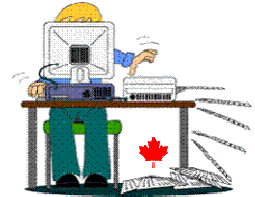


## **Media Watch...**

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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**Compiled & Annotated by Barry R. Ashpole**

**Perceptions of the patient's psychological well-being: Scroll down to [Specialist Publications](#) and 'Quality of life in fatal disease: The flawed judgement of the social environment' (p.10), in *Journal of Neurology*.**

## **North America**

### **Dartmouth Atlas Project**

#### **Study says many patients enter hospice care too late**

U.S. (MASSACHUSETTS) | *The Boston Globe* – 5 September 2013 – Slightly more patients with terminal cancer are getting hospice care during the end of their lives, but they are still entering hospice care too late – within days of death – finds a new national analysis of Medicare patients conducted by Dartmouth researchers.<sup>1</sup> And many are still dying in hospitals, often hooked to ventilators in an intensive care unit, despite studies showing that most cancer patients prefer to die at home. The percentage of end-stage cancer patients who died in the hospital decreased from 29% on average to 25% from 2003 to 2010, but there are huge variations among hospitals: In Massachusetts in 2010, about 13% of terminally ill cancer patients treated at North Shore Medical Center in Salem died there compared with 41% of those treated at MetroWest Medical Center in Framingham. The project researchers receive funding from non-profit groups to determine how medical resources are distributed and used in the U.S. In the analysis, they also found that the percentage of cancer patients receiving hospice care rose nationwide from an average of 55% to 61%. "These trends can be called encouraging, but most of the hospice care received was within the last three days of life," said Dr. David Goodman, lead author of the [Dartmouth] report. What's more, the average number of days patients spent in the intensive care unit during the last month of life increased by 21%, which Goodman said could be driven by hospitals looking for more generous insurance payments for expensive services. <http://www.bostonglobe.com/lifestyle/health-wellness/2013/09/04/end-life-care-for-cancer-patients-varies-widely-boston-area-hospitals/oRvjIXDvIWLPrfffcy9bJ/story.html>

1. 'Trends in Cancer Care Near the End of Life: A Dartmouth Atlas of Health Care Brief,' September 2013. [http://www.dartmouthatlas.org/downloads/reports/Cancer\\_brief\\_090413.pdf](http://www.dartmouthatlas.org/downloads/reports/Cancer_brief_090413.pdf)

Cont.

Noted in Media Watch, 3 September 2012, #269 (p.3):

- U.S. | CENTER TO ADVANCE PALLIATIVE CARE – 27 August 2012 – **'Palliative care in hospitals continues rapid growth trend.'** Palliative care in U.S. hospitals has increased for the 11th consecutive year.<sup>1</sup> The number of hospitals with a palliative care team increased from 658 (24.5%) to 1,635 (65.7%)... <http://www.capc.org/news-and-events/releases/08-27-12>

1. 'A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Center to Advance Palliative Care, 2011. <http://www.capc.org/reportcard/>

Of related interest:

- U.S. | *THE NEW YORK TIMES* – 4 September 2013 – **'Deciding when to enter a palliative care unit.'** It's a tough situation: you have a fatal condition. You require care beyond what family members can provide at home. But with a prognosis of more than six months to live, you are not ready for hospice care. And an intensive care unit is too, well, *intensive*, to say nothing of expensive. So what do you do? Now there's another option. Some hospitals are offering so-called palliative care units. [Palliative care] has long been associated with hospice care – that is, given at the very end of life and often, but not always, at your home. It is becoming increasingly clear palliative care can help patients who suffer from serious chronic conditions but who are not necessarily expected to die imminently,

and who may still benefit from some forms of high-tech treatment. <http://www.nytimes.com/2013/09/04/your-money/deciding-when-to-enter-a-palliative-care-unit.html?ref=health&r=0>

### Specialist Publications

**'Cost savings vary by length of stay for inpatients receiving palliative care consultation services'** (p.11), in *Journal of Palliative Medicine*.

**'Frequency of Medicare recertification surveys for hospices is unimproved'** (p.11), in U.S. Department of Health & Human Services report.

### Values conflict at the end of life

U.S. | *THE NEW YORK TIMES* – 3 September 2013 – How do surrogates actually make decisions for relatives who can no longer direct their own care? It's hardly a hypothetical question: a British study published ... in 2004 found 40% of hospitalized patients lacked the mental capacity to make decisions because they were unconscious, delirious, demented or otherwise cognitively impaired.<sup>1</sup> [In a recent study] Dr. [Alexia] Torke and her colleagues talked to 35 surrogates who had made major decisions – about life-sustaining treatments, surgery or other procedures, or about where the patient would go when discharged – on behalf of incapacitated seniors admitted to two Indianapolis hospitals.<sup>2</sup> These were not legally designated health care proxies, for the most part, because most patients had no advance directive and hadn't chosen a decision maker. The surrogates were simply the family members – mostly daughters – to whom the doctors turned for guidance. What these relatives disclosed ... in face-to-face interviews ... mirrored what several other studies have found: surrogates often base their judgements on considerations other than what the patients want. <http://newoldage.blogs.nytimes.com/2013/09/03/values-conflict-at-the-end-of-life/?ref=health&r=0>

1. 'Prevalence of mental incapacity in medical inpatients and associated risk factors: Cross-sectional study,' *The Lancet*, 2004;364(9443):1421-1427. <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2804%2917224-3/fulltext>
2. 'Making decisions for hospitalized older adults: Ethical factors considered by family surrogates,' *Journal of Clinical Ethics*, 2013;24(2). <http://www.clinicalethics.com/>

Cont.

Noted in Media Watch, 1 July 2013, #312 (p.8):

- *JOURNAL OF CLINICAL ETHICS*, 2013;24(2). **“He got his last wishes”: Ways of knowing a loved one's end-of-life preferences and whether those preferences were honored.** While many surrogates indicate they have some knowledge of their loved one's preferences, how surrogates obtain such knowledge is not well understood. Additionally, although research indicates that the emotional burden of end-of-life decision making is diminished when surrogates have knowledge that a loved one's preferences are honored, it remains unclear how surrogates come to know these preferences were carried out. <http://www.clinicalethics.com/>

Of related interest:

- U.S. (MARYLAND) | *The Baltimore Sun* – 4 September – **'New form directs doctors in life-threatening situations.'** Maryland Order for Life Sustaining Treatment form contains physician's or nurse practitioner's orders designating a patient's wishes regarding CPR (cardiopulmonary resuscitation) and other life-sustaining treatments such as ventilators, feeding tubes, blood transfusions, dialysis and others. This differs from the living will, which is signed by the patient and is not a physician's order. Nursing homes and other health care facilities/programs are required to offer it to patients when they are admitted, and it accompanies the patient from one facility to another. The receiving institution is required to honor the form and should review it on admission and when there has been a change in the patient's condition. <http://www.baltimoresun.com/health/blog/bs-hs-expert-molst-form-20130904.0.5088862.story>

## International

### **At that hour: Dealing with death**

U.K. | *The Independent* – 3 September 2013 – In Ireland, passing on the news quickly is considered an important part of the response to death and this is not just in villages or small towns. My brother received a letter of condolence from the chief executive of the very large organisation he works for. It is standard practice for Human Resources departments to send an email around when someone loses a family member. My boss in London had been very supportive, but I thought guiltily of work colleagues whose parents or spouses may have died and whose loss I had failed to acknowledge. Yet unless they had worn a black armband, how would anyone in a big workplace even know of their sorrow? The Irish are not known for being any less emotionally repressed than their British neighbours but they do death

very well. Funerals come with up to three opportunities for mourners to show up: there's the waking of the body, which is often in the home, the "removal" to the church, and, on the final day, a funeral mass and burial followed by a reception or meal. <http://www.independent.co.uk/life-style/health-and-families/features/at-that-hour-dealing-with-death-8795121.html>

#### **Extract from *The Independent* article**

Would attitudes to ageing be more compassionate and attitudes to life itself more fulfilling if funerals were not regarded as necessarily ghastly and mortality as something that happens only to other, less lucky people?

### Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.12.

## End-of-life care in Scotland

### **End of life patients' hospital time cut by one day**

U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) – 3 September 2013 – Efforts to ensure patients spend less time in hospital towards the end of their lives have resulted in them enjoying just one more day at home in their final six months over the last five years, statistics show.<sup>1</sup> Research reveals that in 2007-2008, the average time spent in hospital during the last six months of life in Scotland was 17.5 days. By 2011-2012, this had dropped to just 16.5 days. The report comes as hospitals face increasing demand to cope with an ageing population, meaning the National Health Service needs to care for more people in the community to reduce pressures on inpatient beds. Leading doctors have also warned that this can increase the risk of "boarding" – where patients are moved from ward to ward to cope with a rising number of admissions. In 2008, the Scottish Government published its ... plan to improve end of life care across the country.<sup>2</sup>  
<http://www.scotsman.com/news/health/end-of-life-patients-hospital-time-cut-by-one-day-1-3070652>

1. 'Percentage of End of Life Spent at Home or in a Community Setting,' Information Services Division, National Services Scotland, 27 August 2013. <https://isdscotland.scot.nhs.uk/Health-Topics/Health-and-Social-Community-Care/Publications/2013-08-27/2013-08-27-End-of-Life-Care-Summary.pdf?54406374693>
2. 'Living & Dying Well: A national action plan for palliative and end of life care in Scotland,' The Scottish Government, 2008. <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

## Elder care in the U.K.

### **Older people should be supported to carry on living at home**

U.K. | *The Guardian* – 2 September 2013 – The U.K. care sector, buckling under the weight of our rapidly ageing population, is driving many older people into residential care before it is absolutely necessary. This is a great tragedy, with a shocking economic cost matched only in scale by its personal devastation on individuals, who naturally wish to maintain their independence at home. So why is there a growth in residential care, at a time when our policy agenda supposedly wants to see more people supported at home? There are multiple factors, all of which point towards a disjointed care system and a lack of focus on maintaining independence. To start at the beginning of the process, the current local authority tendering system for homecare stacks the deck in favour of large providers, who generally pursue a volume driven business model that is focused on delivering functional care, cheaply. As a result, niche specialist homecare providers are increasingly becoming isolated from the local authority market and,

therefore, specialist care is at risk of becoming the province of wealthy self-funders.  
<http://www.theguardian.com/social-care-network/2013/sep/02/support-older-people-live-at-home>

#### **Specialist Publications**

'Palliative care in Mainland China' (p.6), in *Asia Pacific Journal of Health Management*.

'Palliative care research on the island of Ireland over the last decade: A systematic review and thematic analysis of peer reviewed publications' (p.7), in *BMC Palliative Care*.

'Negotiating palliative care in the context of culturally and linguistically diverse patients' (p.8), in *Internal Medicine Journal*.

'Patient and family perceptions of hospice services: "I knew they weren't like hospitals,"' (p.8), in *Journal of Primary Health Care*.

Cont.

Of related interest:

- U.K. | *The Daily Telegraph* – 3 September 2013 – **'Elderly care crises claims a million family homes.'** More than one million families have been forced to sell their homes in just five years to meet cost of paying for residential care, new figures revealed. The estimate ... is far higher than government projections have previously suggested. But charities and pension experts said it represented one of the first realistic attempts to quantify the scale of the hidden care funding crisis. <http://www.telegraph.co.uk/finance/personalfinance/10283259/Elderly-care-crisis-claims-a-million-family-homes.html>
- U.K. | *The Guardian* – 4 September 2013 – **'Rise in cost of dying drives up rate of "funeral poverty."** The total cost of dying has risen faster than inflation to £7,622 ... with one in five people struggling to pay for a funeral.<sup>1</sup> Since 2007, burial fees have risen 69%, cremation fees by 51%. <http://www.theguardian.com/money/2013/sep/04/rise-cost-dying-funeral-poverty>
  1. 'When it's gone, it's gone: The paradox of saving for funeral costs,' Sun Life Direct. [http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site\\_Build/About\\_Sun\\_Life\\_Direct/News\(1\)/sun\\_life\\_direct\\_cost\\_of\\_dying\\_report\\_2013.pdf](http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site_Build/About_Sun_Life_Direct/News(1)/sun_life_direct_cost_of_dying_report_2013.pdf)

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

#### **High burden of palliative needs among older ICU survivors transferred to post-acute care facilities: A single center study**

*ANNALS OF THE AMERICAN THORACIC SOCIETY* | Online – 29 August 2013 – Adults with chronic critical illness have a high burden of palliative needs, but little is known about the actual use and potential need of palliative care services for the larger population of older ICU survivors discharged to post-acute care facilities. The median age was 78 (71-84) years, and 54% received mechanical ventilation for a median 7 (3-16) days. Six subjects (2.6%) received a palliative care consultation during the hospitalization. However, 87% had at least one potential palliative care need; 22% had chronic wounds, 37% were discharged on supplemental oxygen, 17% received chaplaincy services, 23% preferred to not be resuscitated, and 8% were designated "comfort care." The six-month mortality was 40%. Older ICU survivors from a single center who required post-acute facility care had a high burden palliative care needs and a high six-month mortality. The in-hospital post-critical acute care period should be targeted for palliative care assessment and intervention. <http://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201303-039OC>

Of related interest:

- *CURRENT OPINION IN CRITICAL CARE* | Online – 28 August 2013 – **'Assessing the impact of palliative care in the intensive care unit through the lens of patient-centered outcomes research.'** Previous studies ... have used heterogeneous outcomes, conceptualized as: systems-related, content-related, clinician or patient/family-related. Few outcomes were used in multiple studies and many had insufficient power and questionable generalizability and impact. Although nearly all previous studies incorporated family-related outcomes, not one incorporated patient-centered outcomes, such as health-related quality of life, patient symptom score, or consensus between patient goals and care provided. [http://journals.lww.com/critical-care/Abstract/publishahead/Assessing\\_the\\_impact\\_of\\_palliative\\_care\\_in\\_the.99581.aspx](http://journals.lww.com/critical-care/Abstract/publishahead/Assessing_the_impact_of_palliative_care_in_the.99581.aspx)

#### [Quotable Quotes](#)

*Anyone with gumption and a sharp mind will take the measure of two things: what's said and what's done.*  
**Seamus Heaney, Irish poet (1939-2013)**

## Palliative care in Mainland China

*ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT*, 2013;8(1):9-13. Predictable deaths from diseases like cancer account for approximately 83% of deaths in China. Despite the growing numbers of terminally ill people from all diseases, palliative care is in its infancy. Factors that have slowed the development of palliative care include cultural values that encourage efforts to cure (even when such treatment is likely to be futile) over the alleviation of suffering, limited public policies and funding for palliative care, and poor education of healthcare professionals about end-of-life care. To improve the palliative care of people in China who are terminally ill, efforts should be made to integrate best practice into the healthcare system, while being sensitive to, and preserving cultural values. In this paper, suggestions are made for the future development of palliative care in China. Through working on the issues highlighted in this paper China has an opportunity to improve the end-of-life care of people who are terminally ill. Journal contents page, with link link to article: <http://www.achsm.org.au/members-services/journal/journal-2013---/>

Noted in Media Watch,  
13 February 2012, #240 (p.8):

### End-of-life care in Hong Kong

*ASIAN JOURNAL OF GERONTOLOGY & GERIATRICS*, 2011;6(2):103-106. The Hong Kong government does not have a clear policy on developing high-quality end-of-life care services as a critical part of health care, nor on promoting dying in place, either at home or in a residential care home for the elderly. [http://hkag.org/Publications/AJGG/V6N2/RA1\\_JKH%20Luk.pdf](http://hkag.org/Publications/AJGG/V6N2/RA1_JKH%20Luk.pdf)

Noted in Media Watch, 27 August 2012, #268 (p.5):

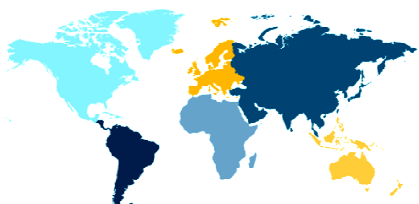
- *Global Times* (Beijing) | Online – 21 August 2012 – **'A new start for end-of-life care.'** Shanghai Municipal Health Bureau has issued guidelines for a pilot program to set up hospice centers in each of the city's 17 districts. The pilot program is one of the city's first steps toward developing end-of-life care in the city, where hospitals can't handle the burden of terminally ill patients. <http://www.globaltimes.cn/content/728297.shtml>


Noted in Media Watch, 13 February 2012, #250 (p.5):

- Channel News Asia (Beijing) | Online – 9 February 2012 – **'China faces shortage on hospice care.'** With over 400 patients, Song Tang hospice is one of the oldest and biggest hospices in China. The 24-year-old hospice had to move seven times in the past 2 decades, due to traditional notions and biases associated with death and dying. But over the past decade, there has been a perceptible change in mindset with the concept of ageing and dying, and that's mainly due to a change in family and social structure, as well as a rapidly aging society. <http://www.channelnewsasia.com/stories/southeastasia/view/1181930/1.html>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 September 2013 – **'Improving the quality of end-of-life care in long-term care institutions.'** Knowledge gaps among RCHE [residential care homes for the elderly] staff existed in the areas of mortality relating to chronic diseases, pain and use of analgesics, feeding tubes, dysphagia, sputum management, and attitudes towards end-of-life care issues... Residents and family members highlighted the preference for death over suffering, planning for death, misconceptions about life-sustaining treatments and the advance directive document, and service gaps in advance care planning. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0190>



 World hospice &  
palliative care day  
Voices for hospices 2015

<http://www.worldday.org/>

12 October 2013

## **Palliative care research on the island of Ireland over the last decade: A systematic review and thematic analysis of peer reviewed publications**

*BMC PALLIATIVE CARE* | Online – 4 September 2013 – As palliative care research continues to expand ... questions exist about the nature and type of research undertaken in addition to the research priorities for the future. This review, which is the first stage of a larger scale study to identify the research priorities for palliative care on the island of Ireland, examined palliative care research conducted on the island over the last decade. Whilst there has been a welcome growth in palliative care research across Ireland, this has largely been needs-based and small scale studies. In contrast, international researchers and decision makers recommend the need for more outcomes focused multidisciplinary research. <http://www.biomedcentral.com/content/pdf/1472-684X-12-33.pdf>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 September 2013 – **'Research priorities for geriatric palliative care: Goals, values, and preferences.'** Priorities ... now include empirical testing of communication approaches for surrogates and for diverse populations, exploration of meaningful ways to communicate prognosis, and expansion of intervention research. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.9475>

## **Hospitals should be rated on their care of older people, Royal College of Physicians recommends**

*BRITISH MEDICAL JOURNAL* | Online – 3 September 2013 – The Royal College of Physicians is to review its training and assessment processes in light of the Francis inquiry, to ensure that trainee doctors are encouraged to focus on quality and that their competence in raising concerns and treating patients with dignity is assessed. In a detailed response to Robert Francis's public inquiry into failings at Mid-Staffordshire National Health Service Foundation Trust, the college has pledged to strengthen doctors' leadership skills and to publish new guidance on raising concerns, to help implement the inquiry's recommendations.<sup>1</sup> <http://www.bmj.com/content/347/bmj.f5389>

1. *Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry*, February 2013. Executive summary, Vols. 1-3. [Noted in Media Watch, 11 February 2013, #292 (p.5)] <http://www.midstaffspublicinquiry.com/report>

## **The use of weblogs within palliative care: A systematic literature review**

*HEALTH INFORMATICS JOURNAL* | Online – 30 August 2013 – The use of weblogs has had a huge impact within the healthcare sector, and palliative care users have found a way to express themselves using this technology. The objective of this article is to review current research on palliative care service users' experience of using weblogs. Results show that palliative care bloggers find blogging therapeutic and beneficial. Weblogs empowered individuals leading to health behaviour change while also giving them access to social support thus fostering well-being. However, there is lack of robust evidence showing the benefits of blogging using clinical measures or other scientific methods. Given the growth of these weblogs by palliative care patients, research is required to strengthen evidence for their benefit and to evaluate their effectiveness. <http://jhi.sagepub.com/content/early/2013/08/28/1460458213475894.abstract>

Noted in Media Watch, 1 April 2013, #299 (p.3):

- U.S. | National Public Radio – 28 March 2013 – **'Why more patients should blog about illness and death.'** Blogging and sharing about illness is helping to open up the conversation about death that we so often avoid. It empowers patients to talk about illness outside the typical frame of "the battle" ... <http://www.npr.org/blogs/health/2013/03/26/175383540/why-more-patients-should-blog-about-illness-and-death>

## Negotiating palliative care in the context of culturally and linguistically diverse patients

*INTERNAL MEDICINE JOURNAL* | Online – 4 September 2013 – There is an increasing emphasis on meeting the healthcare needs of culturally and linguistically diverse (CALD) communities in Australia. Negotiating the point of futility and the transition to specialist palliative care requires not only effective communication but also sensitivity to cultural and linguistic specificities. This can be a challenging process for clinicians, patients and families. The authors outline some of the key challenges currently facing many clinicians in the context of CALD patients, with particular reference to the transitioning of patients to specialist palliative care. They suggest a focus on further research that can systematically document and model existing CALD-specific clinical processes and pathways, which can then support the development of targeted educational interventions. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12244/abstract>

Noted in Media Watch, 12 August 2013, #318 (p.5):

- AUSTRALIA (VICTORIA) | Pro Bono News – 9 August 2013 – **'Funds to access palliative care for ethnic communities.'** Almost 24% of Victorians were born overseas; however people from Culturally & Linguistically Diverse [CALD] backgrounds only account for 7% of palliative care clients. The Culturally Responsive Palliative Care Community Education project would engage with the Chinese, Italian, Maltese, Turkish and Vietnamese communities. <http://www.probonoaustralia.com.au/news/2013/08/funds-access-palliative-care-ethnic-communities>

Noted in Media Watch, 15 October 2012, #275 (p.4):

- AUSTRALIA | ProBono News (Windsor, Victoria) – 11 October 2012 – **'Report calls for national conversation on palliative care.'** The Senate has released a long-awaited report into the state of palliative care in Australia,<sup>1</sup> calling for a national conversation on palliative care. The [Senate] recommendations also focus on the needs of specific groups such as Indigenous Australians and CALD communities. <http://www.probonoaustralia.com.au/news/2012/10/report-calls-national-conversation-palliative-care#>

1. 'Palliative Care in Australia,' Senate Community Affairs Committee Secretariat, 2012. [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate\\_Committees?url=claccte/palliative\\_care/report/index.htm](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=claccte/palliative_care/report/index.htm)

Of related interest:

- *JOURNAL OF PRIMARY HEALTH CARE*, 2013;5(3):206-213. **'Patient and family perceptions of hospice services: "I knew they weren't like hospitals."** The vision for palliative care service provision in New Zealand is for all people who are dying and their families to have timely access to culturally appropriate, quality palliative care services. An Auckland hospice's records show that the ethnically diverse population statistics were not reflected in the referrals for hospice services. The aim of this research was to gain a patient-and-their-family perspective on the hospice, including exploration of components of service care that could be improved for various cultural groups. Four key themes emerged: 1) hospice personnel's approach to patients; 2) quality of service; 3) cultural barriers; and, 4) strategies for future improvement. It was determined the latter two were the most significant to address in this article. <http://www.mzcgp.org.nz/assets/documents/Publications/JPHC/September-2013/JPHCOSPBraySept2013.pdf>

Noted in Media Watch, 6 May 2013, #304 (p.12):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 3 May 2013 – **"Where do I go from here?" – A cultural perspective on challenges to the use of hospice services.'** Based on a Western view of palliative care, the vision outlined in the New Zealand Palliative Care Strategy is to deliver palliative care services, including hospice services, to all patients and their families requiring them in the context of an increasingly pluralistic and multi-cultural society. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12038/abstract>



## **Continuous deep sedation until death in nursing home residents with dementia: A case series**

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 3 September 2013 – The objective of this study was to describe the characteristics of continuous deep sedation until death and the prior decision-making process of nursing home residents dying with dementia and to evaluate this practice according to features reflecting sedation guideline recommendations. Eleven of 117 deceased residents with dementia and nine of 64 residents with advanced dementia were sedated. Two of the 11 sedated residents were not considered to be terminal. Sedation duration ranged from 1 to 8 days. Two received artificial food and fluids during sedation. Five were partly or fully competent at admission and three in the last week. Four had expressed their wishes or had been involved in end-of-life decision-making; for eight residents, the GP discussed the resident's wishes with their relatives. Relatives reported that five of the residents had one or more symptoms while dying. Nurses of three residents reported that the dying process was a struggle. For two residents, sedation was effective. Continuous deep sedation until death for nursing home residents does not always guarantee a dying process free of symptoms and might be amenable to improvement. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12447/abstract>

Noted in Media Watch, 15 July 2013, #314 (p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 11 July 2013 – '**Estimating the potential life-shortening effect of continuous sedation until death: A comparison between two approaches.**' The accuracy of these estimations [that continuous sedation until death may have a life-shortening effect] can be questioned. The aim of this study is to compare two approaches to estimate the potential life-shortening effect of continuous sedation until death. <http://jme.bmj.com/content/early/2013/07/10/medethics-2013-101459.abstract>

### **Media Watch: Editorial Practice**

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

### **Distribution**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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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.

## Quality of life in fatal disease: The flawed judgement of the social environment

*JOURNAL OF NEUROLOGY* | Online – Accessed 3 September 2013 – Decisions to prolong or shorten life in fatal diseases like amyotrophic lateral sclerosis (ALS) are strongly influenced by healthy individuals, such as caregivers and physicians. Furthermore, many believe that amyotrophic lateral sclerosis patients should decide ahead of time on advanced directives to circumvent confounding effects of subsequent cognitive impairments. The ability of healthy persons ... to anticipate patients' quality of life (QoL), depression and vital decisions was determined in a cross-sectional approach. [In this study] eighty-nine ALS patients, 86 caregivers and 102 age-matched healthy subjects were asked to judge ALS patients' QoL and depression and the patients' wish for hastened death. Patients judged their own, the caregivers judged that of the patient under their care, healthy subjects were asked to judge that of a virtual patient. Additionally, healthy persons were asked to judge their own QoL and depression. Patients reported

a satisfactory well-being and a low wish for hastened death. Healthy persons rated the patients' QoL significantly lower and the rate of depression significantly higher. The wish for hastened death was significantly lower in the patient group compared to what healthy subjects thought the patient would wish. The assessment by others was closely related to the persons' own well-being. Significant differences were identified between caregiver's perspectives and the patient's own perception of their psychological well-being. <http://link.springer.com/article/10.1007/s00415-013-7068-y>

### Extract from *Journal of Neurology* article

The authors' data suggest that caregivers and the general public significantly underestimate the QoL of ALS patients. A positive affective state can indeed be preserved in a progressive, fatal disease.

Noted in Media Watch, 7 June 2010, #152 (p.5):

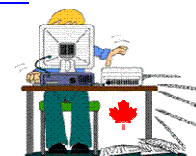
- *AMYOTROPHIC LATERAL SCLEROSIS* | Online – 17 March 2010 – '**Meaning in life in patients with amyotrophic lateral sclerosis.**' Compared to the general population, ALS patients list more meaning-relevant areas, are more likely to list partner, and less likely to list health. <http://informahealthcare.com/doi/abs/10.3109/17482961003692604>

## Resource utilization among individuals dying of pediatric life-threatening diseases

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 September 2013 – Little information exists on the number of resources utilized by individuals living with and dying of pediatric life-threatening diseases (LTDs). This study quantifies end of life resource utilization among the pediatric population in British Columbia, Canada. During the fiscal year of death and the fiscal year prior to death, children/adolescents and young adults dying of a pediatric LTD respectively experienced 5.3 and 3.7 hospital discharges, spent 48 and 39 days in the hospital, and required approximately 222 and 230 medical services. Infants were discharged once on average, and required 21 medical services. Resource utilization was very high for all three age groups, demonstrating the intense need for care by children dying of disease. These findings call for strengthening palliative care services in the province. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0110>

### 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>



### **Cost savings vary by length of stay for inpatients receiving palliative care consultation services**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 September 2013 – Cost savings associated with palliative care (PC) consultation have been demonstrated for total hospital costs and daily costs after PC involvement. This analysis adds another approach by examining costs stratified by hospital length of stay (LOS). Significant savings per admission were associated with shorter LOS: for stays of 1 to 7 days, costs were lower for all PC patients by 13% (\$2,141), and for survivors by 19.1% (\$2,946). For stays of 8 to 30 days, costs were lower for all PC patients by 4.9% (\$2,870), and for survivors by 6% (\$2,487). Extrapolating the per admission cost across the PC patient groups with lower costs, these programs saved about \$1.46 million for LOS under a week and about \$2.5 million for LOS of 8 to 30 days. Patients with stays >30 days showed no differences in costs, perhaps due to preferences for more aggressive care for those who stay in the hospital more than a month. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0163>

### **Seriously ill hospitalized patients' perspectives on the benefits and harms of two models of hospital CPR discussions**

*PATIENT EDUCATION & COUNSELING* | Online – 3 September 2013 – The authors created two videos depicting a hospital doctor discussing CPR with a seriously ill patient. One depicted a values-based approach with a doctor's recommendation, and one an information-focused approach without a recommendation. Half of [study] participants reported no preference between the videos; 35% preferred the information-focused, and 15% the values-based. Participants' reactions to the discussion components varied. They identified both benefits and harms with components in both videos, though most felt comfortable with all components except for the doctor's recommendation in the values-based video. Only 40% would feel comfortable receiving a recommendation, while 65% would feel comfortable with the doctor eliciting their CPR preference as in the information-focused video. [http://www.pec-journal.com/article/S0738-3991\(13\)00310-8/abstract](http://www.pec-journal.com/article/S0738-3991(13)00310-8/abstract)

### **The ability of informal primary caregivers to accurately report cancer patients' difficulties**

*PSYCHO-ONCOLOGY* | Online – 29 August 2013 – This study assessed informal primary caregivers' ability to report patients' physical, psychological, and social difficulties. Caregivers correctly reported 67% of physical, 69% of psychological, and 40% of social difficulties experienced in patients. They falsely reported 28% of physical, 37% of psychological, and 22% of social difficulties not experienced by patients. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3362/abstract>

### **Frequency of Medicare recertification surveys for hospices is unimproved**

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Office of the Inspector General – 29 August 2013 – The authors found that the frequency of recertification surveys has not improved since 2005. Seventeen percent of State-surveyed hospices had not been recertified within the 6 years prior to the index date of 28 February 2013, with some hospices experiencing longer intervals since their last survey. They also found that in 12 States, more than 25% of hospices had not been recertified within the previous 6 years. These findings illustrate that Centers for Medicare & Medicaid Services' [CMS] use of fluctuating annual targets does not ensure timely recertification surveys of all hospices and raises concerns about whether CMS and contracted State survey agencies can ensure hospice compliance with Medicare CoPs [conditions of participation] and quality-of-care requirements for hospices. Therefore, the authors reiterate the recommendation that CMS seek statutory or regulatory timeframes for the frequency of hospice recertification surveys. CMS could consider setting this survey frequency standard at 3 years, to match the 3-year interval used by accrediting organizations (as approved by CMS); however, given resource limitations, setting a mandatory frequency-even for an interval of more than 3 years-could help to ensure improvement in survey frequency and avoid lengthy intervals between surveys for individual hospices. <http://oig.hhs.gov/oei/reports/oei-06-13-00130.asp>

## Media Watch Online

### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/](http://APHN.ORG/CATEGORY/MEDIA-WATCH/)

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

### Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

### 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>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/?s=ashpole>

### 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>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 September 2013 – **'Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: A qualitative study.'** In Switzerland, helping with assisted suicide under certain conditions is not prosecuted. With approximately 300 cases annually, this leaves behind a large group of bereaved people where its consequences are mostly unknown. This study aimed to explore family involvement in decision making prior to assisted suicide, and to examine their ways of coping during the bereavement period. Bereaved families express moral dilemmas, feelings of isolation and secrecy in the management of assisted suicide in Southern Switzerland. These features seem underestimated and not sufficiently recognised by the healthcare professionals. <http://spcare.bmj.com/content/early/2013/09/03/bmjspcare-2013-000483.abstract>

Cont.

- *THE GERONTOLOGIST* | Online – 2 September 2013 – '**Discussing physician-assisted dying: Physicians' experiences in the U.S. and The Netherlands.**' PAD [physician-assisted dying] discussions, which ranged from theoretical discussions to actual requests, could be gateways to discussions of other end-of-life issues important to patients and could strengthen doctor-patient relationships. Physicians [i.e., study participants] found discussions to be emotionally intense, but often rewarding. Where PAD was legal, physicians utilized existing criteria to guide communication, and discussions were open and honest with patients and colleagues. Where PAD was illegal, conversations were less explicit, and physicians dealt with requests in relative isolation. In addition, physicians' views of their professional role, patients' rights, and religion influenced both their willingness to have and the content of PAD discussions. <http://gerontologist.oxfordjournals.org/content/early/2013/08/31/geront.gnt087.abstract>
- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2013;13(2):237-242. '**The right to pain control.**' Since the passage of the Patient Protection & Affordable Care Act in 2010, public concern persists about health care rationing and the use of quality-of-life criteria in end-of-life counseling by public providers of health care funding. Advisors to the Obama administration have shown an overriding concern for the cost rather than the quality of highly technical interventions in cases of life-threatening illness. Subtle encouragement of physician-assisted suicide has been detected in hospice and long-term-care facilities. Modern advances have made pain control an achievable right. Recognizing the right of patients ... to obtain effective pain control is an important factor in the opposition to health care rationing and euthanasia. <http://ncbcenter.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,9;journal,1,50;linkingpublicationresults,1:119988,1>

## Worth Repeating

### **Communication about end-of-life care between language-discordant patients and clinicians: Insights from medical interpreters**

*JOURNAL OF PALLIATIVE MEDICINE*, 2005;8(5):1016-1024. Communication about health care and especially end-of-life care is difficult for clinicians and patients when they do not speak the same language. The purpose of this study was to improve understanding of how to approach discussions between language-discordant patients and clinicians about terminal or life-threatening illness. The authors developed three frameworks... The first ... addresses physician and interpreter professionalism, including humanistic qualities and emotional support capabilities important for high quality care. The second ... is physician-centered and highlights communication skills, as well as coordination with other providers and cultural sensitivity. The third ... is interpreter-centered, focusing on role conflicts, including struggles concerning expectations to provide strict interpretation versus being a cultural broker. Interpreters' recommendations for improving quality of this care include pre-meetings with interpreters before encounters involving delivery of bad news and explicit discussions with interpreters about whether the clinician expects strict interpretation or cultural brokering. Interpreter recommendations provide physicians and health care organizations with specific tools that may improve quality of communication about end-of-life discussions. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2005.8.1016>

Noted in Media Watch, 16 July 2012, #262 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 July 2012 – '**Interpretation for discussions about end-of-life issues: Results from a national survey of health care interpreters.**' The majority of interpreters have experience with end-of-life discussions but, independent of interpreter training and experience, only half report that these discussions usually go well. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0032>

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Barry R. Ashpole  
Guelph, Ontario CANADA

'phone: 519.837.8936  
e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)