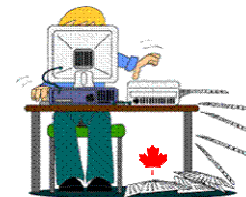


Media Watch...

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

Research: Scroll down to [Specialist Publications](#) and 'Advancing the science of hospice care: Coalition of Hospices Organized to Investigate Comparative Effectiveness' (p.10), in *Current Opinion in Supportive & Palliative Care*.

Canada

Canadian study that noted awareness in vegetative patients called flawed

CTV NEWS | Online report – 25 January 2013 – A team of researchers is questioning the findings of a highly publicized study that claimed bedside EEG [electroencephalography] testing showed evidence of conscious awareness in three patients diagnosed as being in a vegetative state. That study, published two years ago¹ ... was conducted by neuroscientist Adrian Owen ... and colleagues at Western University's Centre for Brain & Mind, in collaboration with Cambridge University in the U.K. and the University of Liege in Belgium. Patients in a vegetative state, usually caused by a brain injury, appear awake but cannot communicate and seem to have no conscious awareness. Owen's team used an EEG ... machine to look for awareness in 16 vegetative patients based on brain signals generated by two mental-imagery tasks they were asked to perform – making their right hand into a fist, followed by a separate request to wiggle their toes. EEG patterns picked up from separate parts of the brain in three of the 16 patients suggested they had understood the requests and performed the tasks. They repeatedly generated electrical brain activity that matched responses seen in healthy volunteers, the study said. But researchers at Weill Cornell Medical College in New York have challenged the interpretation by Owen's team that the brain-wave patterns indicate conscious awareness in these patients, saying the study was flawed.² <http://www.ctvnews.ca/health/canadian-study-that-noted-awareness-in-vegetative-patients-called-flawed-1.1129122>

1. 'Bedside detection of awareness in the vegetative state: A cohort study,' *The Lancet*, 2011;378(9809):2088-2094. [Noted in Media Watch 14 November 2011] [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61224-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext)
2. 'Reanalysis of "bedside detection of awareness in the vegetative state: a cohort study,"' *The Lancet*, 2013;381(9863):289-291. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)60125-7/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60125-7/fulltext)

Mediating conflicts

Stroke victim's wife fights physicians to keep him on artificial life support

ONTARIO | *The Toronto Star* – 24 January 2013 – As Dennis Daye lay unconscious in Sunnybrook Health Sciences Centre, his wife and physician sat in a hospital hearing room five floors above, locked in dispute over whether to keep him alive or let him die. A massive stroke last month brought the 65-year-old retired truck driver to Sunnybrook, where doctors removed a large section of his skull due to swelling – a trauma that stole much of his brain function and continues to place him in medical peril. Dr. Robert Fowler, one of Daye's physicians, testified before a Consent & Capacity Board panel. Daye's unknown wishes for life or death in these circumstances – and the kind of medical care that is now in his best interests – are now under dispute before the provincial board that mediates end-of-life conflicts between physicians and substitute decision-makers. On the one side of that debate are Sunnybrook physicians ... who wish to remove life-sustaining care and allow Daye to die peacefully. On the other, Daye's wife and substitute decision-maker, Pilar, who wants

her husband, a status Mohawk who attended Christian church services, to be treated with traditional, plant-based medicine. Daye is the latest in a string of patients whose medical fortunes have become a matter of vigorous contention at Sunnybrook. <http://www.thestar.com/news/gta/article/1319274--stroke-victim-s-wife-fights-physicians-to-keep-him-on-artificial-life-support>

Specialist Publications

'Finding common ground to achieve a "good death": Family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study' (p.9), in *BMC Family Practice*.

'Awareness of palliative care and end-of-life options among African Canadians in Nova Scotia' (p.11), in *Journal of Transcultural Nursing*.

U.S.A.

Is community care better than nursing homes? Survey says: It's hard to tell

SENIOR HOUSING NEWS | Online – 27 January 2013 – Home- and community-based services (HCBS), initially touted as a cost-saving method of delivering long-term care compared to institutional settings, may not actually be a significantly superior setting in which to receive care, suggests a report from the Agency for Healthcare Research & Quality (AHRQ). AHRQ reviewed several studies comparing different long-term care models and concluded there's not enough evidence to truly assess their relative effectiveness in relation to each other. It may be more accurate to simply consider HCBS as a preferred model among consumers, rather than one that provides better care at a lower cost, the report's authors say. "The weakness of the literature stands in sharp contrast to the importance of the topic," says the

AHRQ. "Many stakeholders want to know about the relative effectiveness of alternative modes of LTC [long term care]. As budgets tighten and as demographically driven demand increases, states and other entities are seeking more efficient ways to deliver LTC." <http://seniorhousingnews.com/2013/01/27/is-community-care-better-than-nursing-homes-survey-says-its-hard-to-tell/>

Specialist Publications

'Capturing activity, costs, and outcomes: The challenges to be overcome for successful economic evaluation in palliative care' (p.13), in *Progress in Palliative Care*.

Cont.

1. 'Long Term care for Older Older Adults: A Review of Home and Community Based Services Versus Institutional Care,' Agency for Healthcare Research & Quality, Comparative Effectiveness Review No. 81. November 2012. http://effectivehealthcare.ahrq.gov/ehc/products/369/1277/CER81_Long-Term-Care_FinalReport_20121023.pdf

Stealth medical futility: You can't handle the truth!

NATIONAL REVIEW | Online Commentary – 25 January 2013 – Futile care theory claims that doctors and hospital bioethics committees should be empowered to refuse wanted life-sustaining treatment based on their beliefs that the patient's life is not worth living or too expensive to maintain (or both). But this flies in the face of patient autonomy, supposedly a prime directive of bioethics theory. Over the years I have noticed that autonomy receives the most robust respect in mainstream bioethics when it leads to death, e.g., refusing unwanted treatment (which I support) and euthanasia (which I oppose). But it is impolitic to say autonomy is a one-way street, so futilitarians are always looking for ways to justify withholding treatment they don't think should be provided without getting their metaphorical hands caught in the cookie jars. Latest example, an article in the *Journal of Clinical Ethics*,¹ arguing that doctors could simply withhold information that patients or surrogates need to make an informed choice about life-extending treatment. <http://www.nationalreview.com/human-exceptionalism/338843/stealth-medical-futility-you-cant-handle-truth#>

1. 'A different approach to patients and loved ones who request futile treatments,' *Journal of Clinical Ethics*, 2012;23(4):291-298. [Noted in Media Watch, 21 January 2013] http://www.clinicalethics.com/single_article/tr0abia7r7A.html

Living and dying in prison

MAINE | *The Free Press* (Rockland) – 24 January 2013 – Steve, 59, is one of 14 trained hospice volunteers, inmates at ... Maine State Prison. He administers to other inmates who are sick and dying, if they request it. The right to die with some kind of dignity, even behind barbed wire, is recognized as an international human right. All of the inmates are carefully screened before being accepted into the prison hospice program. To be sure, they are in for serious crimes: arson, assault, murder, rape. Some will be in for a very long time. Some are nearing the end of long sentences. Some probably will never get out. Serving as hospice volunteers won't change any of that. It doesn't give them any special inmate privileges, except to go to the medical building to volunteer. It doesn't reduce their sentence by one single day. They know that. That's not why they do it. <http://freepressonline.com/main.asp?SectionID=52&SubSectionID=78&ArticleID=24126>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.15.



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>

Why doctors should provide spiritual care as well

WISCONSIN | WUWM News (Milwaukee) – 24 January 2013 – During the last two decades [Betty Ferrell] also been studying what terminal cancer patients need as they approach the end of their lives – as a researcher and professor at the City of Hope Medical Center in Los Angeles. She and her research colleagues there developed a quality of life model for these patients measuring four dimensions. While physical and increasingly psychological and social needs are being met by medical caretakers, Ferrell found one critical component lacking: spiritual care. Even as supportive treatment like palliative care is being incorporated more often into treatment plans for the seriously ill and dying, Ferrell finds a hesitation to discuss spiritual matters – even when faith is an important part of a patient's life. "Patients are sometimes reluctant to talk about their religious beliefs or spirituality, health care

providers are very nervous at talking with patients about religious beliefs or spirituality," she says. But that may come down to a misunderstanding about what spiritual care really is. Many people assume spirituality refers to religion, but it is more about what those patients value in their lives, what connections they need to have a "good life." http://www.wuwm.com/programs/lake_effect/lake_effect_segment.php?segmentid=10083

Specialist Publications

'Knowledge, attitude and practices regarding the role of spirituality in current medical practice amongst medical professionals in a tertiary care hospital' (p.10), in *Journal of Evolution of Medical & Dental Sciences*.

Louisiana will continue Medicaid hospice program

LOUISIANA | *The Advertiser* (Lafayette) – 22 January 2013 – Governor Bobby Jindal's administration [has] scrapped plans to shutter Louisiana's Medicaid hospice program, meaning the state will continue to provide end-of-life care to people on their death beds who can't afford private insurance. <http://www.theadvertiser.com/viewart/20130123/NEWS01/130123042/Louisiana-will-continue-Medicaid-hospice-program>

Hospices, wary of costs, may be discouraging patients with high expenses

KAISER HEALTH NEWS | Online – 21 January 2013 – Many people who are terminally ill delay entering hospice care until just a few days or weeks before they die, in part because they or their families don't want to admit that there's no hope for a cure. A recent study¹ ... found that there may be another reason that patients don't take advantage of the comprehensive services that hospice provides: restrictive enrollment policies that may discourage patients from signing up. A survey of nearly 600 hospices nationwide found that 78% had enrollment policies that might restrict patient access to care, especially for those with high-cost medical needs. The policies included prohibitions on enrolling patients who are receiving palliative radiation or blood transfusions or who are being fed intravenously. To qualify for hospice care under Medicare, a patient's doctor and a hospice medical director

must certify that the patient has six months or less to live. Patients must also agree not to seek curative care. Once a patient chooses to enter hospice, the benefits include medical treatment for non-curative purposes such as pain and symptom management as well as emotional and spiritual support for patients and their families. Most patients receive hospice care at home. <http://www.kaiserhealthnews.org/Features/Insuring-Your-Health/2013/012213-Michelle-Andrews-on-hospice-care.aspx>

Specialist Publications

'Capturing activity, costs, and outcomes: The challenges to be overcome for successful economic evaluation in palliative care' (p.13), in *Progress in Palliative Care*.

Cont.

1. 'Hospices' enrollment policies may contribute to underuse of hospice care in the U.S.,' *Health Affairs*, 2012;31(12):2690-2698. [Noted in Media Watch, 10 December 2012]
<http://content.healthaffairs.org/content/31/12/2690.abstract>

Noted in Media Watch, 7 January 2013:

- *THE NEW YORK TIMES* | OpEd – 3 January 2013 – **'On the way to hospice, surprising hurdles.'** <http://newoldage.blogs.nytimes.com/2013/01/03/hospice-obstacles/>

End-of-life care rarely discussed

MASSACHUSETTS | *The Boston Globe* – 21 January 2013 – On an average day in Massachusetts, 144 people die. One is an infant. A few are children. Some are middle-aged, most are over 75. These observations lead to a 32-page report, released nearly two years ago by a state convened expert panel charged with recommending improvements to Massachusetts's lagging system for end-of-life care. Since then, few of the panel's recommendations have been implemented. Precious final days for many Massachusetts residents are still not spent the way they would have chosen – at home with loved ones – but in a hospital. And health-care providers do not routinely discuss end-of-life care preferences with patients, said Dr. Lachlan Forrow, director of ethics and palliative care programs at Beth Israel Deaconess Medical Center, and chair of the expert panel. "I am truly baffled," For-

row said about the lack of progress. "We are making practical recommendations for everyone to be taken care of in the way he or she would want to be." Budget cuts have stalled progress on many of the panel's recommendations, health officials said, particularly ones that suggested the state develop regulations, monitor caregiver training, and post information for consumers.

<http://bostonglobe.com/lifestyle/health-wellness/2013/01/21/massachusetts-slow-launch-end-life-care-services/FGvM2IUgzEae2GUAKL09IN/story.html>

Specialist Publications

'Advance care planning and the quality of end-of-life care in older adults' (9), in *Journal of the American Geriatric Society*.

Noted in Media Watch, 21 March 2011:

- MASSACHUSETTS | WGBH News (Boston) – 17 March 2011 – **'Report offers new recommendations for end-of-life care.'** A report by a panel convened by Massachusetts health officials says that all too often, doctors don't discuss end of life care with their patients. And, as a result, patients are likely to receive costly and unwanted hospitalization and medical interventions. <http://www.wgbh.org/articles/index.cfm?tempid=2282>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *Los Angeles Times* – 20 January 2013 – **'Prosecutors going easier on assisted suicide among elderly.'** When an elderly man helps his suffering wife end her life, is it murder or love? Recent cases show prosecutors leaning toward a gentler judgment. <http://www.latimes.com/news/local/la-me-suicide-assist-20130120,0,588699.story>

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

Study looks at cost of dying

NEW ZEALAND | *Western Leader* (Auckland) – 25 January 2013 – Dying can be an expensive process. Dr. Tess Moeke-Maxwell should know. The researcher has recently completed a three-year Health Research Council-funded study into Māori experiences of dying, Kia Ngawari . The study revealed that poverty often plays a factor in the type of care and resources people can access. "One gentleman, when I visited him, had all his medicines lined up on the table. What he was actually doing was working out which tablets would last him until benefit day and which ones he didn't have enough money to buy," she says. "He was going to talk to the pharmacist to see if he could buy just enough tablets to get him through to payday because he couldn't afford to buy whole boxes, even with the government subsidy." <http://www.stuff.co.nz/auckland/local-news/western-leader/8222001/Study-looks-at-cost-of-dying>

Noted in Media Watch, 22 March 2010:

- NEW ZEALAND | University of Waikato – 15 March 2010 – '**Study looks at dying, death, bereavement among Māori.**' <http://www.waikato.ac.nz/news-events/media/2010/03Study%20looks%20at%20dying.%20death.%20bereavement%20among%20M%C4%81ori%20.shtml>

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

Current and future needs for hospice care: An evidence-based report

U.K. | Cicely Saunders International – 24 January 2013 – The report focuses on crucial factors for hospice care planning, such as U.K. mortality and other epidemiological data. It shows that the number of U.K. deaths is predicted to escalate from 2015 onwards, especially for older people who are more likely to suffer from chronic, debilitating conditions. The report presents the current evidence on preferences for place of care and place of death in the U.K. It shows that most people would prefer to die at home, but also that there is a substantial proportion who would prefer to die in hospices or palliative care units, particularly among older people. Finally, the report also presents what is currently known about the effectiveness and cost-effectiveness of hospice care, and highlights crucial gaps in the evidence such as uncertainty about which models of hospice care work better. Evidence-based recommendations for future hospice care planning are provided. Download report at: <http://www.helpthehospices.org.uk/our-services/commission/reports/>

Liverpool Care Pathway

BBC News – 24 January 2013 – '**Care Minister incentives pledge.**' Payments to hospitals using the Liverpool Care Pathway should only be made if it could be demonstrated it improved the care of dying patients <http://www.bbc.co.uk/news/uk-england-21183202>

The Telegraph – 24 January 2013 – '**Lord Carlile: Medics should face General Medical Council over Liverpool Care Pathway.**' <http://www.telegraph.co.uk/news/uknews/9825342/Lord-Carlile-medics-should-face-GMC-over-Liverpool-Care-Pathway.html>

BBC News – 22 January 2013 – '**More than 10,000 patients placed on plan.**' Almost half of the acute hospital trusts in the East [of England] have been offered incentives by the government to put dying patients on a programme that allows doctors to withdraw treatment. More than 10,000 patients in the region have been put on the Liverpool Care Pathway in the last three years [of life]. <http://www.bbc.co.uk/news/uk-england-21141281>

Cont.

Of related interest:

- U.K. (ENGLAND & WALES) | *The Guardian* – 21 January 2013 – **'Providing quality end of life care in a time of austerity.'** A recent survey commissioned by Home Group discovered that almost two thirds of councils across the U.K. will not be able to cope with the needs of terminally ill residents in the future.¹ <http://www.guardian.co.uk/housing-network/partner-zone-home-group/nhs-end-of-life-care>

1. *A Good Death: The Role of the Local Authority in End of Life Care*, Local Government Information Unit, November 2012. [Noted in Media Watch, 3 December 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>

Let elderly people 'hurry up and die', says Japanese minister

JAPAN | *The Guardian* (U.K.) – 22 January 2013 – Japan's new government is barely a month old, and already one of its most senior members has insulted tens of millions of voters by suggesting that the elderly are an unnecessary drain on the country's finances. Taro Aso, the finance minister, said that the elderly should be allowed to "hurry up and die" to relieve pressure on the state to pay for their medical care. "Heaven forbid if you are forced to live on when you want to die. I would wake up feeling increasingly bad knowing that [treatment] was all being paid for by the government," he said during a meeting of the national council on social security reforms. "The problem won't be solved unless you let them hurry up and die." Aso's comments are likely to cause offence in Japan, where almost a quarter of the 128 million population is aged over 60. <http://www.guardian.co.uk/world/2013/jan/22/elderly-hurry-up-die-japanese>

Pauper's funerals at record levels

U.K. (ENGLAND) | *Yorkshire Evening Post* – 22 January 2013 – Soaring funeral costs and the effects of the recession have left hundreds of families in Leeds unable to afford to give their loved ones a final farewell. <http://www.yorkshireeveningpost.co.uk/news/latest-news/top-stories/leeds-in-2013-pauper-s-funerals-at-record-levels-1-5340428>

Noted in Media Watch, 2 July 2012:

- U.K. | Dying Matters – Accessed 28 June 2012 – **'Paupers' funerals "set to rise."** The number of so-called 'paupers' funerals' is set to rise in the as the disparity between the rising cost of funerals and the state contribution puts increasing pressure on an already stretched system, warns a new study.¹ <http://www.dyingmatters.org/news/paupers-funerals-set-rise>

1. *Cost of Dying Special Report: Affording a Funeral*, University of Bath and Sun Life Direct, June 2012. [http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site_Build/About_Sun_Life_Direct/News\(1\)/SF%20Funeral%20Payment%20Research%20-%2020220612.pdf](http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site_Build/About_Sun_Life_Direct/News(1)/SF%20Funeral%20Payment%20Research%20-%2020220612.pdf)

End-of-life care in Ireland

Palliative care a postcode lottery

IRELAND | *Belfast Telegraph* – 21 January 2013 – Terminally ill patients are denied adequate palliative care depending on where they live, a new report has found.¹ Nearly half the counties in Ireland have no in-patient hospice units, with the North East, South East and the Midlands among those at a geographical disadvantage due to a lack of beds. Professor Mary McCarron, dean of health sciences at Trinity College Dublin, which published the report, said more needs to be done to ensure everyone has access to quality care. <http://www.belfasttelegraph.co.uk/news/local-national/republic-of-ireland/palliative-care-a-postcode-lottery-16264166.html>

1. *Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report*, Trinity College Dublin, January 2013. [Noted in Media Watch, 21 January 2013] http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_Republic_of_Ireland.pdf

Cont.

Noted in Media Watch, 3 December 2012:

- U.K. (ENGLAND & WALES) | *The Daily Telegraph* – 28 November 2012 – **'Terminally ill face postcode lottery...'** <http://www.telegraph.co.uk/health/healthnews/9708827/Terminally-ill-face-postcode-lottery-in-end-of-life-care.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Irish Times* (Dublin) – 21 January 2013 – **'Absolute ban on assisted suicide is justified to protect the vulnerable.'** The High Court ruled the ban on assisted suicide is justified to protect vulnerable people from involuntary death and does not breach personal autonomy and equality rights under the Constitution and European Convention on Human Rights. <http://www.irishtimes.com/newspaper/finance/2013/01/21/1224329096462.html>

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

Death certificates present final medical complication

AMERICAN MEDICAL NEWS | Online – 21 January 2013 – Death certificates are vital documents that serve as the primary source of information for families, insurance companies and authorities about a patient's cause of death. The information helps policymakers set public health goals and research funding priorities. But signing a death certificate is not always a straightforward process. Physicians often face uncertainties about an individual's cause of death or how to answer the portions of certificates they are responsible for. Although the basic format has changed little in the last few decades, doctors face difficulties as some states attempt to convert from paper to eCertificates. <http://www.ama-assn.org/amednews/2013/01/21/prsa0121.htm>

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.

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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.

Finding common ground to achieve a "good death": Family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study

BMC FAMILY PRACTICE | Online – 22 January 2013 – Substitute decision-makers are integral to the care of dying patients and make many healthcare decisions for patients. Unfortunately, conflict between physicians and surrogate decision-makers is not uncommon in end-of-life care and this could contribute to a "bad death" experience for the patient and family. The authors aim to describe Canadian family physicians' experiences of conflict with substitute decision-makers of dying patients to identify factors that may facilitate or hinder the end-of-life decision-making process. This insight will help determine how to best manage these complex situations, ultimately improving the overall care of dying patients. The family physicians expressed a desire to achieve a "good death" and described their role in positively influencing the experience of death. Finding common ground to achieve a "good death" for the patient emerged as an important process which includes: 1) building mutual trust and rapport through identifying key players and delivering manageable amounts of information; 2) understanding one another through active listening and ultimately; and, 3) making informed, shared decisions. Facilitators and barriers to achieving common ground were identified. Barriers were linked to conflict. The inability to resolve an overt conflict may lead to an impasse at any point. A process for resolving an impasse is described.

<http://www.biomedcentral.com/content/pdf/1471-2296-14-14.pdf>

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 25 January 2013 – '**Advance care planning and the quality of end-of-life care in older adults.**' Seventy-six percent of subjects [i.e., study participants] engaged in ACP [advance care planning]. Ninety-two percent of ADs [advance directives] stated a preference to prioritize comfort. Subjects who engaged in ACP were less likely to die in a hospital, more likely to be enrolled in hospice, and less likely to receive hospice for 3 days or less before death. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12105/abstract>

Palliative care: Knowing when not to act

OXFORD UNIVERSITY PRESS | Online – 23 January 2013 – Accessed One of the things that has always puzzled me is the number of palliative care services that have the word 'pain' in the title. Why do we concentrate so much on that one, admittedly unpleasant, symptom? Why 'Pain and Palliative Care Services' rather than, for example, 'Vomiting and Palliative Care Service,' 'Dyspnoea and Palliative Care Service,' or even 'Sadness, Anger, Existential Anguish and Palliative Care Service'? That's the problem with trying to describe palliative care. The whole point of palliative care is that it is holistic – a word that has acquired a certain flakiness, but which in reality simply refers to looking at the wholeness of a person, rather than focusing on only one domain (such as physical symptoms), or even one specific symptom (such as pain). But the purpose of a definition, by definition, is to set limits around a concept. There is a sense in which defining something as holistic is a contradiction in terms. Yet that is what we have to do in palliative care, if we are to communicate some sense of the task of caring for children and adults with life-limiting conditions; a sense that encompasses both the idea that it is holistic and that it is specialist (there are some things you need to learn to do to do it well). The clue to the nature of palliative care is in the name: 'care.' It is a care whose aim is not cure. In the U.K. we have recently seen the results of misunderstanding what palliative care is all about. <http://blog.oup.com/2013/01/palliative-liverpool-care-pathway/>

Cont.

Advancing the science of hospice care: Coalition of Hospices Organized to Investigate Comparative Effectiveness [CHOICE]

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2012;6(4):459-464. There is very little high-quality evidence to guide clinical practice in hospice care. In the areas of medical therapy, patient-centered and family-centered outcomes, and patient safety, there are numerous high-impact questions for which answers are needed. Although randomized controlled trials are the gold standard for research, such trials are difficult, time consuming, and expensive to conduct in a hospice population. Moreover, they cannot examine the implementation of therapies in real-world settings. Therefore, there is a need for novel, complementary approaches to research in this unique population. This article describes the initial experience of ... a national network of hospices that use electronic health record-based data collection procedures to answer key questions relevant to clinical care and policy. By using a rich source of existing data to conduct observational studies, CHOICE is able to overcome many of the most significant challenges of randomized controlled trials in hospice. However, this approach also created unique challenges related to governance and privacy concerns. http://journals.lww.com/supportiveandpalliative-care/Abstract/2012/12000/Advancing_the_science_of_hospice_care_Coalition.9.aspx

N.B. This issue of the journal includes several articles on the challenges in conducting clinical trials in supportive and palliative care. Contents page: <http://journals.lww.com/supportiveandpalliativecare/pages/currenttoc.aspx>

Rapid response teams, do not resuscitate orders, and potential opportunities to improve end-of-life care

JOURNAL OF CRITICAL CARE | Online – 22 January 2013 – Rapid response teams (RRTs) were created to stabilize acutely ill patients on the ward, but recent studies suggest that RRTs may improve end-of-life care (EOLC). In a retrospective review, the typical consultation was for an elderly patient with chronic illness. More than 90% had a "full resuscitation" order at the time of consultation. One third were admitted to the intensive care unit within 48 hours of the RRT consultation, and 24.7% ultimately died. Twenty-seven (9.3%) had a patient/ family conference on the ward within 48 hours of the RRT consultation, 24 (8.3%) of whom changed their resuscitation order as a result. Among those who changed their resuscitation order, fewer than 20% were referred to the palliative care or spiritual care service, or prescribed comfort medications as needed, within 48 hours of the RRT consultation; 2 patients died without receiving any common EOLC orders, and 15 (63%) died before discharge. [http://www.jccjournal.org/article/S0883-9441\(12\)00329-2/abstract](http://www.jccjournal.org/article/S0883-9441(12)00329-2/abstract)

Knowledge, attitude and practices regarding the role of spirituality in current medical practice amongst medical professionals in a tertiary care hospital

JOURNAL OF EVOLUTION OF MEDICAL & DENTAL SCIENCES, 2013;2(3):204-225. This study on spirituality shows a huge gap between physician's perception and practice. A comprehensive report on concept and application of spirituality in health management is lacking. It reveals that what matter most to medical practitioners is not the religious preaching of pre-designated rituals but well documented scientifically proved spiritual concepts to manage health and disease individually and collectively. Induction of medical scientist in spirituality related research shall boost confidence of medical practitioners in spirituality and generate reliable data. Based on this study, there is an urgent need to undertake concerted and collaborative work by dedicated and qualified professionals to redefine place of spirituality in health and disease as was norm during ancient time. http://www.jemds.com/data_pdf/MM%20jain-KNOWLEDGE%20ATTITUDE%20AND%20PRACTICES%20REGARDING.pdf

Cont.

Of related interest:

- *NURSING INQUIRY*, 2013;20(1):5-10. **'Nursings' need for the idea of spirituality.** Spirituality, like its predecessor religion, will likely continue to play an enduring role in providing fundamental meaning for nursing work. <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1800.2012.00608.x/abstract>

Noted in Media Watch, 24 December 2012:

- *JOURNAL OF CLINICAL ONCOLOGY* | Published online – 17 December 2012 – **'Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and ...'** <http://jco.ascopubs.org/content/early/2012/12/13/JCO.2012.44.6443.abstract>

N.B. This issue of Media Watch (p.7) includes a listing of articles on spiritual care noted in past issues of the weekly report.

Awareness of palliative care and end-of-life options among African Canadians in Nova Scotia

JOURNAL OF TRANSCULTURAL NURSING | Online – 22 January 2013 – The caregivers [i.e., study participants] met three times to 1) discuss their experiences; 2) receive a presentation from the palliative care service; and, 3) discuss whether those services would be beneficial. This was followed by a community meeting to discuss the findings. Knowledge of options for palliative care services is limited. Information ... is not filtering down to the community in a way that is meaningful to families [who] tend to self-select services that assist them in providing care in the home setting. There is a need to engage Black communities ... in developing culturally appropriate services. <http://tcn.sagepub.com/content/early/2013/01/21/1043659612472190.abstract>

"Death panels"

The hazards of correcting myths about health care reform

MEDICAL CARE, 2013;51(2):127-132. Misperceptions are a major problem in debates about health care reform and other controversial health issues. The authors conducted an experiment to determine if more aggressive media fact-checking could correct the false belief that the [Patient Protection & Affordable Care Act would create "death panels." Participants from an opt-in Internet panel were randomly assigned to either a control group in which they read an article on Sarah Palin's claims about "death panels" or an intervention group in which the article also contained corrective information refuting Palin. The correction reduced belief in death panels and strong opposition to the reform bill among those who view Palin un-

favorably and those who view her favorably but have low political knowledge. However, it backfired among politically knowledgeable Palin supporters, who were more likely to believe in death panels and to strongly oppose reform if they received the correction. <http://www.ncbi.nlm.nih.gov/pubmed/23211778>

Extract from *Medical Care* article

The results [of this "experiment"] underscore the difficulty of reducing misperceptions about health care reform among individuals with the motivation and sophistication to reject corrective information.

Noted in Media Watch, 26 November 2013:

- *THE NEW YORK TIMES* | OpEd – 24 November 2012 – **'Care at the end of life.'** At the height of the debate over health care reform, there was an uproar over a voluntary provision that encouraged doctors to discuss with Medicare patients the kinds of treatments they would want as they neared the end of life. <http://www.nytimes.com/2012/11/25/opinion/sunday/end-of-life-health-care.html?emc=eta1&r=0>

Palliative care for children with cancer

NATURE REVIEWS: CLINICAL ONCOLOGY | Online – 22 January 2013 – Paediatric palliative care has emerged as a primary approach and as its own medical subspecialty, the overall aim of which is to ease suffering for children with life threatening illness and their families through a concurrent model of care. However, most discussions have been focused on the transition to palliative care when no realistic hope for cure exists. Because the course of cancer is so unpredictable, this idea is misleading. Indeed, palliative care is increasingly being recognized as being about not just how to cope with the process of dying, but also about how to engage in living when faced with a life-threatening illness. By improving familiarity with palliative care and building

relationships with palliative care specialists, the paediatric oncology clinician will ensure the best care possible for children and families is provided, regardless of outcome.

<http://www.nature.com/nrclinonc/journal/vaop/ncurrent/abs/nrclinonc.2012.238.html#top>

Extract from *Nature Reviews* article

This article examines our current understanding of several areas of palliative care, with the ultimate message that palliative care is simply a novel term for the total care of a child and family, an approach that should be applied consistently and concurrently regardless of disease status.

End-of-life care in Africa

Current state of palliative and end-of-life care in home versus inpatient facilities and urban versus rural settings in Africa

PALLIATIVE & SUPPORTIVE CARE | Online – 23 January 2013 – Because palliative care [PC] in sub-Saharan Africa may not fit the style of delivery of PC in the global north, exploring the evidence can serve to reduce existing barriers and help streamline national policies that determine the optimal setting to implement formal palliative and end-of-life services. Opioid availability and distribution is best accessed at the inpatient level, and hence, pain and end-of-life symptoms are best managed at this level. Despite the great need, nurses' lack of prescription power in the home-based setting is a shortcoming. Home deaths have not been adequately studied, but research suggests PC generally causes economic strain, psychosocial distress on family members, and increased risk of transmission of communicable disease. Hospice is understudied but shows favorable outcomes. Funding and research need to focus on development of inpatient palliative and hospice care units in urban areas. In rural areas, the priority should be a home-based care model that

involves nurses ... privileged to prescribe opioids and adjunctive medication therapies. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8823800&fulltextType=RV&fileId=S1478951512000612>

Most nurses are avoiding palliative care – survey indicates

KENYA HOSPICES & PALLIATIVE CARE ASSOCIATION | Online – 24 January 2013 – 80% of nurses working in rural areas have no idea of palliative care, 80% fear the process of breaking bad news, 55% feel it consumes time, 65% fear burn out after prolonged care, while 50% fear prescribing morphine and causing addiction to patients. This is according to a survey by Ongata Ngong palliative care community based organisation. Despite increasing palliative care awareness and short course trainings by different bodies/hospices, fewer nurses are willing to work in this field. <http://kehpc.org/2013/01/most-nurses-are-avoiding-palliative-care-survey-indicates/>

Capturing activity, costs, and outcomes: The challenges to be overcome for successful economic evaluation in palliative care

PROGRESS IN PALLIATIVE CARE | Online – 25 January 2013 – Palliative care, as with other health care services, is faced with the difficulty of competing for limited health care resources. Health care decision makers seek to maximize 'value for money' when selecting services to fund. The challenges for the palliative care community are to a) demonstrate the cost effectiveness of its interventions in comparison to other health services; and, b) provide evidence that the resources currently allocated are being used efficiently. Health economic evaluation can be conducted to support this. In this paper different economic approaches to evaluating health care services are introduced. Providing examples from (home based) palliative care the authors consider the opportunities to progress this work. They also describe the related challenges of capturing activity, costs, and outcomes. Although the very nature of this area of care presents unique methodological challenges that will need to be overcome, appropriate analyses will allow comparisons across the wider health sector and strengthen the argument for palliative care services. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000046>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2013;19(1):3. **'Speaking truth to power: A challenge for the field of palliative care.'** http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=96510:article=IJPN_19_1_3
- *REVIEW OF SOCIAL ECONOMY* | Online – 21 January 2013 – **'Economics, ethics and thanatology: Lessons from the ancients.'** <http://www.tandfonline.com/doi/abs/10.1080/00346764.2012.761757>

Working together-apart: Exploring the relationships between formal and informal care networks for people dying at home

PROGRESS IN PALLIATIVE CARE | Online – 25 January 2013 – Informal caring networks contribute significantly to end-of-life (EOL) care in the community. However, to ensure that these networks are sustainable, and unpaid carers are not exploited, primary carers need permission and practical assistance to gather networks together and negotiate the help they need. The authors' aim in this study was to develop an understanding of how formal and informal carers work together when care is being provided in a dying person's home. They were particularly interested in formal providers' perceptions and knowledge of informal networks of care and in identifying barriers to the networks working together. Their findings show that formal providers are aware, and supportive, of the vital role informal networks play in the care of the dying at home. A number of barriers to formal and informal networks working together more effectively were identified. In particular, the authors found that the Australian policy of health-promoting palliative is not substantially translating to practice. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000047>

Of related interest:

- *NURSING INQUIRY* | Online – 22 January 2013 – **'Co-creating possibilities for patients in palliative care to reach vital goals: A multiple case study of home-care nursing encounters.'** <http://onlinelibrary.wiley.com/doi/10.1111/nin.12022/abstract;jsessionid=021083236C29050C7E390809AFB9D346.d01t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *PEDIATRIC BLOOD & CANCER* | Online – 17 January 2013 – **'Hospital-based home care for children with cancer: Feasibility and psychosocial impact on children and their families.'** This study indicates hospital-based home care is a feasible alternative to hospital care for children with cancer... <http://onlinelibrary.wiley.com/doi/10.1002/pbc.24474/abstract>

Cont.

- **PSYCHO-ONCOLOGY** | Online – 21 January 2013 – '**Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial.**' This research demonstrates relatively short psycho-educational interventions can enable family caregivers to feel more prepared and competent in the role of supporting a dying relative. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3242/abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- **AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE** | Online – 23 January 2013 – '**Attitude toward euthanasia scale: Psychometric properties and relations with religious orientation, personality, and life satisfaction.**' End-of-life decisions (ELDs) represent a controversial subject, with ethical dilemmas and empirical ambiguities that stand at the intersection of ethics and medicine. In a non-Western population, the authors examined individual differences in perceiving ELDs that end the life of a patient as acceptable and found that an attitude toward euthanasia (ATE) scale consists of two factors representing voluntary and non-voluntary euthanasia. Also, acceptance of ELDs that end the life of a patient negatively correlated with life satisfaction, honesty-humility, conscientiousness, and intrinsic and extrinsic personal motivation toward religion. <http://ajh.sagepub.com/content/early/2013/01/22/1049909112472721.abstract>

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Links,' then to 'Media Watch')

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>

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>

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Worth Repeating

At the end of life, denial comes at a price

U.S. | *THE NEW YORK TIMES* – 3 April 2009 – Like the rest of us, doctors struggle to talk about dying. These conversations with patients occur haltingly, awkwardly and often not at all. But a study published recently¹ ... suggests just how costly that silence may be, both in health care dollars and in patients' suffering. A team of investigators, led by researchers at the Dana-Farber Cancer Institute in Boston, interviewed 603 patients with advanced cancer. They asked the patients, who had about six months left to live, whether their doctors had discussed their wishes for end-of-life care. The majority – 69% – said those conversations had not taken place. And in the last week of life, those patients who had talked with their doctors wound up with medical bills that were on average 36% lower – \$1,876 compared to \$2,917 – than those of patients who did not have end-of-life conversations with their doctors. Dr. Holly Prigerson, a professor of psychiatry at Harvard Medical School and an author of the study, explained that the patients who never talked about their end-of-life wishes were more likely to be resuscitated, intubated or put in intensive care – or all of the above. Patients who had had those conversations generally opted for comfort, or palliative, care at home or in a hospice at much lower cost. But wouldn't aggressive, more expensive care at least offer dying patients a bit more time at the end of life? Not according to this study. The patients not only did not live longer overall, but based on reports from family members and other caregivers, they also suffered more physical distress in the end. These correlations may not prove a cause-and-effect relationship between end-of-life conversations and outcomes. Still, Dr. Prigerson said, "The study suggests that as costs go up, the misery and suffering index also goes up." <http://newoldage.blogs.nytimes.com/2009/04/03/at-the-end-of-life-denial-comes-at-a-price/>

1. 'Health care costs in the last week of life: Associations with end-of-life conversations,' *Archives of Internal Medicine*, 2009;169(5):480-488.
<http://archinte.jamanetwork.com/article.aspx?articleid=414825>

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