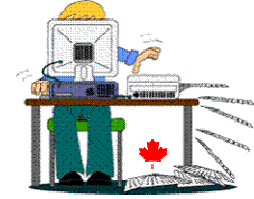


Media Watch...

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.

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

Compiled & Annotated by Barry R. Ashpole

Pediatric palliative care: Scroll down to [Specialist Publications](#) and 'Moving toward quality palliative cancer care: Parent and clinician perspectives on gaps between what matters and what is accessible' (p.11), in *Journal of Clinical Oncology*.

Canada

Elder, home & end-of-life care

Patients needing long-term care clog hospitals

CBC NEWS | Online report – 29 November 2012 – Elderly Canadians waiting in hospitals to get a long-term care bed creates a ripple effect of delays in the health-care system, two new reports show.^{1,2} The Canadian Institute for Health Information's 2012 focus on wait times offers a portrait of people in hospital beds who are waiting to be transferred to a long-term care facility or back home with support services. On any given day, about 5% of acute hospital beds are occupied by these "alternate level care" patients, and 85% of them are seniors. <http://www.cbc.ca/news/health/story/2012/11/29/seniors-waits-hospital-long-term-care.html>

1. 'Health care in Canada, 2012: A focus on wait times,' Canadian Institute for Health Information, November 2012. https://secure.cihi.ca/free_products/HCIC2012-FullReport-ENweb.pdf
2. 'Seniors and alternate level of care: Building on our knowledge,' Canadian Institute for Health Information, November 2012. https://secure.cihi.ca/free_products/ALC_AIB_EN.pdf

Of related interest:

- MANITOBA | CTV News (Winnipeg) – 26 November 2012 – **'Province rolls out health-care program aimed at helping seniors stay in homes longer.'** <http://winnipeg.ctvnews.ca/province-rolls-out-health-care-program-aimed-at-helping-seniors-stay-in-homes-longer-1.1054614>

Extract from CBC report

What happened to seniors discharged from acute care between 2007 and 2011:

Long-term care 9.7%
Home with support 12.8%
Home without support 64%
Died 6.2%
Rehabilitation facility 6.2%
Other 1.1%

Cont.

- BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 1 December 2012 – **'In-home caregivers sometimes need help.'** In-home caregivers free up 30,000 hospital and long-term care beds. <http://www.timescolonist.com/health/home+caregivers+sometimes+need+help/7638555/story.html>

Home care agency stands behind rule barring care providers from speaking publicly

ONTARIO | *The Record* (Kitchener) – 29 November 2012 – The local Community Care Access Centre has been plagued by problems in recent years, culminating this summer with a call for Health Minister Deb Matthews to appoint a supervisor to overhaul the troubled agency. That came from the Waterloo Wellington Local Health Integration Network, which hired an independent company to review the agency after years of an unstable budget and services. The report pointed to failure of leadership at the highest level that resulted in organizational dysfunction directly affecting client care, with service cuts often done with little notice to rein in a looming annual deficit. <http://www.therecord.com/news/local/article/845207--home-care-agency-stands-behind-rule-barring-care-providers-from-speaking-publicly>

Noted in Media Watch, 26 November 2012:

- ONTARIO | *The Record* (Kitchener) – 20 November 2012 – **'Debate home-care policy in public.'** <http://www.therecord.com/opinion/editorial/article/838991--debate-home-care-policy-in-public>

Nova Scotia palliative care program a 'rude awakening'

NOVA SCOTIA | CBC News (Halifax) – 27 November 2012 – The wife of a man dying of a rare form of cancer says Nova Scotia isn't doing enough to support palliative care patients who want to die at home. Seana Collins of Wolfville is calling on the provincial government to pay the cost of nutritional therapy replacement, which is the liquid food many palliative care patients need to stay alive. Balfour Collins, 44, was first diagnosed with a form of thyroid cancer seven years ago, when he was living in Alberta. After his diagnosis, Collins' family decided to return to his home province of Nova Scotia. In Alberta, nutritional therapy replacement and

accompanying equipment was paid for [by the province] and delivered to the Collins. <http://www.cbc.ca/news/health/story/2012/11/27/ns-palliative-care-food.html>

Extract from CBC report

The cost of the food would be covered if Balfour Collins opted to stay in hospital, but because he wants to die at home, he must pay for the food and equipment needed to deliver it. The cost is between \$500 and \$1,000 a month.

Noted in Media Watch, 20 February 2012:

- NOVA SCOTIA | *Daily News* (Truro) – 15 February 2012 – **'Palliative home care patients eligible for free drug coverage.'** <http://www.trurodaily.com/News/Local/2012-02-15/article-2896085/Palliative-home-care-patients-eligible-for-free-drug-coverage/1>

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>



A life interrupted: Hassan Rasouli's journey from an earache to a high-stakes battle over end-of-life decisions

ONTARIO | *Toronto Life* – 27 November 2012 – Two years ago, Hassan Rasouli checked into Sunnybrook ... [Health Sciences Centre] ... to have a brain tumour removed, fell into a coma, and provoked a [federal] Supreme Court battle over who decides to pull the plug. Then, one day, he awoke. <http://www.torontolife.com/daily/informer/from-print-edition-informer/2012/11/27/a-life-interrupted/>

Noted in Media Watch, 26 November 2012:

- ONTARIO | CTV News (Toronto) – 19 November 2012 – **'Family to take end-of-life fight to Supreme Court of Canada.'** <http://www.ctvnews.ca/canada/family-to-take-end-of-life-fight-to-supreme-court-of-canada-1.1043995>

Half-hearted medical care for hopeless cases

ONTARIO | *Toronto Star* – 25 November 2012 – It's a phrase that appears nowhere in hospital policy manuals or medical charts. Doctors or nurses will never utter it in discussions with patients or family members. But in quiet hospital corners, the words are whispered among medical professionals. Certain that no recording devices are turned on, doctors and nurses will quietly admit that "slow code" – a lackadaisical approach to sustaining life for those who demand aggressive treatment but are thought to be beyond hope – is an element of end-of-life care in this country. Medical experts interviewed for this story say they never engage in slow codes. But some researchers and bioethicists suggest it's making a resurgence. Dr. John Lantos, director of the Children's Mercy Bioethics Center in Kansas City and co-author of a journal article titled 'Should the 'slow code' be resuscitated?' says the clandestine practice is happening far more than medical professionals openly concede.¹ <http://www.thestar.com/news/canada/article/1292712--half-hearted-medical-care-for-hopeless-cases>

1. 'Should the "slow code" be resuscitated?' *American Journal of Bioethics*, 2011;11(11):8-12. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.603793?prevSearch=Lantos&searchHistoryKey=>

U.S.A.

Sadness in the wake of the death of a loved one

Weekend vote will bring controversial changes to psychiatrists' bible

NATIONAL PUBLIC RADIO | Online report – 30 November 2012 – This weekend [1-2 December], 20 people from around the country will meet ... to take a vote. A passing stranger who stumbled on this group wouldn't see much of anything, just a bunch of graying academic types sitting around a table. But millions of people will be touched by that vote because the graying academic types are voting to approve the 5th edition of the *Diagnostic & Statistical Manual* [DSM-5] – the bible of psychiatry. There will be a new way to think about sadness in the wake of the death of a loved one: In the last DSM (DSM-4), psychiatrists were warned away from diagnosing major depression in people who had recently lost someone they loved, because grief in the face of loss was seen as a normal – not abnormal – response. This is a small change, but to critics, emblematic of a much larger and more sinister problem: the expansion of behaviors considered abnormal. <http://www.npr.org/blogs/health/2012/11/30/166252201/weekend-vote-will-bring-controversial-changes-to-psychiatrists-bible>

Specialist Publications

Of related interest:

'From hope to despair, and back: Being the wife of a patient in a persistent vegetative state' (p.13), in *Quality Health Research*.

Forced to choose: Nursing home vs. hospice

NEW YORK TIMES | Online article – 30 November 2012 – An older person, someone who will die within six months, leaves a hospital. Where does she go? Almost a third of the time, according to a recent study from the University of California, San Francisco, records show she takes advantage of Medicare's skilled-nursing facility benefit and enters a nursing home. But is that the best place for end-of-life care? In terms of monitoring her vital signs and handling IVs – the round-the-clock nursing care the skilled-nursing facility benefit is designed to provide – maybe so. But for treating end-of-life symptoms like pain and shortness of breath, for providing spiritual support for her and her family, for palliative care that helps her through the ultimate transition – hospice is the acknowledged expert. She could receive hospice care, also covered by Medicare, while in the nursing home. But since Medicare only rarely reimburses for both hospice and the skilled-nursing facility benefit at the same time, this hypothetical patient and her family face a financial bind. If she opts for the hospice benefit, which does not include room and board at the nursing home, then she will be on the hook for hundreds of dollars a day to remain in the facility. <http://newoldage.blogs.nytimes.com/2012/11/30/forced-to-choose-nursing-home-vs-hospice/>

Noted in Media Watch, 8 October 2012:

- REUTERS | Online report – 1 October 2012 – '**Do seniors turn to the right places at end of life?**' A new study says almost one third of Medicare's beneficiaries use the program to pay for end-of-life care at nursing homes, which may not be equipped to treat or prevent pain and suffering.¹ <http://www.reuters.com/article/2012/10/01/us-do-seniors-turn-to-the-right-places-a-idUSBRE8901B520121001>

1. 'Use of the Medicare post-hospitalization skilled nursing benefit in the last 6 months of life,' *Archives of Internal Medicine*, published online 1 October 2012. [Noted in Media Watch, 8 October 2012.] <http://archinte.jamanetwork.com/article.aspx?articleid=1368358>

Austerity program at San Diego Hospice brings layoffs

CALIFORNIA | *North County Times* (Escondido) – 29 November 2012 – More than 180 San Diego Hospice employees received layoff notices ... as the organization implements an austerity plan designed to keep it operating in the face of ongoing Medicare audits. Chief Executive Kathleen Pacurar said ... that the cuts include temporarily shutting down San Diego Hospice's most visible presence in the community, a 24-bed specialty hospital in Hillcrest. The move is the result of Medicare temporarily shutting off reimbursement payments in early November, causing the hospice, one of the largest in the nation, to temporarily stop admitting patients. Those Medicare payments have since resumed, removing doubts about the organization's survival. But heightened federal scrutiny of its patient admittance practices continues, forcing the hospice to downsize. Pacurar said that 95% of hospice services are delivered to patients in their homes, and that work will continue unabated. http://www.nctimes.com/lifestyles/health-med-fit/austerity-program-at-san-diego-hospice-brings-layoffs/article_f05e415a-bc97-5d24-b487-d3b879e1bdb4.html

Noted in Media Watch, 19 November 2012:

- CALIFORNIA | *U-T San Diego* – 12 November 2012 – '**Hospice threatened by Medicare audit.**' <http://www.utsandiego.com/news/2012/nov/12/hospice-threatened-by-medicare-audit/>

'Do-not-resuscitate' order at issue in Minnesota Supreme Court case

MINNESOTA | *Star Tribune* (Minneapolis) – 27 November 2012 – A drunken driver's claim that he was not responsible for the death of a 93-year-old woman killed in a 2010 crash because her "do-not-resuscitate" order kept her from potentially life-saving medical care will be reviewed by the Minnesota Supreme Court. <http://www.startribune.com/local/east/181099801.html?refer=y>

While number of patients receiving hospice care increases, larger percentage have short length of service

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online report – 27 November 2012 – A record number of dying persons in the U.S. – an estimated 1.65 million patients – received care from the nation's hospices in 2011, reports the NHPCO. Approximately 44.6% of all deaths in the U.S. were under the care of a hospice program. This is up from 41.9% in 2010. <http://www.nhpc.org/i4a/pages/index.cfm?pageID=6846>

1. 'Facts and Figures: Hospice Care in America,' NHPCO, November 2012. [Noted in Media Watch, 5 November 2012.] http://www.nhpc.org/files/public/Statistics_Research/2012_Facts_Figures.pdf

Aiding the doctor who feels cancer's toll

NEW YORK TIMES | Online column – 26 November 2012 – The woman was terminally ill with advanced cancer, and the oncologist who had been treating her for three years thought the next step might be to deliver chemotherapy directly to her brain. It was a risky treatment that he knew would not, could not, help her. When Dr. Diane E. Meier asked what he thought the futile therapy would accomplish, the oncologist replied, "I don't want Judy to think I'm abandoning her." In a recent interview, Dr. Meier said, "Most physicians have no other strategies, no other arrows in their quiver beyond administering tests and treatments. To avoid feeling that they've abandoned their patients, doctors throw procedures at them. Under the Affordable Care Act ... unnecessary procedures may decline as more doc-

tors are reimbursed for doing what is best for their patients over time, not just for administering tests and treatments. But more could be done if physicians were able to step away from the misperception that everything that can be done should be done.

<http://well.blogs.nytimes.com/2012/11/26/aiding-the-doctor-who-feels-cancers-toll/>

Specialist Publications

Of related interest:

'The lived experience of physicians dealing with patient death' (p.9), in *BMJ SUPPORTIVE & PALLIATIVE CARE*.

A study of home help finds low worker pay

NEW YORK TIMES | Online report – 26 November 2012 – Nannies, caregivers and housecleaners earn a median wage of about \$10 an hour, and few receive benefits like health insurance or paid sick days, according to the first-ever national statistical study of domestic workers.¹ Domestic workers are generally not covered by federal or state minimum wage laws. The study was based on interviews with nannies, caregivers and housecleaners who now work in the U.S., but originally came from 71 countries. http://www.nytimes.com/2012/11/27/business/a-study-of-home-help-finds-low-worker-pay-and-few-benefits.html?_r=0

1. 'Home Economics: The Invisible and Unregulated World of Domestic Work,' National Domestic Workers Alliance, Center for Urban Economic Development, University of Illinois at Chicago Data Center, November 2012. <http://www.domesticworkers.org/pdfs/HomeEconomicsEnglish.pdf>

Media Watch posted on Palliative Care Network-e Website

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

International

New National Health Service trusts fear distorted death rate data

U.K. | *The Daily Telegraph* – 2 December 2012 – New NHS [National Health Service] trusts fear mortality data will give the impression they are unsafe because by running hospices they show up as having high death rates. New style organisations are springing up in the NHS which run both hospital services and some community-based patient services which may include hospices. One way in which trusts are judged is on their mortality data published annually by Dr. Foster Hospital Guide. This calculates the proportion of deaths above or below what would be expected given the population the hospital serves and the kind of patients it treats. However, it is claimed, the figures will not take into account palliative care services for the dying such as hospices. Therefore trusts which have a large number of palliative care beds could look as though more of their patients die than would be expected to. <http://www.telegraph.co.uk/health/healthnews/9714506/New-NHS-trusts-fear-distorted-death-rate-data.html>

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

Terminally ill face postcode lottery in end-of-life care

U.K. | *The Daily Telegraph* – 28 November 2012 – Terminally ill people in London can expect a worse death than almost anywhere in the country, a study by the Office for National Statistics suggests. Analysis of a data from almost 50,000 bereaved people found wide variations in the standards of dignity, respect and basic care provided to their loved ones in different areas. Relatives of people who had died were asked to rate their satisfaction with the treatment provided by hospital staff, GPs or community nurses in the last three months of their loved-ones' lives. While trusts in the South West of England were rated most highly of all, those in most areas of London came in the bottom 20% of the country. For example, asked whether their loved ones had "always" been treated with dignity and respect by community nurses, only 62.1% of those in north-west London said yes while in Cornwall the rate was 88.7%. Asked the same question, about GPs, only 60.9% in south-east London said yes, while in Somerset the rate was 83.1%. <http://www.telegraph.co.uk/health/healthnews/9708827/Terminally-ill-face-postcode-lottery-in-end-of-life-care.html>

Noted in Media Watch, 9 July 2012:

- U.K. (England) | *Daily Mail* – 8 July 2012 – '**Postcode lottery that sees thousands of elderly denied vital care services to be abolished.**' <http://www.dailymail.co.uk/news/article-2170667/Postcode-lottery-sees-thousands-elderly-denied-vital-care-services-abolished.html?ito=feeds-newsxml>

Liverpool Care Pathway

Review into 'end-of-life' care

U.K. | BBC News – 26 November 2012 – The government has ordered an independent review into a controversial regime that allows doctors to withdraw treatment in the last days of life. The Liverpool Care Pathway has come under intense scrutiny recently, with claims that some hospitals are abusing its use to cut costs. Medics say the pathway helps patients avoid unnecessary interventions. <http://www.bbc.co.uk/news/health-20503932>

Noted in Media Watch, 19 November 2012:

U.K. | *Liverpool Daily Post* – 15 November 2012 – '**People behind the controversial Liverpool Care Pathway speak out in its defence.**' <http://www.liverpooldailypost.co.uk/liverpool-news/regional-news/2012/11/15/people-behind-the-controversial-liverpool-care-pathway-lcp-speak-out-in-its-defence-99623-32234356/>

Noted in Media Watch, 12 November 2012:

U.K. | *The Spectator* – 6 November 2012 – '**Liverpool Care Pathway: What went wrong?**' <http://blogs.spectator.co.uk/beewee/2012/11/liverpool-care-pathway-what-went-wrong/>

THE LANCET, 2012;380(9855):1714-1717. '**The misrepresentation of palliative care in the U.K.**' [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)61971-0/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61971-0/fulltext)

Cont.

Of related interest:

- LOCALGOV.COM.UK | Online report – 30 November 2012 – '**Councils must seize end of life care agenda.**' More than half of councils admit their procedures for allowing people to spend the final days of their lives with dignity, in their own home, are not fit for purpose, a survey has revealed.¹ <http://www.localgov.co.uk/index.cfm?method=news.detail&id=107996>
- 1. 'A good death: the role of the local authority in end of life care,' Local Government Information Unit, November 2012. <http://www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf>

Power over life and death: The amorality of modern medicine

AUSTRALIA | ABC News – 27 November 2012 – [The] drive to think practically, mechanically and efficiently is not merely where medicine has gone. It is where Western cultures have gone. Medicine both produces and is produced by the metaphysics of efficient causation rampant in Western cultures. This metaphysics of efficient causation is also what drives modern liberal governments bent on efficient control of bodies, living and dying. It reduces life to its mechanisms of control, at both the level of the body and at the level of the body politic. Since in this metaphysics, life comes from nowhere (no meaningful formal causation), is headed nowhere, and has no particular purpose (no final causation), we are left with bodies caught in the social apparatuses of liberalism. On this Western metaphysics of efficient causation, we are little more than corpses figuring out when to embrace death. <http://www.abc.net.au/religion/articles/2012/11/27/3642313.htm>

Parliamentary Group for Hospice & Palliative Care

Call for better support for seriously ill young people moving into adult care

U.K. | National Council for Palliative Care – 27 November 2012 – The All Party Parliamentary Group (APPG) 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 The recommendations put to the group were drawn from the 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. The STEPP Project was carried out by a research team based at the Social Policy Research Unit at the University of York. The APPG heard that, despite examples of good practice around the country, the care and support of young people with life-limiting conditions and their families can be compromised. <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, 27 November 2012: http://www.togetherforshortlives.org.uk/assets/0000/2262/FINAL_APPG_key_findings_paper_2.pdf

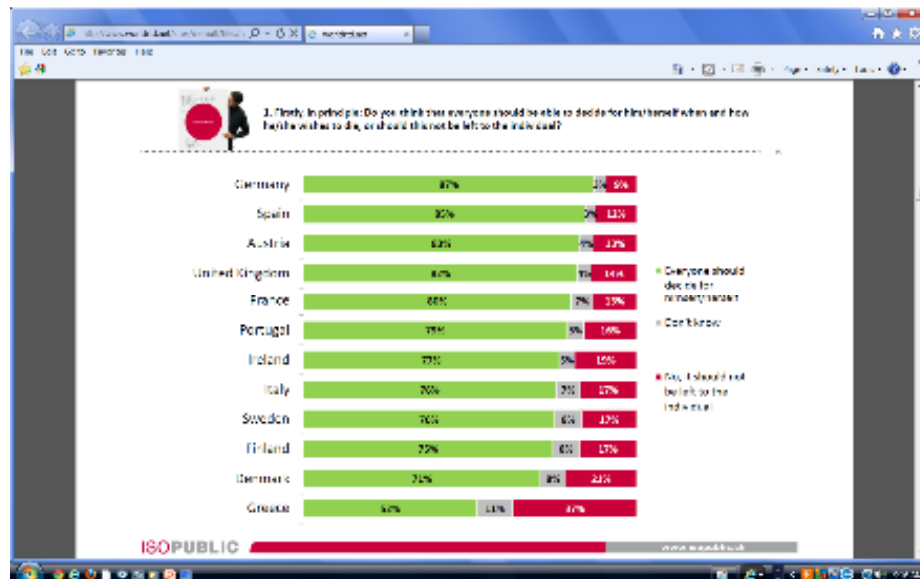
Of related interest:

- U.K. (England) | BBC News – 1 December 2012 – '**Care home regulation criticised by Norman Lamb.**' Regulation of the care sector is not fit for purpose, care minister Norman Lamb has said as he unveiled proposals on English care homes for consultation. <http://www.bbc.co.uk/news/health-20564151>
- U.K. | Help the Hospices – 23 November 2012 – '**End of life care and dementia raised in parliament.**' <http://www.helpthehospices.org.uk/our-services/running-your-hospice/policy/public-affairs/hospice-care-in-parliament/end-of-life-care-and-dementia-raised-in-parliament/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) – 27 November 2012 – **'Why the Kirk [Church of Scotland] opposes an assisted suicide law.'** Grey areas and muddy waters – those are the places where the vulnerable can get lost. And there could be no muddier water to be found than when you begin to explore the issue of assisted suicide. Although the Church of Scotland continues to oppose the legislation to allow assisted suicide, we do not do so lightly, nor do we come from a place of absolutes or black and whites. We come to this decision from a place of deep concern for others and a reverence for human flourishing. We come from an understanding of humanity as something to be found in community, not in autonomy – that truly no one is an island, and our actions impact one another, sometimes in profound ways that go far beyond the "individual" decision we make. <http://www.scotsman.com/news/sally-foster-fulton-why-the-kirk-opposes-an-assisted-suicide-law-1-2660681>
- SWITZERLAND | ISO Public – Accessed 28 November 2012 – **'Assisted suicide in the view of Europeans.'** Report: <http://www.worldtrd.net/sites/default/files/newsfiles/Isopublic%20Engels.pdf>



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

[End-of-life care in Australia](#)

Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis

BMC HEALTH SERVICES RESEARCH | Published online – 23 November 2012 – Most palliative care services have had little jurisdictional or local planning. With few exceptions, this 'organic' process has been built around community interests and goodwill as well as the availability of existing hospital stock rather than sound principals of health service planning. Population-based service planning may require further affirmative action to overcome some of the geographical difficulties highlighted by this current study. Better use of new models of care with emerging technologies such as video-conferencing for clinical consultations and family conferences may relieve some burden related to poor proximity to services. This becomes an overwhelming imperative for areas where long distances need to be travelled by caregivers, families and friends in metropolitan peri-urban and rural areas when inpatient services are dislocated from that person's own environment. <http://www.biomedcentral.com/content/pdf/1472-6963-12-424.pdf>

A qualitative analysis of the elements used by palliative care clinicians when formulating a survival estimate

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 30 November 2012 – For patients with advanced and/or incurable disease, clinicians are often called upon to formulate and communicate an estimate of likely survival duration. The objective of this study was to gain a deeper appreciation of this process by identifying and exploring the specific elements that may inform and/or impact a clinician's estimate of survival (CES). For any given patient, several elements have the potential to inform and/or impact the process of CES formulation. Study participants were aware of objective clinical factors known to correlate with actual survival duration and likely integrate this information when formulating a CES. Formulation occurs within a larger context comprised of a number of elements that may influence individual estimates. These elements exist against a background of awareness of the overall likelihood of CES inaccuracy. Clinicians are encouraged to develop a personalised and standardised approach to CES formulation whereby an awareness of the menu of potentially impacting elements is consciously integrated into an individual process. <http://spcare.bmj.com/content/early/2012/11/30/bmjspcare-2012-000320.abstract>

The lived experience of physicians dealing with patient death

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 30 November 2012 – This article presents five essential themes that provide a concise description of the lived experience of patient death for these physicians. These themes indicate that physicians can experience very strong and lasting emotional reactions to some patient deaths, and also that patient death can elicit intense experiences related to professional responsibility and competence. A key finding is the description of a complex process of managing the balance between personal and professional reactions in the face of patient death. The implication is that difficulties negotiating this balance may lead to unintended lapses in compassion and suboptimal outcomes in patient care. <http://spcare.bmj.com/content/early/2012/11/30/bmjspcare-2012-000326.abstract>

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.

Spiritual issues in clinical practice

Incorporating theology into medical education

CANADIAN MEDICAL ASSOCIATION JOURNAL | Published online – 28 November 2012 – It's a simple proposition: All Canadian physicians should receive mandatory training in the provision of "spiritual health care." There are those, such as Dr. Harold G. Koenig, professor of psychiatry and behavioral sciences and associate professor of medicine at the Duke University Medical Center in North Carolina, who hold unequivocal positions on the issue. "All medical schools in Canada should include a dedicated, required course on spirituality and medicine to expose students to the research on religion, spirituality and health, and how this affects medical outcomes; the rationale behind integrating spirituality into patient care; how to take a spiritual history and address spiritual needs; when to refer patients to chaplains and the limitations and boundaries involved in physicians addressing spiritual issues," Koenig writes. "Currently, the only physicians who are assessing and addressing spiritual issues in clinical practice are devoutly religious physicians. Thus, addressing spiritual issues is physician-centered. This is the opposite of the way it should be. Health care should be patient-centered, not doctor-centered. The reason why spiritual issues should be assessed and addressed is because of their importance to patients, effects on medical decisions, and impact on health outcomes." http://www.cmaj.ca/site/earlyreleases/28nov12_incorporating-theology-into-medical-education.xhtml

Of related interest:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Published online – 27 November 2012 – '**Zen meets medicine.**' http://www.cmaj.ca/site/earlyreleases/27nov12_zen-meets-medicine.xhtml
- *PALLIATIVE & SUPPORTIVE CARE* | Published online – 27 November 2012 – '**The impact of patient quality of life and spirituality upon caregiver depression for those with advanced cancer.**' <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8764691&fulltextType=RA&fileId=S1478951512000570>

Palliative medicine and geriatric emergency care: Challenges, opportunities, and basic principles

CLINICS IN GERIATRIC MEDICINE, 2013;29(1):1-29. Patients with serious or life-threatening illness are likely to find themselves in an emergency department at some point along their trajectory of illness, and they should expect to receive high-quality palliative care in that setting. Recently, emergency medicine has increasingly taken a central role in the early implementation of palliative care. This article presents an overview of palliative care in the emergency department and describes commonly encountered palliative emergencies, strategies for acute symptom management, communication strategies, and issues related to optimal use of hospice service in the emergency department. [http://www.geriatric.theclinics.com/article/S0749-0690\(12\)00086-9/abstract](http://www.geriatric.theclinics.com/article/S0749-0690(12)00086-9/abstract)

Instruments used to measure the effectiveness of palliative care education initiatives at the undergraduate level: A critical literature review

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 30 November 2012 – The goal of the present review is to ascertain what tools exist to measure the effectiveness of undergraduate palliative care education initiatives. Overall inconsistencies in the amount of validation information provided and a narrow focus on aspects of palliative care competence was apparent. No universally applicable validated questionnaire to assess the effectiveness of undergraduate palliative care education could be identified. <http://spcare.bmj.com/content/early/2012/11/30/bmjspcare-2012-000306.abstract>

End-of-life care in adults with congenital heart disease: Now is the time to act

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Published online – 28 November 2012 – This review focuses on the changing picture of adult CHD [congenital heart disease] with more complex patients surviving, the challenges of balancing life-prolonging intervention, the barriers to discussing the end-of-life (EOL) issues and draws on the experience of other specialities in managing young patients. <http://www.ncbi.nlm.nih.gov/pubmed/23196380>

Ethical palliative family nursing care: A new concept of caring for patients and families

HEALTHCARE LAW ETHICS & REGULATION, 2012;14(4):115-121. Nursing has a duty to educate, communicate, and resource patients and families during the period in which the solution to an ethical dilemma is predetermined by evidence-based practice. There is a gap in the quality of care provided or the interpretation of the quality of care being provided during difficult ethical situations requiring a systematic change to increase patient and family comfort and satisfaction. http://journals.lww.com/jonalaw/Abstract/2012/10000/Ethical_Palliative_Family_Nursing_Care_A_New.4.aspx

Is work stress in palliative care nurses a cause for concern? A literature review

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2012;18(11):561-567. Palliative care nurses are at risk of work stress because their role involves exposure to frequent deaths and family grieving. Little is known about their degree of stress or whether they suffer stress or burnout more than nurses in other disciplines. Sixteen papers were included in the review. Although work demands were a common cause of stress in the studies reported, there was no strong evidence that palliative care or hospice nurses experienced higher levels of stress than nurses in other disciplines. Common causes of stress were the work environment, role conflict, and issues with patients and their families. Constructive coping styles appeared to help nurses to manage stress. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=95407;article=IJPN_18_11_561_567

Pediatric palliative care

Moving toward quality palliative cancer care: Parent and clinician perspectives on gaps between what matters and what is accessible

JOURNAL OF CLINICAL ONCOLOGY | Published online – 26 November 2012 – The National Consensus Project (NCP) published a set of standards for quality palliative care delivery. A key step before applying these guidelines to pediatric oncology is to evaluate how much families and clinicians value these standards. The authors aimed to determine which elements of palliative care are considered important according to bereaved parents and pediatric oncology clinicians, and to determine accessibility of these elements. [Study participants] highly value a majority of palliative care elements described in the NCP framework. Children with advanced cancer may not be receiving key elements of palliative care despite parents and clinicians recognizing them as important. Evaluation of barriers to provision of quality palliative care and strategies for overcoming them are critical. <http://jco.ascopubs.org/content/early/2012/11/26/JCO.2012.44.8936.abstract>

Of related interest:

- 2 MINUTE MEDICINE | Published online – Accessed 2 December 2012 – '**Pediatric patients not receiving quality palliative care despite agreement between parents and caregivers on valued elements of care.**' <http://www.2minutemedicine.com/pediatric-patients-not-receiving-quality-palliative-care-despite-agreement-between-parents-and-caregivers-on-valued-elements-of-care/>
- *DEATH STUDIES* | Published online – 28 November 2012 – '**Exploring children's understanding of death...**' <http://www.tandfonline.com/doi/full/10.1080/07481187.2011.623216>

Cont.

- *PEDIATRIC* | Published online – 26 November 2012 – '**Supporting the family after the death of a child.**' <http://pediatrics.aappublications.org/content/early/2012/11/21/peds.2012-2772.abstract>

Opportunity lost: End-of-life discussions in cancer patients who die in the hospital

JOURNAL OF HOSPITAL MEDICINE | Published online – 20 November 2012 – End-of-life discussions are associated with decreased use of life-sustaining treatments in patients dying of cancer in the outpatient setting, but little is known about discussions that take place during terminal hospitalizations. The majority of patients with advanced cancer [i.e., study participants] are considered to have decisional capacity at the time of their terminal hospitalization. Many lose decisional capacity before having an end-of-life discussion and have surrogate decision-makers participate in these discussions. These patients received more aggressive ... treatments prior to death and represent a missed opportunity to improve end-of-life care. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.1989/abstract>

Informed decision making in advance care planning: Concordance of patient self-reported diagnosis with physician diagnosis

SUPPORTIVE CARE IN CANCER | Published online – 23 November 2012 – The majority of patients with advanced cancer [i.e., study participants] correctly identified their cancer diagnosis. However, almost 40% were not in full agreement with their physicians regarding diagnosis, a situation that has bearing on efforts to engage in shared decision making and advance care planning. <http://link.springer.com/article/10.1007/s00520-012-1654-x>

Of related interest:

- *BMC PALLIATIVE CARE* | Published online – 27 November 2012 – '**Older patients' attitudes towards and experiences of patient-physician end-of-life communication: A secondary analysis of interviews...**' <http://www.biomedcentral.com/content/pdf/1472-684X-11-24.pdf>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 29 November 2012 – '**Advance care planning beyond advance directives: Perspectives from patients and surrogates.**' [http://www.jpsmjournal.com/article/S0885-3924\(12\)00504-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00504-0/abstract)

Managing pain in advanced cancer: A survey of U.K. general practitioners and community nurses

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 29 November 2012 – Respondents [to a postal survey] reported receiving training in most areas of palliative care throughout their careers, with the exceptions of syringe driver use and bereavement care. High levels of knowledge concerning pain management and syringe driver use were found, with no significant differences in the overall knowledge between the professions. Some important gaps were identified for future educational focus. Regression analyses did not identify characteristics that explained the variation in knowledge scores. Both groups had a high level of knowledge concerning key issues in pain management and syringe driver use that should equip them well for their central role in palliative care. Recommendations for the focus of future education sessions are made. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00496-4/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00496-4/abstract)

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 29 November 2012 – '**Survey of Italian general practitioners: Knowledge, opinions, and activities of palliative care.**' [http://www.jpsmjournal.com/article/S0885-3924\(12\)00503-9/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00503-9/abstract)

Hospice day care

The Snog & Grog Club: Social personhood in hospice care

QUALITY HEALTH RESEARCH | Published online – 27 November 2012 – The popularity of British hospice day care signals the expanding boundaries of palliative care beyond end-stage illness. The author examines the ways hospice philosophy was interpreted and implemented in an outpatient day therapy setting... Findings suggest that hospice day care staff members used several strategies to help patients cope and retain a sense of personhood while facing numerous emotional and physical challenges associated with life-threatening illness. Health professionals in the U.S. will need to prepare for patients accessing hospice and palliative care services earlier in the illness trajectory to take advantage of these opportunities for patient support and advocacy. <http://qhr.sagepub.com/content/early/2012/11/27/1049732312467707.abstract>

- *HEALTH & PLACE* | Published online – 26 November 2012 – **"I am closer to this place' – Space, place and notions of..."** <http://www.sciencedirect.com/science/article/pii/S1353829212001931>

From hope to despair, and back: Being the wife of a patient in a persistent vegetative state

QUALITY HEALTH RESEARCH | Published online – 27 November 2012 – In this study the authors examined the meaning of being the wife of a vegetative patient over time. The research was based on semi-structured interviews with 12 wives of husbands who were diagnosed with persistent vegetative state between 1 year 2 months and 10 years prior to the interview. They found that there were two contradicting forces common to all of the wives across time. First, there was a process of finding significance in the situation based on acceptance of the husband's condition and focusing on positive emotions and values such as love, commitment, and loyalty. Second, the wives described an increase in negative emotions such as sadness, pain, loneliness, loss, and grief. These findings are discussed in the context of research and theoretical literature about coping processes and the meaning of caring for patients in a persistent vegetative state. <http://qhr.sagepub.com/content/early/2012/11/22/1049732312467537.abstract>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Editorial – 28 November 2012 – **'fMRI for vegetative and minimally conscious states.'** The BBC's Panorama programme 'The Mind Reader: Unlocking My Voice'¹ ... provided important insights into the devastating experience of patients who live in vegetative or minimally conscious states and the families who support them. It also provided useful information on the use of functional magnetic resonance imaging (fMRI) to explore evidence of localised brain activity that might indicate underlying awareness. However, the programme failed to distinguish clearly between the two states and gave the impression that 20% of patients in a vegetative state show cognitive responses on fMRI. This claim needs to be clarified and put into perspective. <http://www.bmj.com/content/345/bmj.e8045>

1. 'The Mind Reader: Unlocking My Voice,' Panorama, BBC, 13 November 2012. [Noted in Media Watch, 19 November 2012.] <http://www.bbc.co.uk/programmes/b01ny377>

Evidence-based comfort care for neonates towards the end of life

SEMINARS IN FETAL & NEONATAL MEDICINE | Published online – 22 November 2012 – The provision of care to the newborn or young infant at the end of life is primarily motivated by concern and compassion. When examining the evidence base for most interventions, it is lacking – but this is not unique to this aspect of neonatal care. Nevertheless, a redirection of care from cure-oriented and life-extending measures to comfort and limitations of life-sustaining technologic interventions requires the neonatologist to apply practical knowledge skillfully and with prudence. Clinicians can acknowledge that patient needs require managing their end-of-life symptoms now; neither these patients nor their families should have to wait for research to catch up to their current needs. <http://www.sciencedirect.com/science/article/pii/S1744165X1200131X>

Cont.

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Published online – 26 November 2012 – '**General Medical Council guidance on neonatal palliative care.**' <http://www.bmj.com/content/345/bmj.e8000>
- *JOURNAL OF OBSTETRIC, GYNECOLOGIC & NEONATAL NURSING* | Published online – 26 November 2012 – '**Clinician confidence and comfort in providing perinatal palliative care.**' <http://onlinelibrary.wiley.com/doi/10.1111/j.1552-6909.2012.01432.x/abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *LAW & CONTEMPORARY PROBLEMS*, 2012;75(4):53-75. '**Mistakes about intention in the law of bioethics.**' Much of law and ethics at the end of life turns on whether there is a moral and legal distinction between killing and letting die. That distinction ... relies on a difference between intention (what one purposely aims to bring about in his actions) and foresight (what one merely believes to be likely or even substantially certain). On this distinction rests the plausibility of the legal prohibition against physician-assisted suicide and many other important moral and legal prohibitions in bioethics, the ethics of warfare, and much else. <http://scholarship.law.duke.edu/lcp/vol75/iss4/4/>
- *REVIEW OF EUROPEAN STUDIES*, 2012;4(5). '**Ethics, the illegality of physician assisted suicide in the U.S., and the role and ordeal of Dr. Jack Kevorkian before his death.**' In this paper, various ethical, moral, and legal arguments, evoked by ethicists, philosophers and legal experts are presented. <http://www.ccsenet.org/journal/index.php/res/article/view/22454>

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>

Worth Repeating

Inconsequential conversation

Being honest about death...

IRISH HEALTH | Online commentary – 9 November 2001 – One question stands apart from the general mix of dialogue that occurs between people and their family doctors. It is a simple direct question that is fraught with overtones. It creates a special moment that some doctors quietly dread. The exact words may vary from person to person but the essence of the question is simple: 'Doctor am I dying?' I remember very well my first experience at attempting to answer this deceptively simple question. It happened twenty-one years ago when I visited a terminally ill woman in her family home. I had completed my postgraduate training in general practice and was now fully engaged in the busy life of an urban GP. The woman was single, in her late sixties and lived with her widowed sister. Her name was Lilly. <http://www.irishhealth.com/article.html?id=3190>

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