide/5194112/story.html

    3. 'Committee on assisted suicide likely to recommend more palliative care,' Canadian Press, 24 October 2011 (noted in Media Watch dated 31 October 2011). http://www.winnipegfreepress.com/canada/breakingnews/committee-on-assisted-suicide-likely-to-recommend-more-palliative-care-132495373.html

Media Watch Online

The weekly report can be accessed at several websites, among them:

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

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

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/news.htm (Scroll down to 'International End of Life Roundup')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

U.S.A.

Tell lawmakers end-of-life care isn't 'optional'

ILLINOIS | *Herald News* (Joliet) – 25 February 2012 – The state is pondering what "optional services" to do away with in an effort to save Medicaid money. Hospice is one of the services considered "optional," which is absurd given the amount of money hospice care saves as well as the comfort and appropriate care hospices provide. The Illinois Hospice & Palliative Care Organization Legislative ... has estimated that Illinois hospices save the state of Illinois an average of $2,309 per hospice patient... http://heraldnews.suntimes.com/opinions/10761705-474/tell-lawmakers-end-of-life-care-isnt-optional.html

A shift from nursing homes to managed care at home

NEW YORK TIMES | Online article – 24 February 2012 – Faced with soaring health care costs and shrinking Medicare and Medicaid financing, nursing home operators are closing some facilities and embracing an emerging model of care that allows many elderly patients to remain in their homes and still receive the medical and social services available in institutions. The rapid expansion of this new type of care comes at a time when health care experts argue that for many aged patients, the nursing home model is no longer financially viable or medically justified. In the newer model, a team of doctors, social workers, physical and occupational therapists and other specialists provides managed care for individual patients at home, at adult day-care centers, and in visits to specialists. Studies suggest that it can be less expensive than traditional nursing homes while providing better medical outcomes. The number of such programs has expanded rapidly, growing from 42 programs in 22 states in 2007 to 84 in 29 states today. http://www.nytimes.com/2012/02/24/nyregion/managed-care-keeps-the-frail-out-of-nursing-homes.html?_r=1&emc=eta1

From Media Watch dated 11 July 2011:

- *COCHRANE REVIEWS* | Online report – 6 July 2011 – **'Hospital at home: Home-based end of life care.'** The authors systematically reviewed the literature to see if the provision of end of life home care reduces the likelihood of dying in hospital and what effect this has on patients' symptoms, quality of life, health service costs and care givers compared with inpatient hospital or hospice care. http://www2.cochrane.org/reviews/en/ab009231.html

From Media Watch dated 20 June 2011:

- CALIFORNIA | *Los Angeles Times* – 19 June 2011 – **'Helping seniors live at home longer.'** Home-based care is increasingly seen as a legitimate and less costly alternative to nursing home care. http://www.latimes.com/health/la-he-long-term-care-20110612,0,5299087.story

Hospices & Palliative Care Centers in the U.S. Industry Market Research Report

NEW YORK | *Times Union* (Albany) – 24 February 2012 – The Hospices & Palliative Care Centers industry has grown rapidly for more than a decade, aided by continued Medicare and Medicaid reimbursement support, an aging U.S. population, rising healthcare costs and a general trend toward at-home end-of-life care. [Market researchers] IBISWorld estimates 7,789 facilities will operate in the industry in 2012, generating $18.9 billion in revenue. In 2012 alone, revenue is expected to jump 8.4%, marking an annualized rate of growth of 9.8% since 2007. http://www.timesunion.com/business/press-releases/article/Hospices-and-Palliative-Care-Centers-in-the-US-3358041.php

'Living wills' and the medical profession: When clinical best intentions clash with patient intent

HUFFINGTON POST | Online article – 21 February 2012 – Knowledge and technology has empowered and enabled us to decide where and how we want to live. It has even given both the healthy and those living with serious illness and incapacity legal protection in determining how they want to die. In England and Wales, such individuals have possessed the right to make what are known as 'Advance Decisions' – or, more commonly, 'living wills' – for the past five years, when the terms of the Mental Capacity Act 2005 came into force. The Act set out the elements needed to make such declarations legally valid, including having those intentions in writing, signed and witnessed. It meant that they had the power to give notice of their intention to refuse treatment in specific future circumstances should they have lost the capacity to decide in the meantime. http://www.huffingtonpost.co.uk/helen-gaskell/living-wills-and-the-medi_b_1290123.html

Specialist Publications

Of particular interest:

'Hope in the context of advance care planning' (p.9), published in *Palliative & Supportive Care*.

Of related interest:

- NEW YORK | *Observer-Dispatch* (Utica) – 26 February 2012 – **'Controversial directives.'** Reproductive health issues have borne the brunt of the controversy over rules for Catholic health care. But one rule on end-of-life care has drawn some fire, as well. Patients in a vegetative state, but who are not dying, must receive artificial nutrition and hydration, even if a feeding tube goes against the patient's previously expressed wishes, according to the U.S. Conference of Catholic Bishops' Ethical & Religious Directives for Catholic Health Care Services. The rule does not apply to dying patients who are given broad leeway for refusing or withdrawing feeding tubes. http://www.uticaod.com/sports/boxscores/x1481611708/Controversial-directives

Do seniors really want to know life expectancy?

USA TODAY | Online report – 21 February 2012 – That may not be a question many elderly adults come right out and ask their doctors. But a lot of them would like to know the answer, says Alexander Smith, an assistant professor of geriatrics at the University of California-San Francisco. That's what most elderly adults told Smith and his colleagues in a recent study.[1] Make no mistake: Part of what these researchers want to get the nation talking about is the big D – death and the kind of end-of-life planning that makes some people fear the creation of "death panels" and the denial of costly health care to the oldest, sickest people. Many elderly people who discuss life expectancy with their doctors may end up getting fewer tests, operations and medications because the short-term risks will exceed any benefit they might get in their remaining time, says Lindsey Yourman, at Scripps Mercy Hospital in San Diego ... lead author on a paper evaluating the prognosis calculators.http://yourlife.usatoday.com/health/story/2012-02-19/Do-seniors-really-want-to-know-life-expectancy/53158420/1

Extract from *USA Today* article

More than half a million people – many clearly not doctors – have visited a website ... called ePrognosis.' On the site: 16 questionnaires that can roughly predict the survival odds of older adults, over periods ranging from six months to five years. These "prognosis calculators" remain under study and were designed for use by doctors and other health professionals.

N.B. ePrognosis: http://www.eprognosis.org/

Cont.

1. 'Prognostic indices for older adults,' *Journal of the American Medical Association*, 2012;307(2):182-192 (noted in Media Watch dated 16 January 2012). http://jama.ama-assn.org/content/307/2/182.abstract

Representative sample of recent lay press articles on prognosis:

- *U.S. NEWS & WORLD REPORT* | Online report – 21 December 2011 – **'Most sick or disabled seniors want docs to say how long they have'** (noted in Media Watch dated 26 December 2011). http://health.usnews.com/health-news/family-health/boomer-health/articles/2011/12/21/most-sick-or-disabled-seniors-want-docs-to-say-how-long-they-have
- CNN (CABLE NEWS NETWORK) | Online report – 24 January 2011 – **'Terminally ill patients need frank conversation about prognosis, cancer group says'** (noted in Media Watch dated 31 January 2011). http://pagingdrgupta.blogs.cnn.com/2011/01/24/terminally-ill-patients-need-frank-conversation-about-prognosis-cancer-group-says/

The cost of dying: Lessons learned

CALIFORNIA | *San Jose Mercury News* – 19 February 2012 – What's a good death? And how do we get there? I've learned a lot about dying in the two weeks since I wrote 'Cost of dying'[1] ... about my father's final days in a hospital bed, far from the natural death he desired. So many [reader's] letters made clear hard-won lessons (see sidebar right). http://www.mercurynews.com/cost-of-dying/ci_19999864?source=rss

1. 'The cost of dying: It's hard to reject care even as costs soar,' *San Jose Mercury News*, 6 February 2012 (noted in Media Watch dated 13 February 2012). http://www.mercurynews.com/health/ci_19898736?source=rss

Lessons learned

1. Much earlier, we need to think – long and hard – about end-of-life care.
2. We need more information, quickly, about our options.
3. As the days go by, we need consistent guidance – and goals.
4. The intensive care unit is being used to ward off a natural end to life – and it shouldn't be.
5. It's much more difficult to stop intensive treatment than to start it.
6. Hospice or palliative care isn't "quitting."
7. Hospitals operate on slim margins – and lose money on long, lingering deaths.
8. Don't abandon us. We feel like failures when doctors disappear.
9. Even with all the planning in the world, it's still awful.

At hospice, military vets help other fighters face end of life

NORTH CAROLINA | *News Observer* (Durham) – 19 February 2012 – The best person to see an old soldier through his last days is another veteran. At least, that's the philosophy behind Hospice of Wake County's new branch of a national effort to match volunteers who have been in military service with patients who are also veterans. Recently the We Honor Veterans program brought former Marine helicopter pilot Steve Eyman, 64, into the life of Bert Montague, 88, who flew more than 30 combat missions ... in World War II. "I've found that there is a special bond," said Eyman ... who has visited about half a dozen veterans as a hospice volunteer. Supported nationally by the Department of Veterans Affairs[1,2] and the National Hospice & Palliative Care Organization, the We Honor Veterans program recognizes and honors the special circumstances of veterans and their families. http://www.newsobserver.com/2012/02/19/1867475/at-hospice-military-vets-help.html

1. 'Understanding veterans' challenges at the end of life,' NewsWorks, 8 February 2012 (noted in Media Watch dated 13 February 2012). http://www.newsworks.org/index.php/local//item/33755-understanding-veterans-challenges-at-the-end-of-life/
2. 'Helping the brave fight their final battle,' *Los Angeles Times*, 28 December 2010 (noted in Media Watch dated 3 January 2011). http://www.latimes.com/health/sc-fam-1228-senior-health-veteran-20101228,0,7667701.story

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GEORGIA | Associated Press (Atlanta) – 21 February 2012 – **'Georgia lawmakers want to outlaw assisted suicide.'** State lawmakers introduced a bill Tuesday that would outlaw assisted suicide in the wake of a recent Georgia Supreme Court ruling that destroyed a long-running criminal case against members of a suicide group. House Bill 1114 would make it a felony to "knowingly and wilfully" assist another person in committing suicide. Under the new legislation, violators would face between one and 10 years in prison if convicted. The bill doesn't exempt doctors — as other states have — and requires that health care providers who violate the statute lose their license to practice. http://www.ajc.com/news/georgia-lawmakers-want-to-1357737.html

- *INTERNATIONAL BUSINESS TIMES* | Online report – 20 February 2012 – **'Rick Santorum's 'involuntary euthanasia' claim outrages Dutch.'** Rick Santorum's claim that The Netherlands advocates mass murder through involuntary euthanasia has prompted a furious backlash from the Western European country, with local news sources calling the Republican a "crazy extreme" candidate making up facts to stir up his political base. "Rick Santorum thinks he knows The Netherlands: Murder of the elderly on a grand scale" fumed the headline of the newspaper *NRC Handelsblad*. The article references an interview, barely played up by the American press, in which Santorum [a Republican candidate for the U.S. presidency] claims that euthanasia makes up "10% of all deaths" in The Netherlands," and that many of those people were essentially murdered by the state. http://www.ibtimes.com/articles/301702/20120220/rick-santorum-euthanasia-netherlands-dutch-backlash.htm

International

Families hide their wealth to avoid care home costs

U.K. (ENGLAND) | BBC Business – 25 February 2012 – Some relatives of pensioners are hiding their parents' full wealth to avoid paying care home fees and many local authorities are failing to use the available legal powers to claw the money back. "I don't think greed was the absolute motive. They just thought the council should pay and if there was a legal way around it, they would take it." John – a not his real name – describes how his brother and sister were able to get away with not telling their local authority about their elderly mother's savings, leaving the council to pick up much of the cost of her residential care. Most people who have more than £23,250 in assets, including their home, have to meet the full cost of care. The threshold differs slightly in Wales and in Scotland care home residents are able to access free personal care. But by not disclosing the truth about their mother's assets, John's siblings protected her wealth – and their own inheritance. http://www.bbc.co.uk/news/business-17147047

Code that makes dignity and respect a right for our elderly is launched

U.K. | *Daily Mail* – 21 February 2012 – A code of conduct designed to guarantee dignity and respect for elderly patients is being launched. Drawn up by the National Pensioners Convention, it sets out minimum standards of treatment and calls for an end to abuse and neglect. A coalition of politicians, regulators and charities has pledged support. [Minister of State for Care Services] Paul Burstow wants it to be displayed in every GP surgery, social services department, hospital ward and nursing home. The code sets out 19 points on how older people should and should not be treated while in hospital or in the community. http://www.dailymail.co.uk/news/article-2104670/Dignity-Code-makes-respect-right-elderly-launched.html?ito=feeds-newsxml

Give up chemo? No way. I owe it to my children to fight for every day of life

U.K. | *Daily Mail* – 21 February 2012 – Dr. Martin Scurr revealed ... [in the *Daily Mail*] ... that if faced with advanced terminal illness, he would turn down gruelling treatment in favour of a pain-free end of life.[1] His article drew a huge response, with many praising his courage and honesty. But what do patients with terminal illnesses think? http://www.dailymail.co.uk/health/article-2103983/Give-chemo-No-way-I-owe-children-fight-day-life.html?ito=feeds-newsxml

1. 'Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo,' *Daily Mail*, 14 February 2012. http://www.dailymail.co.uk/health/article-2100684/Why-doctors-like-die-endure-pain-treatment-advanced-cancer.html

Of related interest:

- U.K. | *The Guardian* – 19 February 2012 – **'How doctors choose to die.'** The newspaper recently published an article[1] on how physicians make different end-of-life choices than their patients. Some of the 165 readers who commented online raised issues that had haunted them for decades. http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors

    1. 'How doctors choose to die,' *The Guardian*, 8 February 2012. When faced with a terminal illness, medical professionals, who know the limits of modern medicine, often opt out of life-prolonging treatment. http://www.guardian.co.uk/society/2012/feb/08/how-doctors-choose-die

From Media Watch dated 23 January 2012:

- U.S. | *Time Magazine* – 16 January 2012 – **'What doctors know – and we can learn – about dying.'** Last month, an essay posted by retired physician Ken Murray[1] ... got a huge amount of attention, some negative but mostly positive. http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit

    1. 'How doctors die,' Zócalo Public Square, Center for Social Cohesion (posting undated). http://zocalopublicsquare.org/thepublicsquare/2011/11/30/how-doctors-die/read/nexus/

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

Palliative care in South Korea

Most advance directives written by patients with advanced cancer or their proxies request only minimally invasive treatments during end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 23 February 2012 – Although it is assumed that most patients with terminal cancer are reluctant to receive life-sustaining treatment, there is a paucity of evidence supporting this assumption. The authors retrospectively analyzed the advance directives of terminal cancer patients to determine the preferences of patients. Patients with cancer who had life expectancy of less than 6 months were admitted to a palliative care unit in Seoul Medical Center from March 2008 to February 2010. Among a total of 247 patients, advance directives were present in the medical records of 168 patients (68.0%). Most of the advance directives were written by the patients' families (95.2%) and they stated that they did not want most of the invasive procedures. Patients with advanced cancer mostly requested that only minimally invasive treatments that eased suffering be performed. http://ajh.sagepub.com/content/early/2012/02/05/1049909111435811.abstract

N.B. South Korea was rated 32nd in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Cont.

Of related interest

- *BC MEDICAL JOURNAL*, 2012;54(2):88. **'Advance care planning.'** Recent changes to the [British Columbia] Health Care (Consent) & Care Facility (Admission) Act and other acts, which include the new legal status of advance directives, are a reminder to both patients and physicians of the benefit of planning for future health care wants and needs. http://www.bcmj.org/gpsc/advance-care-planning

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online article – 19 February 2012 – **'Advance medical directives: A proposed new approach and terminology from an Islamic perspective.'** Islam allows the withholding or withdrawal of treatments in some cases where the intervention is considered futile. However, there is lack of literature and debate about such issues from an Islamic point of view. http://www.springerlink.com/content/t75478016755r287/

- *PALLIATIVE & SUPPORTIVE CARE* | Online article – 21 February 2012 – **'Hope in the context of advance care planning.'** The principle of honoring hope is not necessarily in conflict with the principle of truthful communication. This is clinically significant, as the findings [of this study] suggest we need not disrupt hope that we think of as "unrealistic" as long as it supports the family to live well. Further, advance care planning can be successful even in the context of hoping for a cure. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8499024&fulltextType=RA&fileId=S147895151100068X

Close relatives find meaning to cope with cancer diagnosis and treatment of family members

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 23 February 2012 – The purpose of this grounded theory study was to generate a substantive theory that explains how close relatives such as grandparents, aunts, and uncles of a child with cancer experience palliative care. The participants ... included close relatives of children in palliative care. Semi-structured interviews and journaling were used to collect data. Findings from the data suggested a process of finding meaning which helps close relatives to let go of what they cannot control while holding on to what they can control. Social change implications of this study may include improving health care programming for close relatives utilizing supportive-expressive measures. http://ajh.sagepub.com/content/early/2012/02/05/1049909112436711.abstract

Concept analysis of good death in terminally ill patients

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 23 February 2012 – The findings [of this study] describe the evolution of the good death concept over time from the prehistoric era followed by pre-modern, modern, and post-modern times. In addition, information is presented about surrogate terms, attributes, antecedents, and consequences associated with good death followed by analysis and discussion of the findings. General attributes of a good death include pain and symptom management, awareness of death, patient's dignity, family presence, family support, and communication among patient, family, and health care providers. http://ajh.sagepub.com/content/early/2012/01/23/1049909111434976.abstract

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 23 February 2012 – **'Spiritual needs and spiritual care for veterans at end of life and their families.'** This qualitative study assessed the spiritual needs, spiritual care received, and satisfaction with spiritual care of both Veterans at the end of life and their families. Seventeen Veterans and 9 family members participated. http://ajh.sagepub.com/content/early/2012/01/19/1049909111434139.abstract

- *JOURNAL OF POETRY THERAPY* | Online article – 13 February 2012 – **'The use of poetry in reconciling unfinished business near end-of-life.'** The therapy consisted of a sequence of patient reflection, processing, and action. Reflection resulted in the creation of four short poems that were processed for meaning and emotional content leading to the delineation of unfinished business and a plan of action. http://www.tandfonline.com/doi/abs/10.1080/08893675.2012.654940

New obstacles to improving the quality of end-of-life care in ICU

CRITICAL CARE | Online article – 22 February 2012 – A multifaceted quality improvement intervention was associated with no improvement in quality of dying among ICU decedents, as well as no reduction in resource utilization prior to the withdrawal of life sustaining measures. Based on the results of this study, targeted quality improvement efforts to improve end-of-life care at the ICU level are premature. Instead, research efforts should be focused on interventions that target clinicians earlier in their training or interventions with more direct interaction with patients that can be customized to patient needs. In the meantime, intensivists should not use this study as a reason to avoid paying attention to the needs of dying patients and their families, as this and other studies still indicate that high-quality end-of-life care is valued by caregivers and families alike http://www.biomedcentral.com/content/pdf/cc11194.pdf

Of related interest:

- *NURSING IN CRITICAL CARE* | Online article – 15 February 2012 – **'Thai Buddhist families' perspective of a peaceful death in ICUs.'** Five core qualities emerged that made-up the concept of a peaceful death as described by Thai Buddhist family members who cared for their loved ones while they were dying in ICUs. These core qualities were "knowing death was impending, preparing for a peaceful state of mind, not suffering, being with family members and not alone, and family members were not mourning." Thai Buddhist family members described what they meant by a peaceful death. "This was: preparing for a peaceful state of mind in knowing that one's impending death is not a situation of suffering or being alone, but rather a time of being with family members who are not yet mourning one's death." The findings support that family members should participate in promoting a peaceful death for their loved ones dying in ICUs. http://onlinelibrary.wiley.com/doi/10.1111/j.1478-5153.2012.00495.x/full

Progress in palliative care in Israel: Comparative mapping and next steps

ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Online article – 20 February 2012 – This paper identifies core steps in developing a medical specialty and examines those taken by Israel as compared with the U.S. and England for palliative care. It considers the next steps Israel may take. [A] key step is usually skills development among clinicians; in Israel, few education and training opportunities exist so far. Specialty recognition also has not yet occurred in Israel. Service development remains limited and a major shortage of services exists, compared to the U.S. Research capacity in Israel is also limited. Policy to develop and sustain palliative care in Israel is underway; in 2009, the Ministry of Health established policy for implementing palliative care. However, it still lacks a financially viable infrastructure. We conclude that palliative care in Israel is emerging but has far to go. Adequate resource allocation, educational guidelines, credentialed manpower and specialty leadership are the key factors that palliative care development in Israel needs. http://www.ijhpr.org/content/pdf/2045-4015-1-9.pdf

Of related interest:

- *ISRAEL JOURNAL OF HEALTH POLICY RESEARCH* | Online article – 20 February 2012 – **'Palliative care: Progress, needs, and challenges.'** International work toward making palliative care a basic human right underscores the growing need to ensure comfort and pain relief for the terminally ill. The organizational structures in place for providing such care vary greatly within and across countries; even definition of the term is not uniform. http://www.ijhpr.org/content/pdf/2045-4015-1-10.pdf

From Media Watch dated 8 February 2010:

- *BIOETHICS*, 2010;24(3):134-144. **'Reclaiming the patient's voice and spirit in dying.'** This paper describes the recent regulation of dying in Israel under its Dying Patient Law, 2005. The Law recognizes advance directives in principle, but limits their effect and form through complex medico-legal artifices. http://www3.interscience.wiley.com/journal/123269138/abstract

Rising to the challenge of palliative care for non-malignant disease

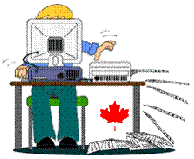
PALLIATIVE MEDICINE, 2012;6(2):99-100. Palliative care developed from within cancer care facilitated by the interest and support of a small but extremely important group of oncologists. Some of these oncologists were among the first doctors to work fulltime in palliative care, abandoning their oncology positions. Initially, many services had regular input from an oncologist. The nursing component of palliative care also has a strong oncology background, and still does in most countries. Modern palliative care would not exist in its present state without this history, core collaborators and general support from oncology. Palliative care is not a neat predetermined package, even in cancer care where advanced incurable illness can usually be identified. Rather, it consists of components that need to be adapted according to the individual situation. It follows that we need to understand the components of the individual case and, in particular, the fundamentals of the disease process. Just as modern palliative care developed under the umbrella of oncology, the widespread development of non-malignant palliative care can only be achieved by a close, meaningful collaboration with specialists in the various non-malignant disease areas. http://pmj.sagepub.com/content/26/2/99.extract

Palliative care consultation service and palliative care unit: Why do we need both?

THE ONCOLOGIST | Online article – 21 February 2012 – Palliative care (PC) infrastructure has developed differently around the globe. Whereas some institutions consider the palliative care unit (PCU) a valuable component, others report that the sole provision of a state-of-the art palliative care consultation service (PCCS) suffices to adequately care for the severely ill and dying. This study presents a direct comparison between patients in a PCU and a PCCS. Results strongly support the hypothesis that the coexistence of both institutions in one hospital contributes to the goal of ensuring optimal high-quality PC for patients in complex and challenging clinical situations.http://theoncologist.alphamedpress.org/content/early/2012/02/21/theoncologist.2011-0326.abstract

From Media Watch dated 20 June 2011:

- *IRISH MEDICAL NEWS* | Online report – 14 June 2011 – **'Unmet needs are highlighted in study.'** Results of research ... reveal that patients with non-malignant diseases, such as chronic obstructive pulmonary disease, motor neurone disease, heart failure and cystic fibrosis, are referred late to the Specialist Palliative Medicine Service at the hospital. This was notwithstanding the finding that 20% of patients with end-stage, non-malignant disease have comparable levels of symptom severity to cancer patients. http://www.imt.ie/news/latest-news/2011/06/unmet-needs-are-highlighted-in-study.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

Media Watch posted on Palliative Care Network-e Website

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

The impact on bereaved carers of being involved in medical student education

PALLIATIVE MEDICINE, 2012;6(2):185-186. Recently bereaved carers of patients who have died in the Leicestershire & Rutland Hospice are invited to be involved in the education of medical students from Leicester University in the care of the dying. The aim of this initiative is that the student's education is grounded in real experience. The carers are contacted randomly approximately 9 months after their bereavement and offered the opportunity of being involved in the education programme. On average a third of the carers invited agree to be involved. They talk to a group of about 15 students with the support of a facilitator. Once they have told their 'story,' the students have the opportunity to ask questions or discuss aspects of the story in more detail. http://pmj.sagepub.com/content/26/2/185.short

Heightened vulnerabilities and better care for all: Disability and end-of-life care

PALLIATIVE & SUPPORTIVE CARE, 2012;10(1):17-26. The purpose of this study was to assess the extent to which vulnerability was present or heightened as a result of either disability or end-of-life policies, or both, when people with disabilities face end of life. Examples ... are evident in discontinuity from formal healthcare providers with knowledge of conditions and impairments, separation from informal care providers and support systems, and lack of coordination with and gaps in disability-related supports. When policies seek to increase the dignity, autonomy, and capacity of all individuals, including those who experience heightened vulnerability, they can mitigate or lessen some of the vulnerability. Specific policies addressing access to community-based palliative care, coordination between long-standing formal care providers and new care providers, and support and respect for informal care providers, can redress these heightened vulnerabilities. Interactions between disability and end-of-life policies can be used to create inclusive end-of-life policies, resulting in better end-of-life care for all people, including people with disabilities. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8487871&fulltextType=RA&fileId=S147895151100054X

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 21 February 2012 – **'Practical approaches toward improving end-of-life care for people with intellectual disabilities: Effectiveness and sustainability.'** In general, the study found that there was a lack of understanding of each other's role between palliative care professionals and ID [intellectual disabilities] staff, with each unsure of what the other service is providing and how it is run. Recommendations include securing a development worker for ID and end-of-life care; conducting training for ID care staff; establishing how ID services are organized within the local area; linking to national training programs; ensuring that senior management is proactively involved; and ensuring that the goals of any initiative are clear and measurable. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0132

Feasibility study

[Hospice] Volunteers as facilitators of communication about pain

RESEARCH ON AGING, 2012;34(2):246-253. A pilot project was developed to determine if volunteers could be trained to facilitate communication about pain with family caregivers. Two hospice volunteers were trained and three family caregivers received the intervention in their homes. Caregivers and volunteers were interviewed about the experience. Both ... reported a rewarding and positive experience. Caregivers prioritized the need to talk with someone, and volunteers preferred working with caregivers instead of administrative support duties. Volunteers could be trained to deliver the intervention material, but information from volunteer visits was not immediately reported to hospice staff members. http://roa.sagepub.com/content/34/2/246.abstract

Pacemaker deactivation: Withdrawal of support or active ending of life?

THEORETICAL MEDICINE & BIOETHICS | Online article – 18 February 2012 – The authors argue that clinicians uncomfortable with pacemaker deactivation are nevertheless correct to see it as incompatible with the traditional medical ethics of withdrawal of support. Traditional medical ethics is presently taken by many to sanction pacemaker deactivation when such deactivation honors the patient's right to refuse treatment. The authors suggest that the right to refuse treatment applies to treatments involving ongoing physician agency. This right cannot underwrite patient demands that physicians reverse the effects of treatments previously administered, in which ongoing physician agency is no longer implicated. The permanently indwelling pacemaker is best seen as such a treatment. As such, its deactivation in the pacemaker-dependent patient is best seen not as withdrawal of support but as active ending of life. That being the case, clinicians adhering to the usual ethical analysis of withdrawal of support are correct to be uncomfortable with pacemaker deactivation at the end of life. http://www.ncbi.nlm.nih.gov/pubmed/22351107

From Media Watch dated 30 May 2011:

- *JOURNAL OF CARDIOVASCULAR MEDICINE* | Online article – 22 May 2011 – **'Ethical issues on defibrillator deactivation in end-of-life patients.'** This article discusses the ethical issues of deactivation of the automatic implantable cardioverter defibrillator (AICD) in end-of-life patients. http://journals.lww.com/jcardiovascularmedicine/Abstract/publishahead/Ethical_issues_on_defibrillator_deactivation_in.99448.aspx

From Media Watch dated 29 November 2010:

- *AMERICAN MEDICAL NEWS* | Online article – 24 November 2010 – **'Turning off heart devices near life's end stirs ethical, legal debates.'** Many physicians believe that deactivating heart devices is a form of physician-aided death, according to a survey published in the *Mayo Clinic Proceedings*.[1] http://www.ama-assn.org/amednews/2010/11/22/prsl1124.htm

    1. *MAYO CLINIC PROCEEDINGS*, 2010;85(11):981-990. **'Perspectives on withdrawing pacemaker and implantable cardioverter-defibrillator therapies at end of life: Results of a survey of medical and legal professionals...'** http://www.mayoclinicproceedings.com/content/85/11/981.abstract

Worth Repeating

"At the foot of a very long ladder": Discussing the end of life with older people and informal caregivers

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2010;40(6):857-869. This article reports findings from one approach of engaging older members of the general public and informal caregivers in discussions about end-of-life care. Listening events were delivered across the U.K. using principles of focus group conduct to facilitate discussions among older people, informal caregivers, and representatives from community groups in four workshops. Participants discussed their feelings, experiences, and concerns about the end of life, guided by the booklet *Planning for Choice in End-of-Life Care*, which was piloted in an earlier study.[1] Three themes arose: communicating about end-of-life issues, factors that influence individuals' concerns about death and dying, and advance care planning. The heterogeneity of stories told not only illustrates how people's responses and needs at the end of life vary greatly but also reveals shared reactions, experiences, and some confusion. The stories also demonstrate people's willingness to engage with concerns associated with the end of life and their conviction that this is an important area of community action and development. http://www.jpsmjournal.com/article/S0885-3924(10)00524-5/abstract

1. *Planning for Choice in End-of-Life Care*, The Peer Education Project Group, Help the Aged, 2006 http://policy.helptheaged.org.uk/NR/rdonlyres/2E92D357-BBDA-4142-AADE-A74742F77C6D/0/planningforchoice140108.pdf

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 tool or change document.

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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.

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