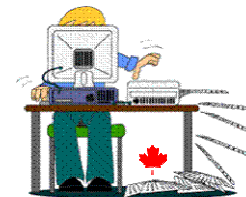


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

End-of-life and home care: Scroll down to [International](#) and 'Dying wish: Terminally ill patients more likely to die in own bed not hospital if they get care at home' (p.7), in the U.K.'s *Daily Mirror*.

Canada

Better home support for dying patients in Vancouver would improve hospital wait times

BRITISH COLUMBIA | *Vancouver Observer* – 13 November 2012 – The Canadian Centre for Policy Alternatives [CCPA] has been following the [province's] "steep decline in home and community care services" since 2001 and their numbers indicate that home and community care services have declined by 14% in the past decade. [A 2012 CCPA report¹] ... explains how "a decade of underfunding and restructuring has led to a home and community care system that is fragmented, confusing to navigate, and unable to meet seniors' needs." These studies are aimed to bring clarity to what had become "a numbers game, with the provincial government claiming it had increased the availability of services despite evidence of a growing crisis in access to care in communities around the province, particularly as a result of the closure of residential care beds." <http://www.vancouverobserver.com/blogs/ethicalhustle/better-home-support-dying-patients-vancouver-would-improve-hospital-wait-times>

1. 'Caring for BC's Aging Population,' Canadian Centre for Policy Alternatives, Ottawa, July 2012. <http://www.policyalternatives.ca/sites/default/files/uploads/publications/BC%20Office/2012/07/CCPABC-Caring-BC-Aging-Pop.pdf>



What can medical students learn from art?

NOVA SCOTIA | CBC News – 12 November 2012 – The late Robert Pope, Dalhousie University Medical School's first artist in residence, captured his journey with cancer on canvas. His work was displayed for medical students so that they could learn from what he experienced. Robert's work is now on permanent, public exhibition in Halifax. <http://www.cbc.ca/news/health/story/2012/11/09/promo-art-medical-school.html>

Footnote: I had the good fortune to work with The Robert Pope Foundation in organizing a national tour of Canada, visiting 50+ cities during the spring and fall of the years 1997-2001. With a parallel education program, Robert's work helped to expose health professionals (and also the general public) to a unique perspective on the illness experience. The artist died in 1992, at the age of 36. **BRA**

Mortality ratios and palliative care coding

Like 'a Lance Armstrong performance,' Canadian hospitals' mortality rates may be too good to be true: Study

THE NATIONAL POST | Online report – 13 November 2012 – It was a rare bit of good news about Canada's health-care system: In the few short years since a federal agency began publishing hospital death rates, the mortality numbers had decreased significantly. A new study, however, concludes that at least some of that improvement was achieved not by better caring for patients, but by manipulating internal statistics.¹ The research documented a "dramatic" rise in the number of patients coded by hospitals as palliative – and therefore removed from the publicly released mortality statistics – suggesting an attempt to game the system and artificially shrink the facilities' death rates. <http://news.nationalpost.com/2012/11/13/canadian-hospitals-may-be-manipulating-death-rates-new-study-suggests/>

1. 'Trends in Canadian hospital standardised mortality ratios and palliative care coding 2004-2010...' *BMJ Open*, posted 5 November 2012. <http://bmjopen.bmj.com/content/2/6/e001729.full.pdf+html>

Noted in Media Watch, 20 June 2011:

- *HEALTH SERVICE JOURNAL* (U.K.) | Published online – 14 June 2011 – '**Patients 'being coded as palliative to cut death rates,' inquiry told.**' <http://www.hsj.co.uk/home/patients-being-coded-as-palliative-to-cut-death-rates-inquiry-told/5031106.article>

Noted in Media Watch, 8 November 2010:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 1 November 2010 – '**Hospital mortality rates [in the U.S.]: How is palliative...**' [http://www.jpmsjournal.com/article/S0885-3924\(10\)00654-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00654-8/abstract)

Vegetative patient Scott Routley says 'I'm not in pain'

ONTARIO | BBC News (U.K.) – 12 November 2012 – A Canadian man who was believed to have been in a vegetative state for more than a decade, has been able to tell scientists that he is not in any pain. It's the first time an uncommunicative, severely brain-injured patient has been able to give answers clinically relevant to their care. Scott Routley, 39, was asked questions while having his brain activity scanned in an fMRI machine. His doctor says the discovery means medical textbooks will need rewriting. Vegetative patients emerge from a coma into a condition where they have periods awake, with their eyes open, but have no perception of themselves or the outside world. Mr. Routley suffered a severe brain injury in a car accident 12 years ago. None of his physical assessments since then have shown any sign of awareness, or ability to communicate. But the British neuroscientist Prof. Adrian Owen – who led the team at the Brain and Mind Institute, University of Western Ontario – said Mr. Routley was clearly not vegetative. <http://www.bbc.co.uk/news/health-20268044>

N.B. BBC interview with Adrian Owen broadcast 13 November 2012: <http://www.bbc.co.uk/news/health-20301107>. The BBC TV Panorama documentary, 'The mind reader: Unlocking my voice,' aired later the same day. Never before filmed, the program spent more than a year with a group of vegetative patients in Britain and Canada: <http://www.bbc.co.uk/programmes/b01ny377>.

Trapped in a motionless body? Scientific advances raise new questions about the 'vegetative' state

THE NATIONAL POST | Online report – 17 November 2012 – [Advances in] science raises numerous clinical and ethical issues, including the question of whether awareness of the world outside makes it more imperative to keep vegetative patients alive – or turns their severe disability into a "living hell." The research even opens the door to asking patients themselves whether they want life sustaining treatment to continue. <http://news.nationalpost.com/2012/11/17/trapped-in-a-motionless-body-scientific-advances-raise-new-questions-about-the-vegetative-state/>

U.S.A.

Assisted living vs. hospice: Who's in charge?

THE NEW YORK TIMES | Online report – 16 November 2012 – Once, older adults moved out of assisted living when they developed life-threatening illnesses, going mostly to nursing homes with round-the-clock care. But now, assisted living facilities usually try to help residents remain in their apartments, even when they're seriously ill and eligible for end-of-life hospice care. That's good news for seniors who want to die at home; about one-third of assisted living residents now do so, according to Maribeth Bersani, senior vice president of public policy at the Assisted Living Federation of America. But arranging for hospice care in assisted living facilities presents challenges. A handful of states – Idaho, Mississippi, Montana, and North Dakota – won't allow hospice services to be provided at assisted living centers, deeming the needs of end-of-life residents too demanding for these facilities. South Carolina requires a waiver for hospice services in assisted living. Other states, including Alaska, Arkansas, Florida, Rhode Island, West Virginia and Vermont, will allow existing residents to receive hospice services but won't accept new residents who require end-of-life care. <http://newoldage.blogs.nytimes.com/2012/11/16/assisted-living-vs-hospice-whos-in-charge/>

Of related interest:

- MASSACHUSETTS | *The Boston Globe* – 19 November 2012 – '**Hospices trying to sell the public on their care.**' Hospices across the country are trying to rebrand and reposition themselves to reach patients earlier and erase the idea that turning to hospice is akin to "giving up." <http://bostonglobe.com/business/2012/11/19/trying-sell-american-public-hospice-care/W5fsBZ3Mk6hHLyJn3xcQL/story.html>
- *THE ATLANTIC* | Online article – 15 November 2012 – '**End-of-life care should be universally provided and need-based.**' Dr. Ezekiel Emanuel, oncologist and chair of the Department of Bioethics at the National Institutes of Health ... has long been a champion of end-of-life care. He speaks with Corby Kummer at *The Atlantic's* Washington Ideas Forum, where he made succinct points about strategies for systematic improvements in our approach to caring for those nearest to death. <http://www.theatlantic.com/health/archive/2012/11/1/end-of-life-care-should-be-universally-provided-and-need-based/265326/>
- *SCIENCE DAILY* | Online article – 14 November 2012 – '**Evolving roles of hospice and palliative care.**' <http://www.sciencedaily.com/releases/2012/11/121114161617.htm>



Medicaid personal-care programs are targets for fraud, investigators say

THE WASHINGTON POST | Online report – 15 November 2012 – Lax requirements for both caregivers and patients, along with poor state and federal oversight, have made the rapidly growing Medicaid personal-care programs an increasingly lucrative target for fraud, according to a federal report.¹ The report, by the Office of the Inspector General [OIG] of the Health & Human Services Department, brings together six years of OIG investigations and 23 reports. It describes programs hindered by poor claims documentation, insufficient monitoring of claims data for fraud and waste, and a crazy-quilt of requirements for care workers in different states. In particular, it faults the federal Centers for Medicare & Medicaid Services for inadequate oversight of the programs, whose costs are shared by states and the federal government, as is the norm for Medicaid. http://www.washingtonpost.com/national/health-science/medicaid-personal-care-programs-target-for-fraud-say-investigators/2012/11/14/9776aba4-2e99-11e2-9ac2-1c61452669c3_story.html

1. 'Personal Care Services: Trends, Vulnerabilities, and Recommendations for Improvement,' Office of the Inspector General of the Health & Human Services Department, Department of Health & Human Services, November 2012. <https://oig.hhs.gov/reports-and-publications/portfolio/portfolio-12-12-01.pdf>

Planning for the inevitable: Taking time for end-of-life decisions

ALJAZEERA | Online article – 13 November 2012 – Americans are embedded in a death-defying culture. But in reality, death is inevitable. Hurricane Sandy hitting the Northeastern U.S. claimed the lives of 110 people unexpectedly and within a very short time. About 600,000 people die of heart disease and 570,000 people die of cancer in the U.S. every year. [These people] ... are the family breadwinners, parents, caregivers, children, community leaders, schoolteachers and activists. They are young, old, ill, well – they are you and me. Whether it comes about suddenly without warning as in the recent hurricane or after a chronic, progressive illness, every day, families are struck by the loss of a loved one and as a result, their

lives change directions. Yet, while we may prepare for financial security for our family, we often fail to prepare for medical treatment choices – leaving our loved ones to make decisions that they may be ill-equipped to make. <http://www.aljazeera.com/indepth/opinion/2012/11/2012111382019297736.html>

[Specialist Publications](#)

Of related interest:

'Preventing family conflict at the end of life' (p.12), in *The Residents' Journal*.

Hospice teams support expectant parents who receive the worst news

OHIO | *The Columbus Dispatch* – 13 November 2012 – As genetic testing has developed to alert expectant parents to serious fetal conditions, health-care systems across the country have developed teams – sometimes referred to as perinatal-hospice or palliative-care workers – to help families plan for unhappy endings. Such care has experienced remarkable growth both in and outside the U.S. Ohio residents involuntarily lost 839 fetuses in 2010 that were an estimated 20 weeks of gestation or over, including stillbirths, according to Ohio Health Department statistics. <http://www.dispatch.com/content/stories/local/2012/11/13/preparing-to-say-goodbye.html>

Hospice threatened by Medicare audit

CALIFORNIA | *U-T San Diego* – 12 November 2012 – San Diego Hospice, which handles end-of-life care for 4,000 patients a year, temporarily stopped accepting new patients over the weekend as it copes with financial problems brought to light by a federal Medicare audit. The temporary suspension ... is but one piece of a larger set of problems at San Diego County's largest hospice program. Those issues could force San Diego Hospice to return millions of dollars to Medicare, Chief Executive Kathleen Pacurar said. Pacurar said she believes there will be enough financial pain to require layoffs of up to 200 of the hospice's 870 employees. Those cuts, she said, will not be made to the bedside workers, who care for dying patients in their homes or in the hospice's San Diego treatment facility... The news comes as hospice care nationwide is under increasing scrutiny ... for its growing costs. According to the Office of Inspector General, hospice payments increase 56% from 2005 to 2009. A 2011 Bloomberg News report pegged the annual value of the hospice market at \$14 billion.¹ <http://www.utsandiego.com/news/2012/nov/12/hospice-threatened-by-medicare-audit/>

1. 'U.S. hospice care revealed as \$14billion market,' Bloomberg News, 6 December 2011 (noted in Media Watch, 12 December 2011). <http://www.bloomberg.com/news/2011-12-06/hospice-care-revealed-as-14-billion-u-s-market.html>

[Media Watch posted on Palliative Care Network-e Website](#)

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

Early end-of-life talks tied to less aggressive care

MASSACHUSETTS | Reuters – 12 November 2012 – Terminally-ill cancer patients are less likely to get aggressive end-of-life treatment, such as chemotherapy in the last two weeks of life, when they talk with their doctors early on about how they want to die, according to a new study.¹ Treatment aimed at keeping those patients alive at the end is often expensive and may not improve patients' quality of life or comfort. Such therapies usually involve more time in the hospital rather than at home or in hospice care. "Aggressive care at the end of life for individual patients isn't necessarily bad, it's just that most patients who recognize they're dying don't want to receive that kind of care," said Dr. Jennifer Mack, the study's lead author from the Dana-Farber Cancer Institute in Boston. Mack and her colleagues ... found that most patients – 88% – had end-of-life discussions, but more than one-third of those took place less than a month before the patient died, when their health was likely already deteriorating. Close to two-thirds of the talks happened while patients were in the hospital. Almost half of study participants received aggressive, life-prolonging care, Mack's team reported... <http://www.reuters.com/article/2012/11/12/us-cancer-aggressive-idUSBRE8AB17Q20121112>

1. 'Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study,' *Journal of Clinical Oncology*, posted 13 November 2012. <http://jco.ascopubs.org/content/early/2012/11/13/JCO.2012.43.6055.full.pdf+html>

Noted in Media Watch, 5 November 2012:

- REUTERS | Online report – 29 October 2012 – '**Cancer doctors often refer their patients to palliative care very late in the course of disease, according to a new survey from Canada.**'¹ <http://www.reuters.com/article/2012/10/29/us-cancer-hospice-care-idUSBRE89S17020121029>

1. 'Referral practices of oncologists to specialized palliative care,' *Journal of Clinical Oncology*, posted 29 October 2012. <http://jco.ascopubs.org/content/early/2012/10/29/JCO.2012.44.0248.abstract>

Noted in Media Watch, 29 October 2012:

- MASSACHUSETTS | National Public Radio (Boston) – 25 October 2012 – '**Many terminal cancer patients mistakenly believe a cure is possible.**'¹ <http://www.npr.org/blogs/health/2012/10/25/163572138/many-terminal-cancer-patients-mistakenly-believe-a-cure-is-possible>

1. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. <http://www.nejm.org/doi/full/10.1056/NEJMoa1204410>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | Associated Press – 16 November 2012 – '**Board won't change assisted-suicide policy.**' The Montana Board of Medical Examiners rejected a request to strike its policy on physician-assisted suicide that opponents criticize as too permissive. The board earlier this year tried to provide some guidance to doctors on that issue, which remains unclear to many. The board's position was that it would consider, on an individual basis, any complaints filed against a doctor for providing "aid-in-dying." <http://www.ajc.com/ap/ap/legislative/medical-board-asked-to-review-assisted-suicide/nS8H7/>
- PUBLIC BROADCASTING SYSTEM | 'Frontline' – 13 November 2012 – '**In 'The Suicide Plan,' Frontline explores hidden world of assisted suicide.**' The documentary takes viewers inside the surprisingly coordinated underground world of assisted suicide in the U.S. told from the perspective of those choosing to end their lives, the activists who put themselves in legal jeopardy by helping others to die, and the law enforcement officials trying to stop the practice that remains illegal in every state except Washington and Oregon. <http://www.pbs.org/newshour/rundown/2012/11/the-suicide-plan-frontline-explores-organized-world-of-assisted-suicide.html>

International

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

People behind the controversial Liverpool Care Pathway (LCP) speak out in its defence

U.K. | *Liverpool Daily Post* – 15 November 2012 – The architects of the Liverpool Care Pathway (LCP) today broke their silence about the controversial model of care that has faced an onslaught of criticism in recent weeks. One national newspaper has even branded the end of life plan now adopted throughout the U.K. as being a "pathway to death." Worryingly, critics of the LCP said that hospitals are even being given financial rewards worth millions of pounds to put patients on the regime. Senior cancer doctor Prof. Mark Glaser accused National Health Service managers of using the pathway to clear beds and achieve targets. But today the people behind the care plan hit back. It has been reported the LCP involves the withdrawal of life-saving treatment with patients sedated and the majority denied nutrition and fluids by tube. But the *Post* was told that the LCP is not a 'one size fits all' prescription but tailored to each patient. And medics say the LCP ... does not recommend

continuous deep sedation but a review of medications and open discussions with relatives. If possible, patients may stop unnecessary treatments and interventions, shifting the focus of care to comfort and dignity. <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/>

Specialist Publications

Of related interest:

'Using end of life care pathways for the last hours or days of life' (p.8), in *British Medical Journal*.

'The misrepresentation of palliative care in the U.K.' (p.8), in *The Lancet*.

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/>
- U.S. | National Library of Medicine – 1 November 2012 – **'What is the Liverpool Care Pathway?'** <http://www.ncbi.nlm.nih.gov/pubmedhealth/behindtheheadlines/news/2012-11-01-what-is-the-liverpool-care-pathway/>

End-of-life care in New Zealand

Funding boost for hospices continued

NEW ZEALAND | *Oxy.co.nz* – 14 November 2012 – Associate Health Minister Jo Goodhew announced that the current Boost Hospice Care funding will be rolled over for a further two years. "The \$15 million per year funding will now continue to 2015 to help hospices cover a shortfall brought about by a challenging fundraising environment, increasing demand for services and rising costs," said Mrs. Goodhew. Introduced in 2009, the Boost Hospice Care funding gave hospices a badly needed additional \$60 million over the four years to June 2013 to help them expand care and services and meet financial challenges. Hospices are partly funded through District Health Boards, with additional funding sourced from community fundraising. The Boost Hospice Care funding increased the proportion of average hospice funding provided by the Government from 50% to 70%. <http://www.voxy.co.nz/health/funding-boost-hospices-continued/5/140501>

Dying wish: Terminally ill patients more likely to die in own bed not hospital if they get care at home

U.K. | *Daily Mirror* – 14 November 2012 – Terminally ill patients are four times more likely to die in their own bed if they get end-of-life care at home. Those who don't get home care are also more likely to need emergency hospital treatment, according to the research by the Nuffield Trust.¹ They studied 60,000 terminally ill patients, half of whom had care from the Marie Curie Nursing Service. Researchers found 8% of Marie Curie patients died in hospital compared with two fifths of those who did not receive the service. And only 12% of those who got the service were admitted to hospital as an emergency at the end of their lives, compared to over a third of patients who did not get home care. <http://www.mirror.co.uk/news/uk-news/marie-curie-nurses-help-terminally-1434473>

1. 'The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life,' Patterns of Care at the End-of-Life Project, Nuffield Trust, November 2012. <http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing>

Noted in Media Watch, 9 July 2012:

- U.K. (ENGLAND) | *The Telegraph* – 3 July 2012 – '**Patients dying in hospital in pain and lacking dignity: Survey.**' <http://www.telegraph.co.uk/health/healthnews/9372138/Patients-dying-in-hospital-in-pain-and-lacking-dignity-survey.html>

Do mothers grieve more deeply than fathers?

U.K. | *The Daily Telegraph* – 13 November 2012 – Both anecdotal and research-based evidence point to gender continuing to play a larger part in shaping the expression of grief – if not its depth – than many might imagine after decades of men and women taking on interchangeable roles at home and in the workplace. The American researcher Dr. Phyllis Silverman, an associate of the Harvard Medical School, has studied the continuing impact of what she terms "traditions of mourning," and how they are often conditioned by the societies in which they are acted out. "Men and women have similar feelings when someone close dies," she maintains. "However, what we do with those feelings, how we cope, seems to be in many ways different for men and women." She points in particular to the ongoing belief of many men that to appear "needy" is a sign of weakness. "In the past 20 years, there have been lots of changes in the roles men and women play in families, yet many men

still insist on appearing strong, able to manage on their own." Margaret Stroebe, Professor ... at Utrecht University [The Netherlands], has published research to demonstrate that in grief women tend towards a "loss-orientated approach" – where they focus on mourning – whereas men prefer what she terms a "restoration-orientated approach" – getting on with work and life. <http://www.telegraph.co.uk/women/womens-life/9675066/Do-mothers-grieve-more-deeply-than-fathers.html>

Specialist Publications

Of related interest:

'Holding parents so they can hold their children: Grief work with surviving spouses to support parentally bereaved children' (p.12), in *OMEGA – Journal of Death & Dying*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | ABC News – 16 November 2012 – '**Survey shows support for legalised euthanasia.**' A new poll shows a majority of Australians support making voluntary euthanasia legal for someone experiencing unrelievable and incurable suffering. <http://www.abc.net.au/news/2012-11-16/survey-shows-australian-support-for-legalised-euthanasia/4376524>

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

End-of-life care in England

The National End of Life Care Programme

BRITISH JOURNAL OF HEALTHCARE MANAGEMENT, 2012;18(11):568-574. In 2008 the Department of Health published a national end of life care strategy for England, the first of its kind in the world. The strategy acknowledged that despite examples of excellent care, many people do not die in their preferred setting or after being involved in planning their care. Despite surveys consistently indicating that most would prefer to die at home or in a community setting such as a hospice, in 2005, 58% of deaths took place in hospital. The strategy also acknowledged that many people experience unnecessary pain and other symptoms and referred to 'distressing reports of people not being treated with dignity and respect.' The low priority accorded end of life care (EoLC) by both the NHS [National Health Service] and social care, partly due to a societal reluctance to discuss death and dying, has led to wide variations in standards. http://www.bjhcm.co.uk/cgi-bin/go.pl/library/article.cgi?uid=95234;article=BJHCM_18_11_568_574

An exploration of the word 'palliative' in the 19th century: Searching the *British Medical Journal* archives for clues

BMJ SUPPORTIVE & PALLIATIVE CARE | Published online – 14 November 2012 – Palliative care went through a significant evolution in the 20th century, but the 19th century has been seen by some scholars as the real turning point toward the more modern concept of hospices and palliative care. Search results brought up a number of case reports, and the word was employed to describe medicines ('use of palliatives') as well as passive, non-active treatment approaches, probably best described as a watch-and-wait strategy. Of note is that the first recorded use of the word in the archives is by a surgeon. Some doctors associated the word palliative with there not being any prospect for cure and only for the relief of symptoms and greater comfort of the patient. There were, however, early reflections on whether palliative treatments may in some cases increase the length of patients' lives. <http://spcare.bmj.com/content/early/2012/11/14/bmjspcare-2012-000288.abstract>

Liverpool Care Pathway

Using end of life care pathways for the last hours or days of life

BRITISH MEDICAL JOURNAL | Online OpEd – 14 November 2012 – There is international consensus about the importance of achieving a "good death" that is comfortable, dignified, and person centred. But controversy persists about the benefits and hazards of using an integrated care pathway to support the care of people who are expected to die soon. National end of life care programmes, in the U.K. and internationally, endorse tools designed to improve standards of care for people dying in the community, care homes, and hospitals. Following more than a decade of development and implementation in many countries, the Liverpool Care Pathway is one of the most widely used of these tools. It has recently become a focus for wider societal, ethical, and professional debates about identification of patients who are dying and shared decision making at the end of life. <http://www.bmj.com/content/345/bmj.e7718>

- *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)

"I don't want to die like that ...": The impact of significant others' death quality on advance care planning

THE GERONTOLOGIST, 2012;52(6):770-781. Multivariate analyses [in this study] revealed "positive" role model effects; persons who witnessed significant others' deaths that occurred at home, were free of problems associated with end-of-life care, and where advance directives were used are more likely to make end-of-life preparations. Open-ended data showed that 19% cited others' deaths as the main trigger for their own planning, with most citing negative factors (pain, connection to machines, coma) that they hoped to avoid. Practitioners should encourage patients to use conversations about others' deaths as springboards for discussions about one's own end-of-life care, and to engage in advance care planning together with family. Implications for health care reform are highlighted. <http://gerontologist.oxfordjournals.org/content/52/6/770.abstract>

- *THE JOURNALS OF GERONTOLOGY* | Published online – 12 November 2012 – '**Persistent problems in end-of-life planning among young- and middle-aged American couples.**' <http://psychsocgerontology.oxfordjournals.org/content/early/2012/11/10/geronb.gbs103.abstract>
- *LEGAL STUDIES*, 2012;32(4):525-550. '**Asset or burden? Informed consent and the role of the family: Law and practice.**' <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-121X.2011.00223.x/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>

**Interdisciplinary education in palliative care:
A bold strategy, solution and political statement**

ILLNESS, CRISES & LOSS, 2012;20(4):375-386. Harsh experience reveals that preparing the interdisciplinary palliative care team members cannot be accomplished by sequestering students in single-discipline training. By combining different ways of knowing and being that are the underlying tenets of interdisciplinary education, we must – by design, curriculum, teaching strategies, and research – reflect the nature and practice of the interdisciplinary palliative care team. This kind of education is an imperative if we are going to meet our own goals to provide physical, emotional, and spiritual care to people at end-of-life. As educators, we must take to heart the responsibility to prepare students with the skills to apply their knowledge within the context of the palliative care setting, as practiced by the interdisciplinary team. This position is supported in the literature, is recommended by Health Canada, and is affirmed by experience in the field.

<http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,12;journal,1,72;linkingpublicationresults,1:103734,1>

Sustaining health care and social services

Families, dependencies, and the moral ground of Health Savings Accounts

JOURNAL OF MEDICINE & PHILOSOPHY | Published online – 11 November 2012 – Health Savings Accounts [HSA] have been marginalized in the West. In Singapore, however, they are foundational to the financing of health care. The author explores the recent scientific literature on the communal nature of human thriving and follows it with a phenomenological account of human dependency. He claims that in securing the material means to sustain life, the family is also involved in the creation of the life-world of the child. That means that the bare necessities of life met in families are not merely about sustaining bodily life but are also part of the meaning-making aspects of life. The family then should have recourse to the material means of life-and-death decisions, because it is in these life-and-death decisions that the families' life-world of values is to be deployed. <http://jmp.oxfordjournals.org/content/early/2012/11/10/jmp.jhs045.abstract>

Does health status affect perceptions of factors influencing dignity at the end of life?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 12 November 2012 – The percentage of [study] respondents who indicated the factors as having a (very) large influence on dignity at the end of life were not significantly different for the three health status groups, except for three physical items on symptoms, roles, and routines. Those items were significantly more influential on dignity for people with a poor health status. Gender, old age, having a partner, and having a belief or religion that is important to one's life were associated with an understanding of factors influential to dignity. Health status seems only to affect the perceptions of physical factors maintaining dignity at the end of life. This might suggest that the understanding of dignity will not substantially change as health status changes and may support starting advance care planning early. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00361-2/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00361-2/abstract)



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>

Palliative care: A long-term care perspective

LONG-TERM CARE MANAGEMENT | Published online – 14 November 2012 – Demographics demonstrate that the fastest growing segment of our society are those who are 85 years or older. While most older adults would acknowledge that given the choice they would prefer to die in their own home, many will die in long-term care facilities. The prediction is that by 2020, 40% or 2 out of 5 older adults will die in a nursing home. Numerous studies have demonstrated the failure and/or the inability of these facilities to meet the palliative and end-of-life needs of the residents they serve. Palliative care, which is often confused with hospice care, is a philosophy of care with a unique set of interventions intended to improve and enhance quality of life in order to provide a "good" death. The WHO defines palliative care as "an approach to care which improves quality of life of patients and families facing life-threatening illness, through prevention, assessment and treatment of pain and other physical, psychological, and spiritual problems." One of the fastest growing trends is hospital palliative care. According to data collected by the Center to Advance Palliative Care, the National Palliative Care Research Center, and the American Hospital Association, about 63% of hospitals now have palliative care teams. Less is known about palliative care in the nursing home environment. Many long-term care facilities are beginning to view palliative care as a subspecialty that needs to be included in their provision of care. Currently, federal regulations often emphasize, and reimburse for curative efforts rather than for end-of-life interventions. This has promoted a strong,

ingrained culture of aggressive medical treatment in the nursing home environment. In the future, the hope is that long-term care residents with a life expectancy of six months or less can navigate a seamless transition from palliative care strategies to hospice services. <http://long-term-care.advanceweb.com/Features/Articles/Palliative-Care-A-Long-Term-Care-Perspective.aspx>

The art of letting go: Referral to palliative care and its discontents

SOCIAL SCIENCE & MEDICINE | Published online – 15 November 2012 – Accompanying patients from active treatment toward specialist palliative care is a complex sphere of clinical practice that can be fraught with interpersonal and emotional challenges. While medical specialists are expected to break 'bad news' to their patients and ease their transitions to specialist palliative care if required, few have received formal training in such interpersonal complexities. Furthermore, there also often exists clinical ambiguity around whether to continue active treatment *vis-à-vis* refocusing on quality of life and palliation. In this paper the authors explore the experiences of twenty Australian medical specialists, focusing on issues such as: dilemmas around when and how to talk about dying and palliation; the art of referral and practices of representation; and, accounts of emotion and subjective influences on referral. The results illustrate how this transitional realm can be embedded in emotions, relationships and the allure of potentially life-prolonging intervention. <http://www.sciencedirect.com/science/article/pii/S0277953612007575?v=s5>

Neuro-oncology and palliative care: A challenging interface

NEURO-ONCOLOGY, 2012;14(Suppl 4):iv3-iv7. Increasingly, the value of formal palliative care consultation and management has been recognized in both cancer and non-cancer medicine. However, there is a paucity of data to definitively guide the provision of palliative care for neuro-oncology patients. This paper aims to review the existing evidence for and describe the interface between palliative care and neuro-oncology, with a particular focus on glioblastoma multiforme. http://neuro-oncology.oxfordjournals.org/content/14/suppl_4/iv3.extract

Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where we are and where we need to go?

NURSING OUTLOOK, 2012;60(6):370-375. This article reports efforts to determine knowledge gaps related to health disparities in psychosocial, cultural, and spiritual aspects of end-of-life care in which the authors draw upon recent literature from multiple databases. Although few data are available, studies show that minorities make little use of hospice, often because of lack of knowledge about hospice or palliative care, family-centered cultures, and preferences for more aggressive end-of-life care than hospice allows. [http://www.nursingoutlook.org/article/S0029-6554\(12\)00237-0/abstract](http://www.nursingoutlook.org/article/S0029-6554(12)00237-0/abstract)

Of related interest:

- *THE GERONTOLOGIST*, 2012;52(6):739-747. '**Cultural competence and providers' values in health care decision making.**' Although existing literature addresses providers' need to attend to patients' cultural values and beliefs ... less attention has been paid to how the corresponding values and beliefs of providers color the care they deliver and their assessments of older adults' decision making capacity. <http://gerontologist.oxfordjournals.org/content/52/6/739.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 12 November 2012 – '**Traditional healers' views of the required processes for a "good death" among Xhosa patients pre- and post-death.**' Care needs before death focused on relief of psychosocial suffering; the importance of the spoken word at the deathbed; and, the importance of a relationship and spiritual connection at the end of life. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00461-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00461-7/abstract)

Holding parents so they can hold their children: Grief work with surviving spouses to support parentally bereaved children

OMEGA – JOURNAL OF DEATH & DYING, 2012;66(1):1-16. A child's adjustment to the death of a parent is greatly influenced by the surviving parent's ability to attend to his or her own grief-related needs, to create and sustain a consistent and nurturing environment, and to encourage the child to express distressing or conflicting thoughts, feelings, and fantasies about the loss. Yet, the surviving parent's grief often compromises their ability to parent consistently and empathically. This article will illustrate how, by providing a holding environment for whole families, clinicians can help parents to facilitate children's grief reactions and, thus, mitigate long-term adverse mental health outcomes. Family Matters programs, designed and implemented in a community agency, use a holistic approach to family support and treatment in a milieu setting. Combining therapeutic work with surviving spouses and bereaved children supports children's grief while facilitating newly single parents as they adapt the structure of family life. When clinical work with families begins before the ill parent dies, the clinicians may build a relationship with the dying parent, prepare the child and surviving spouse for life after loss, and support continuity in family culture. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;journal,1,260;linkingpublicationresults,1:300329,1>

Preventing family conflict at the end of life

THE RESIDENTS' JOURNAL (of the *American Journal of Psychiatry*) | Published Online – Accessed 13 November 2012 – End-of-life care is a time in which to engage with patients and their families, anticipating situations with the potential for conflict can improve care. Awareness of different styles of communication and decision making, especially when different from those with which the physician is comfortable, builds trust with family members. Keeping the focus of end-of-life care on goals of the care, rather than spending time on how to deal with a "difficult" family member, helps the medical team and patient's support system collaborate toward a positive outcome. http://67.228.66.64/data/Journals/AJP/22169/April_2012_Residents%20Journal.pdf#page=3

Cont.

Of related interest:

- *MÉDECINE PALLIATIVE : SOINS DE SUPPORT - ACCOMPAGNEMENT – ÉTHIQUE* | Published online – 15 November 2012 – 'Quelles résonances entre patient et soignants, entre détresse et défenses ? Dialogue entre une psychologue et un médecin.' ('What resonances between patient and caregivers, between distress and defenses? Dialogue between a psychologist and a doctor.') <http://www.sciencedirect.com/science/article/pii/S1636652212000979>

Worth Repeating

Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people

SOCIOLOGY, 2012;44(5):908-924. This article explores how sexual orientation may impact on concerns about, and experiences of, end of life care and bereavement within same-sex relationships. The authors draw on exploratory data from four focus groups with lesbian and gay elders, which formed part of a larger project investigating a range of older people's concerns about end of life care. They set the findings in the context of debates about broader changes to family forms within late modernity, alongside social change and demographic shifts. Their focus on end of life care and bereavement sheds light on a series of relatively neglected issues associated with lesbian, gay and bisexual ageing and, more broadly, the topics of care and support within 'non-traditional' intimate relationships and personal networks. The authors point to the importance of further research into the lives of older lesbians and gay men facing issues of end of life care and bereavement. <http://soc.sagepub.com/content/44/5/908.short>



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Something Missed or Overlooked?

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

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