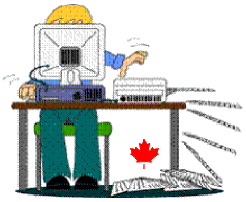
Media Watch...

*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.*

21 October 2013 Edition | Issue #328



Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'The impact of disease on family members: A critical aspect of medical care' (p.12), in *Journal of the Royal Society of Medicine*.

Canada

Rasouli life-support case: Top court upholds life-support right

ONTARIO | CBC News – 18 October 2013 – The Supreme Court of Canada has dismissed an appeal that would have permitted doctors to end life support for a severely brain-damaged man without the consent of his family or a substitute decision maker. In a split decision on what the top court called a "tragic, yet increasingly common conflict," Chief Justice Beverley McLachlin wrote for the majority that, under Ontario's Health Care Consent Act, treatment cannot be confined to something that doctors consider to be of medical benefit to the patient. Moreover, the court dryly observed that if death is considered a manifestation of ill health, then life support serves a preventive purpose. http://www.cbc.ca/news/canada/toronto/rasouli-life-support-case-top-court-upholds-life-support-right-1.2125140

Background on the Hassan Rasouli case

In October 2010, retired engineer Hassan Rasouli underwent minor brain surgery for a benign tumour at Sunnybrook Hospital in Toronto. Days later, a bacterial meningitis infection left him severely brain damaged and comatose. With a prognosis that foresaw next to no chance of meaningful recovery, attending physicians in the intensive care unit announced plans to withdraw life support measures. Rasouli's wife, herself a medical doctor, and two adult children felt it was too early to make a life-ending judgment call. The family got a court injunction to block doctors from pulling the plug. The case has since wound its way up to the nation's top court. **Source:** *The National Post*, 17 October 2013.

N.B. Canadian news media coverage, and commentaries and OpEds in specialist publications in the fields of bioethics and medicine, on the issue of withdrawal or withholding of life-sustaining treatment (notably the Hassan Rasouli case) have been noted on a regular basis in Media Watch. Most recent: Media Watch 22 July 2013, #315 (pp.2-3,7); 27 May 2013, #307 (p.1); and, 17 December 2012, #284 (p.10):

Of related interest:

- *THE NATIONAL POST* | Online – 17 October 2013 – **'Five things to know about upcoming Supreme Court ruling on keeping critically ill patient Hassan Rasouli alive.'** The Rasouli case raises critical issues about end-of-life rights in Canada. Should physicians have final say on when to stop life-sustaining treatment when they feel it has become futile? Or should the families of incapacitated patients be able to defend their wishes for medical intervention and demand continued care? Clear guidelines are lacking. Supporters on both sides of the issue warn of wide-reaching impacts from any decision. Those in favour of allowing doctors to make the call say physicians could be more reluctant to admit patients to the ICU – where the sickest patients undergo aggressive treatment in hopes they will recover and be discharged – if they know they won't have the ability to withdraw life support. Life-sustaining treatment is intended as a stop-gap on the road to recovery, they say, and sustained efforts to keep a body alive are painful, expensive and often do little more than delay the inevitable. Those supporting patient and family choice say Canadians have a right to care that is respectful of, and consistent with, a patient's wishes, worldview and religious beliefs. Some worry the cost of intensive care may motivate decisions on the part of doctors, while the value of an individual's life should be determined by those closest to him or her. http://news.nationalpost.com/2013/10/17/five-things-to-know-about-upcoming-supreme-court-ruling-on-keeping-critically-ill-patient-hassan-rasouli-alive/

Ontario Medical Association agenda

Patients demand better end-of-life care

ONTARIO | *The Windsor Star* – 18 October 2013 – With baby boomers entering their senior years – increasing the number of Canadians dying annually by 40% by 2036 – helping them die well will be as important for physicians as helping them live well. "It's on the front burner now," said Ontario Medical Association president Dr. Scott Wooder, who has made developing a palliative care plan to present to the provincial government the cornerstone of his one-year term in office. http://www.windsorstar.com/health/Patients+demand+better+life+care/9051499/story.html

Specialist Publications

'Quebec proposition of Medical Aid in Dying: A palliative care perspective' (p.14), in *International Journal of Law & Psychiatry*.

Furor over University of British Columbia hospice a prime example of what happens when cultures clash

BRITISH COLUMBIA | *The Province* (Vancouver) – 16 October 2013 – Less than a city lot separates St. John Hospice at the University of B.C. from the condo tower next door. But a huge wall of misunderstanding between some condo owners and the new facility led to a public spat two years ago. It pitted foreign beliefs around death and the dying against compassionate care for the terminally ill. And it showed racism can rear its head when cultural values clash in multicultural Canada. Two years later, many people find the subject too sensitive to talk about. Jim Taylor, a lawyer who wrote a report on the controversy, is still grappling with the cultural divide it revealed. http://www.theprovince.com/Furor+over+hospice+prime+example+what+happens+when+cultures+clash/9043263/story.html

Noted in Media Watch, 24 January 2011, #185 (p.2):

- BRITISH COLUMBIA | *The Globe & Mail* – 18 January 2011 – **'Hospice critics don't speak for us, Chinese community says.'** Distancing themselves from condo owners who have opposed a hospice on cultural grounds, Chinese community representatives ... say the residents' views do not accurately represent Chinese culture or beliefs. While residents' concerns may reflect some aspects of Chinese folklore, it is false to claim that living next door to a hospice is incompatible with Chinese culture. http://www.theglobeandmail.com/news/national/british-columbia/hospice-critics-dont-speak-for-us-chinese-community-says/article1875103/

Research suggests vegetative patients are awake and aware

MACLEANS MAGAZINE | Online – 16 October 2013 – The implications for end-of-life care are potentially huge. When a patient's vegetative state is considered permanent, and families feel their loved ones wouldn't want to live this way, doctors can remove any feeding tubes and end artificial hydration. "The ultimate problem is that you can't talk to the patient and find out what his values and beliefs are," says Toronto lawyer Mark Handelman, an expert in end-of-life decisions, "or when the patient thinks 'enough is enough.'" If [Adrian] Owen [a British neuroscientist who holds the Canada Excellence Research Chair in Cognitive Neuroscience & Imaging at the University of Western Ontario] is correct, it may one day be possible to ask some of these patients to weigh in on their own treatment – and even, perhaps, whether they wish to live as they are. http://oncampus.macleans.ca/education/2013/10/16/inside-a-comatose-mind/

Noted in Media Watch, 28 January 2013, #290 (p.1):

- CTV NEWS | Online – 25 January 2013 – **'Canadian study that noted awareness in vegetative patients called flawed.'** A team of researchers is questioning the findings of a study that claimed bedside EEG [electroencephalography] testing showed evidence of conscious awareness in three patients diagnosed as being in a vegetative state.[1] Researchers at Weill Cornell Medical College in New York have challenged the interpretation ... that the brain-wave patterns indicate conscious awareness in these patients, saying the study was flawed.[2] http://www.ctvnews.ca/health/canadian-study-that-noted-awareness-in-vegetative-patients-called-flawed-1.1129122

    1. 'Bedside detection of awareness in the vegetative state: A cohort study,' *The Lancet*, 2011;378(9809):2088-2094. [Noted in Media Watch, 14 November 2011 #227 (p.4)] http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext

    2. 'Reanalysis of "bedside detection of awareness in the vegetative state: A cohort study,"' *The Lancet*, 2013;381(9863):289-291. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60125-7/fulltext

U.S.A.

Minnesota Supreme Court will decide whether guardians can make the call on life support

MINNESOTA | *The Star-Tribune* (Minneapolis) – 18 October 2013 – The Minnesota Supreme Court will have the final say over whether guardians have the legal authority to disconnect their wards from life support. The court's [recent] announcement that it will review the case of Jeffers Tschumy will, for the first time in nearly 30 years, revisit an end-of-life issue that could affect many of the more than 12,000 Minnesotans under guardianship who don't have health care directives. http://www.startribune.com/local/228405441.html

Specialist Publications

'Medical privacy after death: Implications of new modifications to the Health Insurance Portability & Accountability Act Privacy Rule' (p.12), in *Mayo Clinic Proceedings.*

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

It's not about when one dies, but how

IDAHO MOUNTAIN EXPRESS | Online – 16 October 2013 – The only thing worse than dying is dying badly. Dr. Ira Byock ... is not referring to accidental death; he is speaking to the often over-extended resources utilized to keep people from the inevitable. Unlike most Americans, Byock is not afraid to discuss the option of withholding certain treatments with patients diagnosed with life-ending disease. "This is a hard time in human life, but it's just a part of life," he said in a 2009 interview with 60 Minutes.[1] "Collectively, as a culture, we really have to acknowledge that we are mortal – get over it and start looking at what a healthy, morally robust way for people to die looks like." http://www.mtexpress.com/index2.php?ID=2007148624#.Ul6_dtJwrhc

Extract from *Idaho Mountain Express* article

Talking about and planning end-of-life care "is the antithesis of being ghoulish, it is truly about celebrating life," Byock said. "I think we made a mistake in America too often looking at disease solely through the lens of medicine. While the treatment is medical, illness is personal."

1. 'The cost of dying,' CBS TV (60 Minutes), 22 November 2009. [Noted in Media Watch, 23 November 2009, #124 (p.3)] http://www.cbsnews.com/video/watch/?id=6754650n

Of related interest:

- NEW JERSEY | *Times of Trenton* (OpEd) – 19 October 2013 – **'Tough decisions about end-of-life care require careful consideration.'** Medicare NewsGroup reported that of the $554 billion spent by Medicare in 2011, almost one-third – $170 billion – was spent on patients' last six months of life. And in New Jersey, these costs are higher than in almost any other state. In the city of Trenton, the average annual Medicare expenditure is approximately $10,000, but in the frailest patients above the age of 85 with multiple medical conditions, the cost rises 10-fold to nearly $100,000. Yet, for all this spending, studies have shown we do not live longer and actually have more complications than people in other countries. http://www.nj.com/times-opinion/index.ssf/2013/10/opinion_tough_decisions_about.html

End-of-life rules proposed for Massachusetts health facilities

MASSACHUSETTS | *The Boston Globe* – 16 October 2013 – Health care-providers often fail to discuss end-of-life care preferences with patients, an omission Massachusetts regulators hope to change with proposed new rules that would require physicians and other staffers at hospitals, nursing homes, and health centers to provide information about choices for people near death. Terminally ill patients would receive an informational pamphlet that explains, at a minimum, advanced care planning, and identifies the availability of palliative care – which focuses on preventing or relieving pain and suffering and enhancing quality of life, and includes hospice care. The proposal, presented to the Public Health Council, an appointed body of academics and health advocates that sets regulations, also requires each state-licensed health facility to inform all of its physicians and nurse practitioners to provide end-of-life counseling to terminally ill patients. http://www.boston.com/lifestyle/health/blogs/white-coat-notes/2013/10/16/end-life-rules-proposed-for-massachusetts-health-facilities/vU0leR49koQ2c3fVWARcbJ/blog.html

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

Family caregiving can be stressful, rewarding and life-affirming

NATIONAL PUBLIC RADIO | Online – 16 October 2013 – The stereotype of caring for a family member is that it's so stressful it harms the caregiver's health. But that's not necessarily so. Studies are conflicted, finding that caregiving can harm or help the caregiver. Here's one on the plus side. A study finds people who care for a family member live longer than similar people who aren't caregiving.[1] The scientists didn't ask the caregivers why they might be healthier and presumably happier than similar people who weren't caring for someone. But the 3,503 people who participated represented a broad swath of the American public and may be a better representation of the caregiving experience overall. Just 17% of the people surveyed said they had high levels of caregiving strain. http://www.npr.org/blogs/health/2013/10/16/235384054/family-caregiving-can-be-stressful-rewarding-and-life-affirming

1. 'Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis,' *American Journal of Epidemiology*, 3 October 2013. http://aje.oxfordjournals.org/content/early/2013/10/02/aje.kwt225.abstract?sid=9db52fa7-14d8-40d0-8121-76908f29db39

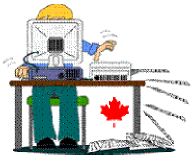
Of related interest:

- CALIFORNIA | Center for Law & Social Policy (Washington, DC) – Accessed 18 October 2013 – **'Signs of culture change: San Francisco passes Family Friendly Workplace Ordinance.'** Workers in San Francisco will soon have a potential avenue to address time-at-work issues. This week, the city's board of supervisors unanimously passed the Family Friendly Workplace Ordinance, which will give workers who have personal caregiving obligations the right to request changes to their working conditions in order to meet these obligations. The new law follows a similar provision passed as a part of an equal pay bill in the state of Vermont earlier this year. http://www.clasp.org/issues/pages?type=work_life_and_job_quality&id=0043

Testing the limits of "terminal"

THE NEW YORK TIMES | Online Commentary – 14 October 2013 – Those studying how best to deploy the tools of intensive care for people with terminal illness are still cautiously defining their terms.[1] There are the terminal conditions some experts prefer to call "lethal," ones that will kill the patient no matter what care is provided... There are the gentlest terminal diseases (among them, of course, life itself). Then there are the mid-range illnesses; intensive care helps some, while for others it just catapults the patient into worse trouble. Our patient almost certainly had a terminal, even lethal disease. But was he a terminal patient? That's really the question. He was far from comprehending his situation, let alone making his peace with it. A CT scan takes less than an hour to issue a fatal diagnosis, but the mind scrambles far behind. And, what are health care dollars, really, but bitcoins to feed time's meter till mind, brain and body are all in the same place? http://well.blogs.nytimes.com/2013/10/14/testing-the-limits-of-terminal/?ref=health&_r=0

1. 'Who is too sick to benefit?' *The Hastings Report*, 2012;42(4):41-47. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5910



Barry R. Ashpole

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

International

Changes to prison funeral leave slammed

AUSTRALIA (WESTERN AUSTRALIA) | *The West Australian* (Perth) – 17 October 2013 – A decision to reduce the number of offenders given leave to attend funerals in a bid to save $500,000 has come under fire from the independent prisons' watchdog, who says the Department of Corrective Services cannot substantiate the saving and has provided an "inconsistent, incoherent and unpersuasive" explanation for the cost-cutting exercise. In a report tabled in State Parliament, Inspector of Custodial Services Neil Morgan said the department had also failed to follow its own guidance on assessing the impact of its policy on Aboriginal prisoners and ignored a recommendation of the 1991 Royal Commission into Aboriginal Deaths in Custody. Annual reports show that 29% of the 1,218 applications for compassionate leave, which can also include visiting a dangerously ill person, were approved last year. This compares to 41% ... the previous year. http://au.news.yahoo.com/thewest/a/-/wa/19438061/changes-to-prison-funeral-leave-slammed/

Home care in the U.K.

Minister warns on rushed home care

U.K. | The Associated Press – 17 October 2013 – Social care officials are to examine whether rushed care visits rob elderly and disabled people of their dignity, [Care & Support Minister] Norman Lamb has announced. The Care Quality Commission has been tasked with looking into whether 15-minute care visits give care workers enough time to respond to people's needs, he said. The health and care regulator will perform "tough checks" to see whether the short visits strip vulnerable people of their dignity and whether they put unfair pressure on staff, Mr. Lamb added. Social care commissioners have faced fury recently after it emerged that the number of 15-minute care visits are on the rise. http://news.uk.msn.com/minister-warns-on-rushed-home-care

Specialist Publications

'The provision of care for residents dying in U.K. nursing care homes' (p.9), in *Age & Ageing.*

'Attitudes among patients and doctors towards rationing of health care services in the National Health Service' (p.10), in *Bulletin of The Royal College of Surgeons of England*.

'Delivering better services for people with long-term conditions: Building the house of care' (p.9), posted online by The King's Fund.

'Economic burden of cancer across the European Union: A population-based cost analysis' (p.11), in *The Lancet Oncology.*

Bereavement grant cut was the easiest option

IRELAND | *The Irish Examiner* (Lapps Quay, Cork) – 15 October 2013 – The Government has defended its decision to cut grants to the families of the deceased. [Public Expenditure Minister] Brendan Howlin said the scrapping of the Bereavement Grant was the fairest way of taking money from older generations. The €850 grant to cover the costs of a funeral was scrapped in today's Budget. But Minister Howlin says the other options would have been much more difficult. "We've done our level best, as with all social welfare payments, to maintain what we call a threshold of decency," he said. He said none of the other available options "recommend themselves as easy." http://www.irishexaminer.com/breakingnews/ireland/bereavement-grant-cut-was-the-easiest-option--howlin-610250.html

> **N.B.** Over 80% of the 29,000 deaths in 2012 were of people over the age of 65. It is estimated that up to 10 people are affected by each death. Therefore, about 290,000 people were newly bereaved in Ireland in 2012. [Source: Irish Hospice Foundation]

End-of-life care in Singapore

Ministry of Health looking to expand palliative care and raise standards

SINGAPORE | Channel News Asia – 15 October 2013 – Demand for palliative care at home is expected to double by 2020, to more than 10,000 patients a year. The Health Ministry is looking to expand the service and also raise the standards of care. Dover Park Hospice is one of nine organisations that offer in-patient and home palliative care in Singapore. It has tied up with Tan Tock Seng Hospital to make hospital visits easier for their patients. Hospice staff can arrange for patients to be treated by specialists as outpatients, to avoid long queues at the hospital. Dr. Wu Huei Yaw, medical director of Dover Park Hospice, said: "At some point in time, if the condition deteriorates further and the family cannot manage anymore, this home care team can also bring the patient into the in-patient hospice. So this three-way collaboration actually helps the patient and family navigate the healthcare system we have here. It does help reduce the level of stress and hopefully improve the quality of life of the patients." Meanwhile, experts estimate that there are more than 2,000 children in Singapore who are born with life-threatening illnesses or cancer. Only a very small number, 2%, are receiving palliative care - whether in a hospice or at home. http://www.channelnewsasia.com/news/singapore/moh-looking-to-expand/848348.html

Controversial Liverpool Care Pathway is of little benefit for dying patients, major study finds

U.K. (ENGLAND) | *The Daily Mail* – 15 October 2013 – The controversial Liverpool Care Pathway has little clinical benefit for dying patients, according to a major new trial.[1] The researchers suggest that any initiative to replace the Liverpool Care Pathway (LCP) in England should be "grounded in scientific evidence" and tested in controlled trials before it is implemented. The LCP was jointly developed by the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospital in the late 1990s with the aim of rolling out the best practice of hospices to hospitals, to provide uniform, high-quality, dignified care for dying patients in the last days or hours of life. However, its effectiveness for improving care for the dying has not been assessed in a randomised trial until now. In the study, The Liverpool Care Pathway Italian Cluster Trial Study Group assessed the impact of the Italian version of the LCP (LCP-I) on the quality of care of adult patients dying with cancer and their families in 16 general medicine hospital wards across Italy. No significant differences in the overall quality of care between the wards in which the LCP-I was implemented and the control wards was noted. Commenting on the findings of the study, David Currow, of Flinders University in Australia, and Amy Abernethy, from Duke Clinical Research Institute in the U.S., said: "Across healthcare there is a need to improve care for people who are dying, which led to widespread uptake of the Liverpool Care Pathway before adequate assessment[2] ... the results of this, the only adequately powered study of LCP so far have not shown clinically meaningful differences for patients – the ultimate measure of useful health policy." http://www.dailymail.co.uk/health/article-2461376/Liverpool-Care-Pathway-little-benefit-study-finds.html

Care pathway scandal "would not have been exposed but for *The Daily Mail* and a free Press" – Top doctor condemns MPs' plan to regulate newspapers

U.K. | *The Daily Mail* – 13 October 2013 – A leading medical figure who helped abolish the Liverpool Care Pathway [LCP] has praised the *Daily Mail*'s campaign as he condemned attempts to fetter the free Press. Dr. Tony Cole – who persuaded ministers to set up the official inquiry that led to the demise of the LCP – ... spoke in the wake of the proposal by ministers that newspapers should accept a new regulator which gives MPs a final say in how regulation should work. http://www.dailymail.co.uk/news/article-2458356/Care-Pathway-exposed-Daily-Mail-free-Press.html

Cont.

1. 'Liverpool Care Pathway for patients with cancer in hospital: A cluster randomised trial,' *The Lancet*, published 14 October 2013. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61725-0/abstract

2. 'Lessons from The Liverpool Care Pathway – Evidence is key,' *The Lancet*, published 14 October 2013. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62039-5/fulltext

Of related interest:

- U.K. (NORTHERN IRELAND) | *The Belfast Telegraph* – 15 October 2013 – **'Marie Curie launch end of life care research.'** Initiated by Marie Curie Cancer Care, a large number of organisations have come together to form "the Palliative and End of Life Care Priority Setting Partnership" with the James Lind Alliance. For the first time, people directly affected will get the chance to have their say in setting research priorities for palliative and end of life care. http://www.belfasttelegraph.co.uk/news/health/marie-curie-launch-end-of-life-care-research-29662051.html

- U.K. (ENGLAND) | *The Burton Mail* – 14 October 2013 – **'Project set to transform end-of-life care.'** Five of Staffordshire's Clinical Commissioning Groups ... are teaming up with Macmillan Cancer Support to change the way people with cancer or those at the end of their lives are cared for and supported. http://www.burtonmail.co.uk/News/Project-set-to-transform-end-of-life-care-provision-20131014133740.htm

Five things to know about China's new aged care law

CHINA | The Associated Press – 14 October 2013 – Elderly parents in China can now sue their grown children for both financial and emotional support. The changes in the law in China reflect an increasingly urgent dilemma across the world: As populations age faster than ever before, families and governments are struggling to decide who will protect and provide for the old. Too often, the answer is nobody. http://www.greenwichtime.com/news/world/article/5-things-to-know-about-China-s-new-aged-care-law-4893276.php

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.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (TASMANIA) | Australian Associated Press – 17 October 2013 – **'Narrow defeat for euthanasia bill in Tasmanian Parliament.'** Tasmania's lower house has rejected voluntary euthanasia by the narrowest of margins. The private members bill, co-sponsored by Labor Premier Lara Giddings and Greens leader Nick McKim, was defeated 13-11 with Speaker Michael Polley effectively using his casting vote against it. Debate in the 25-member House of Assembly had indicated a 12-12 result after all parties had granted a conscience vote on the contentious legislation. With Greens deputy speaker Tim Morris – who supported it – in the chair and unable to cast a vote, it failed by two votes. http://www.news.com.au/national-news/narrow-defeat-for-euthanasia-bill-in-tasmanian-parliament/story-fncynjr2-1226741996382

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

The provision of care for residents dying in U.K. nursing care homes

AGE & AGEING | Online – 16 October 2013 – The object of this study was to identify the care currently provided to residents dying in U.K. nursing care homes. Study participants were residents who had died within 38 nursing care homes in southeast England over a 3-year period. Fifty-six percent of these died within a year of admission. The support from specialist healthcare services to residents during their last 6 months of life was variable. Nursing care homes have established links with some external healthcare providers ... [and] ... included the GP, palliative care nurses and physiotherapy. The provision of health care that meets the needs of future nursing care home residents needs to be "proactively" obtained rather than left to chance. http://ageing.oxfordjournals.org/content/early/2013/10/15/ageing.aft158.abstract

Of related interest:

- THE KING'S FUND (U.K.) | Online – Accessed 18 October 2013 – **'Delivering better services for people with long-term conditions: Building the house of care.'** The house of care model is a deliberate simplification of a complex delivery system with primary care as its cornerstone and personalised care planning at its heart, underpinned by the solid foundation of responsive commissioning. http://ncmn.ca/Resources/Documents/delivering-better-services-for-people-with-long-term-conditions.pdf

- *JOURNAL OF CLINICAL NURSING* | Online – 15 October 2013 – **'When the body is past fixing: Caring for bodies, caring for people.'** Resuscitation and the increasing capability of intensive care to "save" patients have implications for nursing practice in a society where there is an increasing demand that individuals should be able to choose the time of their death. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12380/abstract;jsessionid=4667D783FDBC0C4D58D964198AB79995.f03t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis

AGE & AGEING | Online – 14 October 2013 – Studies relying on death certificate data show that patients with dementia die more commonly in care homes than other locations contrasting with prospective studies which show that death is more common in own residence and hospital. Age (older), gender (male), availability of hospital and nursing home beds and enrolment in hospice, influence place of death. There is very limited evidence of patients, family carers and healthcare providers' views on preferred location of death for patients with dementia and the only study included reported that family carers views are more agreed to rather than patients own views regarding place of death. This study ... raises exploratory questions on end-of-life care for patients with dementia which has implications on health and social care policies related to dementia. http://ageing.oxfordjournals.org/content/early/2013/10/14/ageing.aft151.abstract

Health care in the U.K.

Attitudes among patients and doctors towards rationing of health care services in the National Health Service

BULLETIN OF THE ROYAL COLLEGE OF SURGEONS OF ENGLAND, 2013;95(9):1-5.The National Health Service (NHS) is currently facing perhaps its greatest financial challenge since its inception, with efficiency savings of £15 billion proposed by 2014. Additionally, the rising cost of drugs, new technology, increased patient expectations and a changing population demographic place even greater pressure on an already stretched healthcare budget. The white paper Equity & Excellence: Liberating the NHS sets out the government's vision for the NHS and proposes placing patients at the heart of the health service, giving them greater choice and control over services while empowering doctors. For this to occur, an understanding of patients' and doctors' healthcare priorities is required. The aim of this study was to evaluate the views of patients and junior doctors towards rationing and prioritisation of healthcare services in the NHS. Patients favour a doctor-led approach to rationing but also have strong opinions on which treatments and patient groups should be prioritised. The views of junior doctors, however, generally overlap with those of patients. If healthcare is to be patient-led but guided by doctors, doctors will need to be aware of patient healthcare priorities. http://www.ingentaconnect.com/content/rcse/brcs/2013/00000095/00000009/art00017

Extract from *Bulletin of the Royal College of Surgeons of England* article

In terms of the types of treatments that should be prioritised, both patients and doctors supported those that would prolong or extend life and improve quality of life. This suggests that when assessing cost effectiveness of treatments, not only should there be an emphasis on survival benefits but improvements in quality of life should also be evaluated and regarded with a degree of importance.

Representative sample of articles on health care costs and the issue of rationing noted in past issues of Media Watch:

- *JOURNAL OF LAW, MEDICINE & ETHICS*, 2011;39(2):156-171. **'Just caring: Health care rationing, terminal illness, and the medically least well off.'** Relative to all the other health care needs in our society, especially the need for lifesaving or life-prolonging health care, how high a priority ought the health care needs of persons who are terminally ill have? [Noted in Media Watch, 30 January 2012, #238 (p.13)] http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00585.x/abstract

- *CHEST*, 2011;140(6):1625-1632. **'The ethics and reality of rationing in medicine.'** Rationing is the allocation of scarce resources, which in health care necessarily entails withholding potentially beneficial treatments from some individuals. Rationing is unavoidable because need is limitless and resources are not. [Noted in Media Watch, 12 December 2011, #231 (p.10)] http://chestjournal.chestpubs.org/content/140/6/1625.abstract

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2011;183(11):1242-1243. **'Can rationing possibly be rational?'** Health care expenditures consume more than 50% of revenues in six of Canada's 10 provinces, not including federal transfers, and are on pace to consume some 75% of revenues in five provinces by 2019. [Noted in Media Watch, 4 July 2011, #208 (p.6)] http://www.cmaj.ca/content/183/11/1242.full.pdf+html?sid=3cff7604-7685-4a00-a220-c13dc168b836

- *THE HASTINGS REPORT*, 2011;41(2):23-27. **'Rationing: Theory, politics, and passions.'** As did almost everyone else of a certain persuasion, I recoiled when Sarah Palin invoked the notion of a "death panel" to characterize reform efforts to improve end-of-life counseling. That was wrong and unfair. [Noted in Media Watch, 21 March 2011, #193 (p.9)] http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5163

Cont.

Of related interest:

- *THE LANCET ONCOLOGY* | Online – 14 October 2013 – **'Economic burden of cancer across the European Union: A population-based cost analysis.'** Cancer cost the European Union €126 billion in 2009, with health care accounting for €51·0 billion (40%). The health-care costs of cancer were equivalent to €102 per citizen, but varied substantially from €16 per person in Bulgaria to €184 per person in Luxembourg. Productivity losses because of early death cost €42·6 billion and lost working days €9·43 billion. Informal care cost €23·2 billion. http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70442-X/abstract

How long do I have?

JAMA INTERNAL MEDICINE | Online – 14 October 2013 – Aside from the difficulty of prognosis, there also seems to be a reluctance by many physicians to wade into the murkiness of prognostication, even though patients and families desperately want to know. And if they do discuss prognosis, many times the estimate is overly optimistic ... this overestimate may arise from the emotionally desperate needs of patients (and perhaps physicians) to know the truth, yet maintain hope. However, such optimistic estimates are a temporary comfort that usually result in anger and distrust once the certainty of death settles in. For that reason, physicians should be forthright and honest and reframe hope to a more realistic truth, including relief of symptoms, spending time with family, and having the best quality of life possible, for however long that may be. http://archinte.jamanetwork.com/article.aspx?articleid=1748833

Noted in Media Watch, 1 July 2013, #312 (p.11):

- *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.'** The authors outline an expert practice that provides a stepwise approach to cultivating prognostic awareness in patients cared for by a palliative care clinician... http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0547

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;26(368):2448-2450. **'Uncertainty – the other side of prognosis.'** 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

- *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

Quotable Quotes

I'm skeptical of statistics [vis-á-vis access to palliative care]. *What it really means is that they have access to something that calls itself palliative care. It is exactly 40 years since we did the study* [at the Royal Victoria Hospital, Montreal, Canada][1]*... And, given the significance of the findings, why haven't we done more...* Balfour Mount, *The Globe & Mail*, 13 April 2013.

1. *Dr. Mount "found disastrous communications, isolation, abandonment, and very poor control of pain and other symptoms.*"

Literature review

The impact of disease on family members: A critical aspect of medical care

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 2013;106(10):399-407. The definition of "family" varied across the literature, and a broad definition was accepted in this review. This review shows that a wide variety of aspects of family members' lives can be affected, including emotional, financial, family relationships, education and work, leisure time, and social activities. Many of these themes are linked to one another, with themes including financial impact and social impact being linked to emotional impact. Some positive aspects were also identified from the literature, including family relationships growing stronger. Several instruments exist to measure the impact of illness on the family, and most are disease or specialty-specific. The impact of disease on families of patients is often unrecognised and underestimated. Taking into account the quality of life of families as well as patients can offer the clinician a unique insight into issues such as family relationships and the effect of treatment decisions on the patient's close social group of partner and family. http://jrs.sagepub.com/content/106/10/399.abstract

A definition of "family"

Those closest to the patient in knowledge, care and affection. May include: the biological family; the family of acquisition (related by marriage/contract); the family of choice and friends (including pets). The patient defines who will be involved in his/her care and/or present at the bedside.

Source: *A Model to Guide Hospice Palliative Care: Based on National Principles & Norms of Practice*, Canadian Hospice Palliative Care Association, March 2002.

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2013 – **'Feelings of rewards among family caregivers during ongoing palliative care.'** The greatest source of rewards involved feelings of being helpful to patients. This was closely followed by giving something to patients that brought them happiness and being there for them. The smallest sources of rewards were related to personal growth, self-satisfaction, and personal meaning. There was also an association between rewards and age but not between men and women. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9046114&fulltextType=RA&fileId=S1478951513000540

Medical privacy after death: Implications of new modifications to the [U.S.] Health Insurance Portability & Accountability Act Privacy Rule

MAYO CLINIC PROCEEDINGS, 2013;88(10):1051-1055. Death extinguishes the cognizable privacy rights of the individual, but it does not end the ethical obligations of clinicians to their former patients. In establishing minimum standards for protecting personal health information, the HIPAA [Health Insurance Portability and Accountability Act] Privacy Rule does not create a new substantive privacy interest for decedents. Rather, it erects a nationwide procedural blueprint that governs the use and disclosure of medical records, including those pertaining to deceased individuals. The recently implemented changes respond to more than a decade of experience with HIPAA by minimizing some of the administrative burdens associated with the old rule, while still remaining tethered to the ethical factors that physicians should consider in determining whether to disclose medical information post mortem. Specifically, the new 50-year limit recognizes the potential effect of disclosure on the decedent's reputation and family's sensibilities but calculates that this consideration deserves less deference after approximately 2 generations have passed. Meanwhile, the wider post-mortem access granted to relatives and caregivers reflects the ethical tenet that information subject to disclosure during life should remain so after death. http://www.mayoclinicproceedings.org/article/S0025-6196(13)00475-8/fulltext

Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study

PALLIATIVE MEDICINE | Online – 18 October 2013 – Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Little is known about their transition experiences or how children's hospices can support a young adult population during/following transition. Transition planning [among study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. Moving to a young adult unit was a positive experience for young people as the building/support model recognised their adult status. However, they had unmet needs for emotional support and accessing information/services to realise their aspirations. Parents had unmet emotional needs and were unclear of support available once their children reached adulthood. Staff identified training needs in relation to working with adults, providing emotional support and acting as an advocate/key worker. Providing an appropriate building is only one aspect of developing support for young adults. A different model of support is needed, one which promotes young people's independence and provides emotional support while continuing to support parents and siblings. http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract

Noted in Media Watch, 3 December 2012, #282 (p.7):

- U.K. | National Council for Palliative Care – 27 November 2012 – **'Call for better support for seriously ill young people moving into adult care.'** The All Party Parliamentary Group for Hospice & Palliative Care heard how Government, the National Health Service and professionals can improve care and support to young people with life-limiting and life-threatening conditions.[1] Recommendation were drawn from findings of a major study, the STEPP Project (Supporting health Transitions for young people with life-limiting conditions: researching Evidence of Positive Practice) into health transitions for this group of young people. http://www.ncpc.org.uk/news/call-better-support-seriously-ill-young-people-moving-adult-care

1. Briefing for the All Party Parliamentary Group on Hospice and Palliative Care, 2012: http://www.togetherforshortlives.org.uk/assets/0000/2262/FINAL_APPG_key_findings_paper__2_.pdf

End-of-life care in India

Integrated practice of social work methods: Prospects of social work intervention through community palliative care

SOCIAL WORK CHRONICLE, 2013;2(1):1-12. The practice of social work has a marked difference in country to country context. In a country like India we are based on a method approach, where the application will be done through different methods of intervention. Most of the areas of intervention are employing one or more methods, in some agencies utilizing more than two methods and be a model of integrated approach. In health sector, palliative cares are the emerging model of integrated practice. Especially in the state of Kerala, palliative care is a significant voluntary health movement characterized by the integrated practice of social work methods and it's aimed at the holistic development of the target people. Comparatively this is a new area for social work practice which involves the utilization of social work methods, tools and techniques collaboratively. This paper analyzes the perspective of social work in integrating its six different methods in application on community palliative care and what extent it helps the beneficiaries as a holistic practice. http://informaticspublishing.com/index.php/swc/article/view/37846

N.B. Several articles on social work and end-of-life care are noted in Media Watch, 10 June 2013, #309 (pp.12-13).

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AMYOTROPHIC LATERAL SCLEROSIS & FRONTOTEMPORAL DEGENERATION* | Online – 26 September 2013 – **'Attitudes towards hastened death in ALS: A prospective study of patients and family caregivers.'** The authors aimed to determine the prevalence and stability of wish to hasten death (WTHD) and end-of-life attitudes in ALS patients, identify predictive factors, and explore communication about WTHD. They conducted a study among patients and primary caregivers attending ALS clinics in Germany and Switzerland. Half of the patients could imagine asking for assisted suicide or euthanasia; 14% expressed a current WTHD. These attitudes were stable over 13 months. Two-thirds of patients had communicated their WTHD to relatives; no-one talked to the physician about it, yet half of them would like to do so. http://informahealthcare.com/doi/abs/10.3109/21678421.2013.837928
    - *JOURNAL OF CLINICAL NURSING* | Online – 7 February 2013 – **'Finding meaning despite anxiety over life and death in amyotrophic lateral sclerosis patients.'** Two themes emerged to illuminate the complex life situation of the interviewees: experiences of anxiety over life and death and finding meaning despite the illness. It became clear that the uncertain journey towards death was more frightened than death itself. Despite the incurable disease, which brought feelings of life and death anxiety, physical loss, unfairness, guilt, shame and existential loneliness, they also found meaning in life, which strengthened their will to live. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12071/abstract
- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 11 October 2013 – **'Quebec proposition of Medical Aid in Dying: A palliative care perspective.'** The aim of this article is to provide a palliative care perspective on Quebec's proposition to legalize euthanasia. Based on the epistemological and methodological framework of critical theory, the following questions are raised: 1) In Quebec's current state of the law, is it possible to relieve the suffering of end-of-life patients?; 2) Can the Quebec proposition to legalize euthanasia in specific circumstances be harmful?; and, 3) Is the Quebec proposition on euthanasia compatible with palliative care and social values? Recommendations and alternatives to the ... Quebec proposition are suggested. http://www.sciencedirect.com/science/article/pii/S0160252713000769

Worth Repeating

The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders: Informants, advocates or surrogate decision-makers?

ANNALS OF ONCOLOGY, 2011;22(12):2667-2674. This [cohort] study examines the extent to which relatives of severely ill cancer patients are involved in the decision to limit treatment (DLT), their role in communicating patient wishes, and the incidence of and reasons for disagreement with relatives. Although 63 out of 70 patients [i.e., study participants] had relatives present during their care, only 32% of relatives were involved in DLT. Physicians were more likely to know the end-of-life (EOL) preferences for those patients who had visiting relatives than those without them. Most relatives supported patients in voicing their preferences (68%), but one-third acted against the known or presumed wishes of patients (32%). Disagreements with patients' relatives occurred in 21% of cases, and predominantly when relatives held views that contradicted known patient preferences. If relatives are to play an important part in EOL decision making, we must devise strategies to recognise their potential as patients' advocates as well as their own needs. http://annonc.oxfordjournals.org/content/22/12/2667.full.pdf+html

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2013/10/media-watch/

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)

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/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' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report)

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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/news-events

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

---

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net