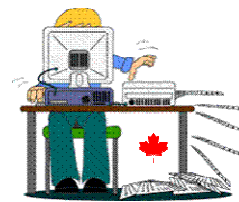


Media Watch...

is intended as an advocacy tool and change document. The weekly report is international in scope and distribution – to 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 inform discussion and encourage further inquiry.

12 November 2012 Edition | Issue #279



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

Compiled & Annotated by Barry R. Ashpole

End-of-life care in the U.K.: Scroll down to [International](#) and 'Liverpool Care Pathway: What went wrong?' (p.5), in *The Spectator*. Also, 'The Liverpool Care Pathway' (p.3), a 'Behind the Headlines' feature posted on the U.S. National Library of Medicine website (under [U.S.A.](#)).

Canada

New Brunswick hospitals latest to offer patients expanded end-of-life care options

NEW BRUNSWICK | *The National Post* – 8 November 2012 – New Brunswick's largest health authority announced it will move from a do or do not resuscitate policy to one that gives patients more choices about end-of-life care, as hospital authorities nationwide increasingly push for Canadians to be clear about their wishes well before they're clinging to life. Patients in the Moncton-area Horizon Health Network will have four options – pull out all the stops to save me; don't revive me but give me intensive care unit care; don't bring me back to life but keep offering relevant treatment; or just keep me comfortable until I die. They'll discuss these options with a member of the health team and a doctor will sign off on it as an order. That conversation is at the core of advance care planning, a relatively new concept in Canada that proponents hope will improve a patient's quality of life before death and come with the added benefit of reduced healthcare spending and fewer court battles over end-of-life care as baby boomers age and rates of chronic disease continue to rise. British Columbia and Alberta have been leaders in implementing the practice, in which patients decide when they would no longer want to be resuscitated, assign a substitute decision-maker who understands their wishes and values, and ensure doctors and hospital staff are in the know. The concept has taken hold in a number of provinces and can be found in Manitoba, Saskatchewan and Ontario hospitals. Alberta is beginning to roll it out province-wide. The Drummond report¹ ... recommended all family health workers start engaging middle-aged patients about what they'd want at end of life. But ... medical ethicists worry these end-of-life plans may be too difficult to apply. <http://news.nationalpost.com/2012/11/08/new-brunswick-hospitals-latest-to-offer-patients-expanded-end-of-life-care-options/>

1. 'Public Services for Ontarians: A Path to Sustainability and Excellence,' Commission on the Reform of Ontario's Public Services, February 2012 (noted in Media Watch, 20 February 2012). <http://www.fin.gov.on.ca/en/reformcommission/>

N.B. Cited is 'Caring for Our Aging Population & Addressing Alternate Level of Care,' Ministry of Health & Long Term Care. http://www.health.gov.on.ca/en/common/ministry/publications/reports/walker_2011/walker_2011.pdf

Edmonton Member of the Legislative Assembly pushes province to adopt compassionate care benefits for workers

ALBERTA | *Edmonton Journal* – 5 November 2012 – A rookie Member of the Legislative Assembly [MLA] is hoping to change Alberta's status as the only province without compassionate care protection for employees who must leave work to look after gravely ill relatives. However, the legislation before MLAs is not a government bill, which means it has less time for debate and a lower likelihood of passing. If it fails, there is a possibility that it could be brought back as a government bill in the spring. Under federal legislation, workers are entitled to take up to eight weeks of leave within a six-month period to care for a relative who has a high risk of dying. The leave is unpaid, though workers can apply for employment insurance benefits during that time. However, it is up to

provinces to ensure workers still have a job waiting for them once their leave is over. <http://www.edmontonjournal.com/news/Edmonton+pushes+province+adopt+compassionate+care/7502345/story.html>

Specialist Publications

Of related interest:

'Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit' (p.9), in *International Journal for Equity in Health*.

Ottawa must find the money to give veterans dignified burials

GLOBE & MAIL | Online OpEd – 5 November 2012 – A national fund that helps defray the costs of funerals for veterans is under-funded and its criteria for eligibility are out of date. Under the current rules, two-thirds of applications for assistance are routinely being denied. For a government that has spent millions on the restoration of war memorials and millions more to celebrate the War of 1812, this amounts to a failure to prioritize its responsibilities toward the men and women who serve the country. <http://www.theglobeandmail.com/commentary/editorials/ottawa-must-find-the-money-to-give-veterans-dignified-burials/article4914213/>

U.S.A.

Grieving students cope at school with hospice help



COLORADO | KKCO11 News (Grand Junction) – 8 November 2012 – [This week] children and teens will know more about grief and dealing with the loss of someone special – 15 November is National Children's Grief Awareness Day. People may be surprised to know how many young people ... are dealing with grief. Hospice & Palliative Care of Western Colorado served nearly 600 children and teens in 2011, with close to 400 of those students participating in school grief groups. With help from hospice, these young people are learning to share their feelings ... after a loss. <http://www.nbc11news.com/home/headlines/Grieving-students-cope-at-school-with-Hospice-help-177994191.html>

Specialist Publications

Of related interest:

'Good grief: Bereavement literature for young adults and A Monster Calls' (p.12), in *Medical Humanities*



Behind the headlines

What is the Liverpool Care Pathway?

U.S. NATIONAL LIBRARY OF MEDICINE | Online posting – 1 November 2012 – There have been several recent news stories about the Liverpool Care Pathway [LCP] ... For example, the [U.K.] *Daily Mail* described the LCP as a "death pathway" and called it a "scandal," claiming that patients are being put on it without the consent of relatives. In another story, the [U.K.] *Daily Telegraph* said that National Health Service hospitals are being given financial rewards for placing terminally ill patients on a "controversial pathway to death." BBC News, meanwhile, has reported a claim by one family that withdrawing food and water amounted to "torture." The LCP ... is intended to improve the quality of care in the final hours or days of a patient's life, and to ensure a peaceful and comfortable death. It aims to guide doctors, nurses and other health workers looking after someone who is dying on issues such as the appropriate time to remove tubes providing food and fluid, or when to stop medication. Its use for some has become controversial, with relatives reportedly claiming it has been used without consent, and some saying it is used inappropriately. <http://www.ncbi.nlm.nih.gov/pubmedhealth/behindtheheadline/news/2012-11-01-what-is-the-liverpool-care-pathway/>

N.B. Original source: 'Choices,' U.K. National Health Service. Scroll down to [International](#) and 'Liverpool Care Pathway: What went wrong?' (p.5), in *The Spectator*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *Boston Herald* – 7 November 2012 – **'Backers of doctor-assisted suicide concede.'** Supporters of a ballot question legalizing physician-assisted suicide for the terminally ill in Massachusetts have conceded defeat, even though the vote is too close to call. A spokesman for the Death With Dignity Act campaign said ... that "regrettably, we fell short." With 93% of precincts reporting early Wednesday, opponents of the measure were ahead by about 38,000 votes. <http://www.bostonherald.com/news/politics/view.bg?articleid=1061172994&pos=breaking>

International

Funding issues in end-of-life care

Patients leave rundown hospice as desperate search begins for money to rebuild

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 9 November 2012 – The Northern Ireland Hospice says it had "no other choice" but to move all terminally ill patients from its existing building [to a temporary facility at Whiteabbey Hospital] because of its dilapidated state. The hospice has made the move even though it doesn't have the £11million needed for redevelopment. The organisation said it was forced into the action because of the poor condition of the Victorian building and facilities at Somerton House in north Belfast. The hospice must now raise the money for the work. <http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/patients-leave-rundown-hospice-as-desperate-search-begins-for-money-to-rebuild-16235451.html>

Hospice care vs. palliative care

THE HOSPITALIST | Published online – 9 November 2012 – "Hospice care" and "palliative care" are not synonymous terms. Hospice care is defined as a comprehensive set of services ... identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care. Palliative care is defined as patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. http://www.the-hospitalist.org/details/article/2784961/Medical_Coding_Hospice_Care_vs_Palliative_Care.html

Palliative care in the Middle East

10,000 Jordanians die every year without receiving palliative care

JORDAN | *The Jordan Times* – 7 November 2012 – Approximately 10,000 Jordanians die every year without receiving the palliative care they need, health experts said. Mohammad Bushnaq, president of the Jordanian Palliative Care & Pain Management Society, said 90% of patients with chronic diseases who need palliative care do not receive it, adding that 10,000 cases out of the 18,000 deaths registered annually in the Kingdom, die while suffering from pain. Bushnaq made the remarks at the opening of the first International Conference for Palliative Care & Pain Management, where he called on all health providers to consider palliative care a priority. Addressing the participants, Adel Bilbeisi, an adviser at the Ministry of Health, said the government is currently developing palliative care services in public hospitals. <http://jordantimes.com/10000-jordanians-die-every-year-without-receiving-palliative-care>

Of related interest:

- UNITED ARAB EMIRATES | *Gulf News* (Abu Dhabi) – 9 November 2012 – **'Doctors call for comfort care to assist cancer patients.'** Despite the increasing awareness of cancer prevention and greater efforts for cancer control ... terminally ill cancer patients often do not receive comfort care that would help improve their quality of life... To achieve the best cancer treatment results, this kind of care, known as palliative care, could even be provided as soon as the patient is diagnosed with cancer... <http://gulfnews.com/news/gulf/uae/health/doctors-call-for-comfort-care-to-assist-cancer-patients-1.1101786>

Noted in Media Watch, 16 April 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Published online – 10 April 2012 – **'Middle East experience in palliative care.'** Palliative care ... was first introduced in Saudi Arabia in 1992 and only recently in countries such as Qatar, Bahrain, and the United Arab Emirates. Although the majority of Middle-Eastern countries, including Palestine, Iraq, Oman and Lebanon are in the capacity building phase, others such as Saudi and Jordan already have localized provision. In the absence of any of the Middle east countries approaching integration with the main-stream service providers, Saudi Arabia and Jordan are currently setting examples of achievement in the field. <http://ajh.sagepub.com/content/early/2012/03/05/1049909112439619.abstract>

Palliative care in Japan

Japan's first hospice for children opens in Osaka

JAPAN | *The Asahi Shimbun* – 6 November 2012 – Japan's first hospice for children opened its doors with at least two others planned around the country. Modeled after Britain's Helen House, the world's first children's hospice, the facility at Yodogawa Christian Hospital will provide care for patients 15 years old and younger. "We want to make this a place where children can find hope for living with their family and friends," said Masaaki Mukubo, superintendent of Yodogawa Christian Hospital. http://ajw.asahi.com/article/behind_news/social_affairs/AJ201211060072

Of related interest:

- JAPAN | *The Asahi Shimbun* – 11 November 2012 – **'Patients to declare wishes for their final days.'** http://ajw.asahi.com/article/behind_news/social_affairs/AJ201211110043

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>

Dementia 'second leading cause of deaths in women'

U.K. | BBC News – 6 November 2012 – Dementia is the second highest cause of death among women. Data from the Office for National Statistics revealed the condition was listed as an underlying cause in one in 10 of the 250,000 deaths in 2011. For men it was the fifth most common cause, accounting for 5% of the 235,000 deaths. The dementia figures were double those recorded a decade ago. For both men and women the most common cause was heart disease accounting for 16% and 11% of deaths respectively. However, the figures ... break cancers down into individual categories. If all the

cancers were added together they would account for 30% of deaths – over twice the number linked to heart disease.

<http://www.bbc.co.uk/news/health-20222765>

Specialist Publications

Of related interest:

'Preferences for end-of-life care: A nominal group study of people with dementia and their family carers' (p.12), in *Palliative Medicine*.

Noted in Media Watch, 20 August 2012:

- U.K. | *The Daily Telegraph* – 16 August 2012 – **'Dementia patients given right to say on end-of-life care.'** The National Health Service watchdog National Institute for Health & Clinical Excellence will require local authorities and health trusts to give people diagnosed with dementia an opportunity to discuss options for care at the end of their life as early as possible while they still have the capacity. <http://www.telegraph.co.uk/health/healthnews/9477623/Dementia-patients-given-right-to-say-on-end-of-life-care.html>
- *DEMENTIA* | Published online – 10 August 2012 – **'Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family...'** <http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract>

N.B. 'My Life Until the End: Dying Well with Dementia,' Alzheimer's Society (noted in Media Watch, 29 October 2012): http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537

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

Liverpool Care Pathway: What went wrong?

U.K. | *The Spectator* – 6 November 2012 – The recent media storm over the Liverpool Care Pathway [LCP] has obscured the progress doctors and nurses have made over the past decades in the U.K. in improving care for patients who are near death. Since the LCP was developed, patients in busy hospitals and other institutions are less likely to be left to die in pain and discomfort. The Pathway itself is simply a framework which reminds professionals to consider, and document, the process of care for people in the last days of life. Without it, some professionals may struggle to shift their focus to important aspects of care such as comfort measures, pain control, communicating with, and supporting, the family, carers and friends. It does not replace clinical judgement, and it is not irreversible – if the diagnosis of dying turns out to be premature, patients can be taken off the pathway. However, it is clear from recent media stories that relatives believe that some seriously ill patients have died prematurely as a result of being treated, or mistreated, under the Pathway, and these concerns should be taken seriously and investigated. If there is something wrong with the LCP or with the way it is being put into practice in certain quarters, we need to get at the facts and take corrective action. Equally, if the allegations are based on, for example, misunderstandings, that too needs to be established so that dying people and their families are not caused needless anxiety. <http://blogs.spectator.co.uk/beewee/2012/11/liverpool-care-pathway-what-went-wrong/>

Cont.

Of related interest:

- U.K. | *The Daily Telegraph* – 9 November 2012 – **'Since when was the matter of life and death none of our business?'** Doctors should stop telling us that our views on how we wish to die are irrelevant . <http://www.telegraph.co.uk/health/elderhealth/9667062/Since-when-was-the-matter-of-life-and-death-none-of-our-business.html>
- U.K. | BBC News – 8 November 2012 – **'Patient treatment preferences 'often misdiagnosed.'** Doctors are failing to really listen to patients' views on how they want to be treated, suggests a study. <http://www.bbc.co.uk/news/health-20253236>
 1. 'Stop the silent misdiagnosis: Patients' preferences matter,' *British Medical Journal*, published 8 November 2012. <http://www.bmj.com/content/345/bmj.e6572>
- U.K. | ITV News – 5 November 2012 – **'Resuscitation case begins: Case to examine 'do not resuscitate' policies.'** A hearing into the circumstances surrounding a hospital's resuscitation policy starts at the High Court. After the factual dispute is resolved, a full judicial hearing is listed for February, which will seek to clarify whether there is a legal duty to inform patients with capacity whether a DNR has been placed on their notes and whether they have any right to be consulted about it. <http://www.itv.com/news/story/2012-11-05/janet-tracey-resuscitation/>
- U.K. | *The Guardian* – 4 November 2012 – **'National Health Service constitution reform to include new end-of-life care commitments.'** Rules on involving patients and families in treatment decisions are being strengthened following an outcry over secretive use of the Liverpool Care Pathway... Under the measures being put out for consultation, health trusts that fail to discuss issues properly could be sued. Doctors who ignore the wishes of patients and relatives face being struck off. <http://www.guardian.co.uk/society/2012/nov/04/nhs-constitution-end-of-life-care>

When is medical treatment futile?

AUSTRALIA | ABC Health Report – 5 November 2012 – Many doctors want to lift the lid on a phenomenon they say is worsening the suffering of many dying Australians. It's called 'limited benefit' or 'futile medical treatment,' where patients with a poor prognosis are given aggressive drug therapy or surgery. <http://www.abc.net.au/radionational/programs/healthreport/wh-en-is-medical-treatment-futile3f/4349592>

End-of-life care in India

Government readies mega plan to make end stage life pain-free

INDIA | *The Times of India* (New Delhi) – 5 November 2012 – Providing people with a comfortable end stage life has finally got the government's attention. The health ministry will inform the Supreme Court that a ... 'National Programme on Palliative Care' has been finalized to make end stage life of patients suffering from cancer and HIV, besides the country's swelling elderly population, as painless as possible. A ministry analysis on the pattern of death says that less than 15% of people in India die suddenly. It has been estimated that less than 2% of people have access to palliative care that can relieve suffering at the end of life. More than 75% patients who visit a hospital are in the late stages of diseases. <http://timesofindia.indiatimes.com/India/Govt-readies-mega-plan-to-make-end-stage-life-pain-free/articleshow/17097382.cms>

Noted in Media Watch, 23 July 2012:

- INDIA | Press Trust of India (New Delhi) – 20 July 2012 – **'Supreme Court directs governments to respond on palliative care policy.'** <http://www.business-standard.com/generalnews/news/sc-directs-govts-to-respondpalliative-care-policy/34709/>

Specialist Publications

Of related interest:

'Little hope for medical futility' (p.11), in *Mayo Clinic Proceedings*.

In Singapore dying at home is expensive

SINGAPORE | *The Real Singapore* – 5 November 2012 – The cost and the "tough work" for caregivers in the case of those who may choose to die at home have put most patients off, although many would like to do so there, said doctors and industry players. This is not desirable, as "modern hospitals are not hospitable to the dying," said Lee Poh Wah, Chief Executive Officer of the Lien Foundation, which launched the Respectance Fund ... to offer funding to financially needy patients who wish to die at home. "They (hospitals) are designed to deliver technical tasks and functions that can drive the dying and their families into a state of deep isolation and disconnectedness," he said, qualifying that dying at home is not suitable for all, such as those in extreme physical and psychological distress. According to hospices and medical social workers, there are currently a few obstacles to a more holistic palliative care framework: Insufficient

advanced palliative teams in hospitals, the high costs and an incomplete, fragmented funding framework, as well as lack of support for caregivers. Hospices say that costs of dying at home can be from the hundreds to the thousands, depending on the condition and equipment needed, as well as any extras that patients can afford. Equipment costs can add up, rendering it more expensive than dying in a hospital.

<http://therealsingapore.com/content/singapore-dying-home-expensive>

Specialist Publications

Of related interest:

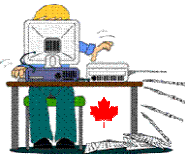
'Supportive, palliative, and end-of-life care for patients with cancer in Asia: Resource-stratified guidelines from the Asian Oncology Summit' (p.11), in *The Lancet Oncology*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (WALES) | BBC News – 8 November 2012 – **"Majority 'back assisted suicide,' says Bangor university study.** Two-thirds of people accept assisted suicide, according to international research by Bangor University.¹ The study of the views of over 62,000 people suggested support was around the same among people with terminal illnesses as for the general public. The main reason given for considering assisted death was unbearable suffering. Other factors such as loss of dignity, loneliness and being a burden were at least as significant as pain in motivating people to consider taking such action. Researchers looked at available international literature published about assisted dying and brought together the views of ordinary people. <http://www.bbc.co.uk/news/uk-wales-20238924>

1. 'Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying.' *Palliative Medicine*, published online 5 November 2012. <http://pmj.sagepub.com/content/early/2012/11/01/0269216312463623>



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>

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

Europall Project

Development of a set of process and structure indicators for palliative care

BMC HEALTH SERVICES RESEARCH | Published online – 2 November 2012 – By measuring the quality of the organisation of palliative care with process and structure quality indicators patients, caregivers and policy makers are able to monitor to what extent recommendations are met, like those of the council of the WHO on palliative care and guidelines. This will support the implementation of public programmes, and will enable comparisons between organisations or countries. <http://www.biomedcentral.com/content/pdf/1472-6963-12-381.pdf>

N.B. Europall Project website: <http://www.europall.eu/>

Of related interest:

- *CLINICAL INTERVENTIONS IN AGING* | Published online – 2 November 2012 – **'The impact of telemonitoring upon hospice referral in the community: A randomized controlled trial.'** <http://www.dovepress.com/the-impact-of-telemonitoring-upon-hospice-referral-in-the-community-a-peer-reviewed-article-CIA>

Integrating palliative care within acute stroke services: Developing a programme theory of patient and family needs, preferences and staff perspectives

BMC PALLIATIVE CARE | Published online – 9 November 2012 – Palliative care should be integrated early into the care trajectories of people with life threatening illness such as stroke. However published guidance focuses primarily on the end of life, and there is a gap in the evidence about how the palliative care needs of acute stroke patients and families should be addressed. This paper presents an explanatory framework for the integration of palliative and acute stroke care. <http://www.biomedcentral.com/content/pdf/1472-684X-11-22.pdf>

Does communication skills training make a difference to patients' experiences of consultations in oncology and palliative care services?

EUROPEAN JOURNAL OF CANCER CARE | Published online – 2 November 2012 – The primary aim of this pilot study was to evaluate whether the advanced communications skills training improves patients' experience of consultations. Healthcare professionals [i.e., study participants] were either part of the intervention group who attended a 3-day communication skills training course or part of the control group who were on the waiting list for training. No differences in the patients' ratings on the Consultation and relational Empathy measure were found between Time 1 (before training) and Time 2 (after training) for the intervention group. Possible explanations for the findings are explored and implications for communication skills training are discussed. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12014/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Of related interest:

- *CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Published online – 8 November 2012 – **'Communication skills training for dialysis decision-making and end-of-life care...'** <http://cjasn.asnjournals.org/content/early/2012/11/07/CJN.05220512.abstract?sid=b783cec2-76e8-42c1-aaa1-0a5ed346d9d5>
- *JOURNAL OF PALLIATIVE MEDICINE* | Published online – 9 November 2012 – **'Errors in palliative care: Kinds, causes, and consequences: A pilot survey of experiences and attitudes of palliative care professionals.'** Professionals acknowledge errors – in particular errors in communication – to be a common and relevant problem in palliative care, one that has, however, been neglected in training and research. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0272>

Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit

INTERNATIONAL JOURNAL FOR EQUITY IN HEALTH | Published online – 1 November 2012 – Family (i.e., unpaid) caregiving has long been thought of as a 'woman's issue,' which ultimately results not only in gendered, but also financial and health inequities. Because of this, gender-based analyses have been prioritized in caregiving research. However, trends in current feminist scholarship demonstrate that gender intersects with other axes of difference, such as culture, socio-economic status, and geography to create diverse experiences. In this analysis the authors examine how formal front-line palliative care providers understand the role of such diversities in shaping Canadian family caregivers' experiences of end-of-life care. In doing so they consider the implications of these findings for a social benefit program aimed at supporting family caregivers, namely the Compassionate Care Benefit (CCB).¹ Findings reveal that experiences of caregiving are not homogenous and access to services and supports are not universal across Canada. Five axes of difference were commonly raised by front-line palliative care providers when discussing important differences in family caregivers' experiences: culture, gender, geography, life course stage, and material resources. The authors' findings reveal inequities with regard to accessing needed caregiver services and resources, including the CCB, based on these axes of difference. <http://www.equityhealthj.com/content/pdf/1475-9276-11-65.pdf>

1. Employment Insurance Compassionate Care Benefits, Service Canada. http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Of related interest:

- *AMERICAN JOURNAL OF HEALTH PROMOTION*, 2012;27(2):84-89. '**Caregiver burden and non-achievement of healthy lifestyle behaviors among family caregivers of cardiovascular disease patients.**' When developing heart-health promotion interventions, caregiver burden should be considered as a possible barrier to prevention among family members of cardiovascular disease patients. <http://www.ajhpcontents.com/doi/abs/10.4278/ajhp.110606-QUAN-241>

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.

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.

"Wrapped in their arms": Next-of-kin's perceptions of how hospital nursing staff support family presence before, during, and after the death of a loved one

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2012;14(8):541-550. Family presence is a vital component of quality end-of-life (EOL) care. The authors conducted face-to-face, in-depth interviews with next-of-kin of deceased veterans to explore perceptions of how hospital nursing staff supported and facilitated family presence during the actively dying phase, at the time of death, and immediately following the patient's death. The authors provide exemplary quotes to contextualize nursing staff behaviors that encouraged, supported, and guided families, enabling them to be present and to function adaptively before, during, and after the loved one's death. In particular, they focus on nursing behaviors that were responsive to family members' needs for information, privacy, intimacy, physical comfort, and emotional reassurance. Nurses' effectiveness in optimizing family support required clinical competency in recognizing the actively dying phase of life and engaging in behaviors that facilitated the delivery EOL care, with thoughtful attention to family needs. http://journals.lww.com/jhpn/Abstract/2012/12000/Wrapped_in_Their_Arms_Next_of_Kin_s_Perceptions.9.aspx

On caring for those who will remain

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2012;308(17):1749-1750. Today is the fourth anniversary of my mother's death. She was a petite powerhouse of a woman – not even 5 feet tall. As a Holocaust survivor, she had experienced some of the worst that life offers. How ironic that she would die due to a freak fall on the way to her neighborhood supermarket, walking hand in hand with my father. Independent to a fault, with a healthy dose of vanity, she would not consider any assistive device like a cane or walker to help her walk more steadily and safely. Yet this was her first significant fall – losing her balance when a passerby knocked into her, causing the tumble, leading to the unfortunate cascade that would be the end of her. She pulled my father down too, neither of them steady without the other, walking through the street, as in life, holding each other up. My father's fall resulted in a hip fracture. Unfortunately, my mother broke several ribs and was in tremendous pain. They made their way home – walking the 4 blocks to their apartment before they called my sister and me – not knowing how they made it back. <http://jama.jamanetwork.com/article.aspx?articleid=1389619>

Impact of hospital case volume on quality of end-of-life care in terminal cancer patients

JOURNAL OF PALLIATIVE MEDICINE | Published online – 9 November 2012 –Significant associations between hospital case volume and quality of EOL [end-of-life] care were identified [in this study] after adjusting for patient and hospital characteristics. Small- and medium-volume hospitals were found to be less likely to administer opioids, and medium-volume hospitals were more likely to provide ICU service or life-sustaining treatments when compared with large-volume hospitals. No significant association between chemotherapy use and case volume was observed. Results showed that the case volume of terminally ill cancer patients was associated with several aspects of quality of EOL care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0361>

Of related interest:

- *POSTGRADUATE MEDICAL JOURNAL* | Published online – 9 November 2012 – '**Offering older hospitalised patients the choice to die in their preferred place.**' Although hospital admission [in this study] was largely appropriate, in a minority judicious ACP [advance care planning] could have avoided death in hospital. The authors recommend: 1) increased use of ACP, with appropriate practicalities planned in advance; 2) wide-scale introduction of the 'Rapid Discharge Home of the Dying Patient' pathway; and, 3) routinely discussing preferred place of death in appropriate key situations. <http://pmj.bmj.com/content/early/2012/11/08/postgradmedj-2012-131161.abstract>

Supportive, palliative, and end-of-life care for patients with cancer in Asia: Resource-stratified guidelines from the Asian Oncology Summit 2012

THE LANCET ONCOLOGY, 2012;13(11):e492-e500. The burden of cancer in Asia is high; 6.1 million new cases were diagnosed in the continent in 2008, which accounted for 48% of new cases worldwide. Deaths from cancer are expected to continue to rise because of ageing populations and modifiable risk factors such as tobacco and alcohol use, diet, and obesity. Most patients who are diagnosed with cancer in Asia have advanced disease that is not amenable to curative treatment, which means that they are likely to have pain and other symptoms and psychosocial concerns. These burdens vary with the economic and political situation of the different countries and are affected by such factors as an absence of screening programmes, insufficient cancer diagnostic and treatment services (especially in sparsely populated and rural areas), legal restrictions on access to drugs to relieve pain, and a medical culture in which quality-of-life considerations are undervalued in relation to imperatives to treat. These issues could be ameliorated by increased investment in cancer screening, removal of restrictions on prescription of opioids, and improvements in medical education to increase recognition of treatment futility. Supportive, palliative, and end-of-life care offer the potential to enhance quality of life, improve pain control, and reduce suffering for patients with cancer and their families, and to give patients a dignified death. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(12\)70380-7/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(12)70380-7/abstract)

Little hope for medical futility

MAYO CLINIC PROCEEDINGS, 2012;87(11):1040-1041. Is there any chance that a determination of medical futility by competent physicians might permit the cessation of treatment for patients regardless of what the patient, the advance directive, or the surrogate decision maker might say? Despite the fact that at least one state, Texas, has recognized physician determination of futility as an adequate basis for ultimately withdrawing care, the future of futility assessment, as well as downstream actions based on those assessments, looks bleak. Some recent cases give ample reason why a society increasingly committed to respecting patient autonomy and family wishes at the end of life will find little role for futility determinations, no matter how sound and deliberative they may be. Further, gaps in medical records and a lack of continuity in patient care often prevent the most sound assessments of appropriateness when patients or their family members are motivated to seek futile care. If futility assessment has no future, then what are physicians to do? They may seek to improve end-of-life care to make it less stressful for patients, family, and staff. They may enhance efforts at early communication and mediation with families as soon as they perceive a gap between hope and medical reality. They may seek another somewhat neglected strategy – creating ways of more clearly framing care and communicating about it – that makes it less likely that futility will ever be reached. These ... issues are addressed in this issue of *Mayo Clinic Proceedings*.^{1,2} [http://www.mayoclinicproceedings.org/article/S0025-6196\(12\)00905-6/fulltext](http://www.mayoclinicproceedings.org/article/S0025-6196(12)00905-6/fulltext)

1. 'End-of-life care decisions: Importance of reviewing systems and limitations after two recent North American cases,' *Mayo Clinic Proceedings*, 2012;87(11):1098-1105. Two recent and unfortunate North American cases involving end-of-life treatment highlight the difficulties surrounding medical futility conflicts. As countries have explored the greater influence that patients and their representatives may play on end-of-life treatment decisions, the benefits and struggles involved with such a movement must be appreciated. These two cases are used to examine the present systems existing in the U.S. and Canada for resolving end-of-life decisions, including the difficulty in defining medical futility, the role of medical ethics committees, and controversies involving surrogate decision making. [http://www.mayoclinicproceedings.org/article/S0025-6196\(12\)00850-6/fulltext?refuid=S0025-6196\(12\)00905-6&refissn=0025-6196](http://www.mayoclinicproceedings.org/article/S0025-6196(12)00850-6/fulltext?refuid=S0025-6196(12)00905-6&refissn=0025-6196)
2. 'Clinical pearls in palliative medicine,' *Mayo Clinic Proceedings*, 2012;87(11):1118-1123. [http://www.mayoclinicproceedings.org/article/S0025-6196\(12\)00815-4/fulltext?refuid=S0025-6196\(12\)00905-6&refissn=0025-6196](http://www.mayoclinicproceedings.org/article/S0025-6196(12)00815-4/fulltext?refuid=S0025-6196(12)00905-6&refissn=0025-6196)

Good grief: Bereavement literature for young adults and *A Monster Calls*

MEDICAL HUMANITIES | Published online – 8 November 2012 – Recent years have seen a proliferation of critically acclaimed novels for young adults dealing with bereavement. This is part of a 'bereavement turn' – a contemporary cultural movement to examine publicly our attitudes to death and grieving. This paper examines the narrative strategies in Patrick Ness's award-winning novel *A Monster Calls* to look at the ways in which the psychic burden of the impending loss of a parent through cancer is managed. The book draws on conventions of children's literature to create a sense of familiarity that helps to balance the emotional stress of the story. The Kübler-Ross stages of grief serve as a heuristic that helps the story deliver catharsis in spite of its inevitably traumatic subject matter. *A Monster Calls* is an important addition to the canon of fictional pathography. <http://mh.bmj.com/content/early/2012/11/07/medhum-2012-010260.abstract>

Fear of the dead, fear of death: Is it biological or psychological?

MORTALITY | Published online – 1 November 2012 – The claim that aversion to dead bodies reflects a non-conscious response to objective physiological danger is thoroughly examined. No evidence is found for the idea that corpses are especially dangerous as potential sources of contamination. While reactions to dead bodies vary greatly among humans, depending on personal and cultural factors, fear of the dead is tied to the awareness of mortality. Humans react to the presence of death by transforming the dead, physically and psychologically. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.734986>

Preferences for end-of-life care: A nominal group study of people with dementia and their family carers

PALLIATIVE MEDICINE | Published online – 5 November 2012 – Quality of care, family contact, dignity and respect were ranked as significant themes by all groups [i.e., study participants]. The analysis revealed three main themes: quality of care, independence and control, and carer burden. People with dementia had difficulty considering their future selves. Carers wanted much control at the end of life... Wishes and preferences of people with dementia and their family carers may differ. To ensure the wishes of people with dementia are respected, their views should be ascertained early in the disease before their ability to consider the future is compromised. <http://pmj.sagepub.com/content/early/2012/11/01/0269216312464094.abstract>

Of related interest

- *JOURNAL OF MEDICAL ETHICS* | Published online – 10 November 2012 – **'Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: Sensitive topics revised before implementation.'** Providing artificial feeding and fluids and discussing euthanasia may be particularly sensitive topics, and guidance on these subjects needs careful consideration of ethical aspects and possible adaptations to local standards and practice. The findings [of this study] may promote cross-national debate on sensitive, core issues regarding end-of-life care in dementia. <http://jme.bmj.com/content/early/2012/11/09/medethics-2012-100903.abstract>

World Aids Day 1 December 2012



Getting to zero. Zero new HIV infections. Zero discrimination. Zero AIDS related deaths.

Hope as virtue: Opens up a new space for exploring hopefulness at the end of life and raises some interesting questions

PHILOSOPHY, PSYCHIATRY & PSYCHOLOGY, 2012;19(3):187-189. Considering hope as a virtue involves taking a fresh perspective where the grounds for possessing and expressing hope can be examined. As with the other virtues, presumably for hope there exists a 'golden mean.' The golden mean of courage lies between timidity and reckless abandonment to danger; 'virtuous' hope lies between despair, where there is no hope at all, and extreme optimism, where hope does not have any grounding in reality. That said ... realistic hope can exist without any great chance of the hoped-for event materializing. In fact, it is very difficult to be sure that a seemingly unrealistic hope is in fact unrealistic. As clinicians, patients often surprise us; for instance, a mother's hope to see her young children grow up when she has been diagnosed with advanced breast cancer might seem unrealistic; however, when the patient survives several years and her hope is realized, it cannot be dismissed as unrealistic, although at the outset it seemed highly improbable. Or a patient with advanced lung cancer and poorly controlled symptoms who decides to holiday abroad against medical advice (because their doctor thinks their hope of enjoying such a holiday is unrealistic) is somehow able to enjoy the holiday despite the odds being stacked against it. In the end, hope may only be judged as realistic or unrealistic after the event. By this token, hope that turns out to be realistic may have seemed to a clinician to be 'extreme optimism' when it was first expressed by the patient; however, maybe hope needs to be judged by how it enables a patient and those around them to face their illness and even flourish in the face of it. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/philosophy_psychiatry_and_psychology/v019/19.3.munday.html

Of related interest:

- *PHILOSOPHY, PSYCHIATRY & PSYCHOLOGY*, 2012;19(3):165-181. **'From hope in palliative care to hope as a virtue and a life skill.'** This paper aims at explicating a theory of hope that is suitable for gravely ill people based on virtue ethics, research in the psychology of "well-being," and the philosophy of palliative care. The working hypotheses of the theory are that hope is conditioned neither by past events nor by present needs, but is not necessarily oriented toward the future, especially the distant future; that hope is related to personal agency and to freedom; and that hope is deliberative, hence evaluative, motivational, and rationally critical. Hope is the valuation of and personal identification with "promotion-focus" goals with an attitude of non-attachment to any one goal. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/philosophy_psychiatry_and_psychology/v019/19.3.barilan.html

Worth Repeating

Emotional labour

Clinicians' attitudes to death and dying

JOURNAL OF HEALTH ORGANIZATION & MANAGEMENT, 2009;23(1):5-22. Clinician [i.e., study participants'] attitudes to death and dying, and clinicians' capacity to engage with the human needs of patients influenced how emotional labour was experienced. Negative effects were not formally acknowledged in clinical workplaces and institutional mechanisms to support clinicians did not exist. Health service providers must openly acknowledge the effect of emotional labour on the care of dying people. By sharing their experiences, multidisciplinary clinicians become aware of the personal, professional and organisational impact of emotional labour as a core element of health care so as to explicitly and practically respond to it. The effect of care on clinicians ... not only affects the wellbeing of clinicians themselves, but also the quality of care that patients receive. <http://www.emeraldinsight.com/journals.htm?articleid=1779000&show=abstract>

Media Watch Online

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/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

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>

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