

Media Watch...

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

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Elder, home, and end-of-life care: Scroll down to [Specialist Publications](#) and 'Hearing the voices of people with high support needs' (p.10), in *Journal of Aging Studies*.

Canada

Employment Insurance benefits extended to families of seriously ill children

CBC NEWS | Online report – 7 January 2013 – The federal government intends to follow through with its promise to create a new employment insurance benefit for parents who need to take time off work to care for seriously ill children [Prime Minister Stephen Harper announced]. The new benefit ... would provide income support for up to 35 weeks... It would be available for parents or legal guardians of minor children (under 18 years of age) with a life-threatening illness or injury. A medical certificate signed by a Canadian-certified pediatrician or medical specialist would be required to be eligible for the benefit. As many as 6,000 families are expected to take advantage of the new assistance each year. It should be in place

by June 2013. It can be combined with the existing compassionate care benefit which provides up to six weeks of employment insurance for people caring for a sick loved one who is at risk of dying within six months. <http://www.cbc.ca/news/politics/story/2012/08/07/pol-stephen-harper-british-columbia.html>

Important Update

The Compassionate Care Benefit website was updated 24 December 2012. http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

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>

U.S.A.

Hospice for the homeless: Faith community unites to help provide death with dignity

UTAH | *Deseret News* (Salt Lake City) – 5 January 2013 – For Kristy Chambers, chief executive officer of Salt Lake City's Fourth Street Clinic, the memory is still troubling – and motivating. "We had a gentleman who came to us who was in the latter stages of his life," she said softly, her upbeat demeanor noticeably shifting at the memory. "He knew he was dying, and he seemed to be at peace with it." The clinic ... exists to provide a wide variety of medical services to [a] growing homeless population. Its effectiveness and capability are the envy of other homeless service providers around the country, and the full resources of the facility were employed on behalf of the man Chambers was talking about. <http://www.deseretnews.com/article/865569987/Hospice-for-the-homeless-Faith-community-unites-to-help-provide-death-with-dignity.html>

Noted in past issues of Media Watch:

- **'Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals,'** *BMC Palliative Care*, 15 September 2012. <http://www.biomedcentral.com/content/pdf/1472-684X-11-14.pdf>
- **'A qualitative study of homelessness and palliative care in a major urban center,'** *American Journal of Hospice & Palliative Medicine*, 5 June 2012. <http://ajh.sagepub.com/content/early/2012/06/03/1049909112448925.abstract>

End-of-life care

Better, if not cheaper, care

THE NEW YORK TIMES | Online OpEd – 4 January 2013 – It is conventional wisdom that end-of-life care is an increasingly huge proportion of health care spending. I've often heard it said that people spend more on health care in the year before they die than they do in the entire rest of their lives. If we don't address these costs, the story goes, we can never control health care inflation. Wrong. Here are the real numbers. The roughly 6% of Medicare patients who die each year do make up a large proportion of Medicare costs: 27 to 30%. But this figure has not changed significantly in decades. And the total number of Americans, not just older people, who die every year – less than 1% of the population – account for much less of total health care spending, just 10 to 12%. The more important issue is that just because we spend a lot on end-of-life care does not mean we can save a lot. We do know that costs for dying patients vary widely among hospitals, which suggests that we can do better. And yet no one can reliably say what specific changes would significantly lower costs. There is no body of well-conducted research studies that has proved how to save 5, 10, much less 20%. Studies find hospice may reduce costs in the last year of life for cancer patients by 10 to 20%. But they find no savings from hospice care for patients who die of other conditions, like emphysema or heart failure. <http://opinionator.blogs.nytimes.com/2013/01/03/better-if-not-cheaper-care/?emc=eta1>

Extract from *The New York Times* article

Even if we can never save a dime, however, there are good reasons to think about changing end-of-life care practices. While end-of-life care has improved considerably over the last 30 years, many Americans still die in hospitals when they would rather die at home. Nearly 20% of deaths occur in an intensive care unit or immediately after discharge, and too many patients experience symptoms like pain that are controllable with appropriate palliative care.

On the way to hospice, surprising hurdles

THE NEW YORK TIMES | Online OpEd – 3 January 2013 – I've often wondered why more families don't call hospice when a loved one has a terminal disease – and why people who do call wait so long, often until death is just days away. Even though more than 40% of American deaths now involve hospice care, many families still are trying to shoulder the burden on their own rather than turning to a proven source of help and knowledge. I've surmised that the reason is families' or patients' unwillingness to acknowledge the prospect of death, or physicians' inability to say the h-word and refer dying patients to hospice care. But maybe there's another reason. A study in *Health Affairs* recently pointed out that hospices themselves may be turning away patients because of certain restrictive enrollment policies.¹ It's possible, too, that physicians who know of these policies aren't referring patients whom the doctors fear wouldn't qualify. Surprisingly, this randomized national survey of almost 600 hospice programs represents the first broad inquiry into enrollment practices, though it's been nearly 30 years since hospice became a Medicare benefit. Nearly 80% of hospice programs, the study found, reported having at least one policy that could restrict access. <http://newoldage.blogs.nytimes.com/2013/01/03/hospice-obstacles/>

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>

Specialist Publications

'Advance directives and HIV: A current trend in the Inner City [of New York]' (p.11), in *Journal of Community Health*.

"Fueling waste, fraud and patient harm"

For-profit nursing homes lead in overcharging while care suffers

BLOOMBERG NEWS | Online – 31 December 2012 – A report by federal health care inspectors in November said the U.S. nursing home industry overbills Medicare \$1.5 billion a year for treatments patients don't need or never receive. Not disclosed was how much worse it is when providers have a profit motive. Thirty per cent of claims sampled from for-profit homes were deemed improper, compared to just 12% from non-profits, according to data Bloomberg News obtained from the inspector general's office of the U.S. Department of Health & Human Services. The figures add to the case – advanced by health care researchers and Medicare overseers in at least six government and academic studies in the last three years – that the rise of for-profit providers is fueling waste, fraud and patient harm in the \$2.8 trillion U.S. health care sector. At nursing homes, 78% of \$105 billion in revenues went to for-profits in 2010, up from 72% in 2002, according to the latest available government breakdowns. <http://www.bloomberg.com/news/2012-12-31/for-profit-nursing-homes-lead-in-overcharging-while-care-suffers.html>

Noted in Media Watch, 18 June 2012:

- FLORIDA | *Palm Beach Post* (Editorial) – 17 June 2012 – '**Stop Medicare subsidy of big-money hospice industry.**' <http://www.palmbeachpost.com/news/news/editorial-stop-medicare-subsidy-of-big-money-hospi/nPXW3/>

N.B. See Media Watch 11 June 2012 (p.11-12) for a listing of articles, reports, etc., on for-profit hospice in the U.S.

Medicare audit

San Diego Hospice sees more layoffs, hospital closure

CALIFORNIA | KPBS News (San Diego) – 31 December 2012 – San Diego's largest hospice operator temporarily shut down its 24-bed hospital in Hillcrest and laid off more staff, as it struggles with an on-going Medicare audit. The hospital is an "extraordinarily expensive facility," according to San Diego Hospice President & CEO Kathleen Pacurar. The closure and layoffs came in anticipation of the hospice provider having to pay back millions of dollars in benefits once the audit is complete, Pacurar said. The audit, which began nearly two years ago, is looking at whether thousands of people who used San Diego Hospice were actually eligible and whether their medical diagnoses were properly documented. Medicare pays for most hospice care and the cost across the country is growing, ballooning from \$2.2 billion in 1998 to \$12.1 billion in 2009, according to government statistics. As a result of the growing cost of hospice, Medicare has been investigating the use of the benefit. <http://www.kpbs.org/news/2012/dec/31/sd-hospice-more-layoffs-hospital-closure/>

Noted in Media Watch, 19 November 2012:

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

Of related interest:

- IOWA | *Siouxland City Journal* – 4 January 2013 – **'Hospice of Siouxland to lay off 28 employees.'** Hospice of Siouxland announced it will lay off 28 part-time and full-time workers due to changes in federal funds. Hospice officials reported a nearly 30% decline in the number of patients they're able to serve because of changing regulations in Center for Medicare and Medicaid Services. http://siouxcityjournal.com/news/local/briefs/hospice-of-siouxland-to-lay-off-employees/article_2ab858ad-689c-5ce1-91c9-fa35cf0775a6.html

"What do you say after you say goodbye?"

Exit lines

THE NEW YORK TIMES | Online – 28 December 2012 – My father spoke to his college roommate every day for 50 years. Though the two lived in different states, 800 miles apart, they were business partners, sounding boards and friends. Then one day my father called and his friend wasn't there. He had died the night before of a terminal illness, which he had never told my father about. The two never said goodbye. I was reminded of this episode last summer when Nora Ephron, the famed raconteur, director and (by all accounts) friend, died after keeping her terminal illness private from nearly everyone she knew. Meryl Streep captured the frustration of many. "We've been ambushed," she said at Ms. Ephron's memorial service. "It's really stupid to be mad at somebody who dies, but somehow I've managed it." Frank Rich added in *New York Magazine*, "Some of us – and that would include me – were pissed off at first."¹ "Afterward I called my dad. He wasn't upset with his friend, he said. Final conversations are difficult. The following day he sent me a poignant, one-sentence e-mail, "What do you say after you say goodbye?" I've wondered about that question ever since. http://www.nytimes.com/2012/12/30/fashion/finding-the-words-or-not-to-say-goodbye.html?_r=0

1. *NEW YORK MAGAZINE* | Online – 19 August 2012 – **'Nora's secret.'** "Everything is copy," Nora Ephron learned from her mother. She kept one thing to herself, though – and left many of us wondering why. <http://nymag.com/news/frank-rich/nora-ephron-2012-8/>

International

End-of-life care in New Zealand

Asians not well informed about health services

NEW ZEALAND | Stuff.com.nz (Wellington) – 4 January 2013 – With more Asians now living in Christchurch than Maori, more needs to be done to ensure they know what health services are available, Partnership Health Canterbury's ethnic liaison officer says. Accessing health services in New Zealand was difficult for many Asian people, with language and cultural differences preventing some from seeking help, especially when it came to end-of-life care. Each culture and religion had different views on death and dying and there was not a blanket Asian culture, he said. When it came to palliative care, many Asians questioned why they would want to go into a hospice when their families would usually take care of them. <http://www.stuff.co.nz/national/health/8141703/Asians-not-well-informed-about-health-services>

Noted in Media Watch, 10 December 2012:

- NEW ZEALAND | Voxy.co.nz – 5 December 2012 – **'University of Canterbury leads research in palliative care services for minority groups.'** Elderly people of Asian background are least likely to access palliative and hospice services due to language and cultural barriers, and lack of information. <http://www.voxy.co.nz/health/uc-leads-research-palliative-care-services-minority-groups/5/142456>

A day in the life of ... a hospice social worker

U.K. | *The Guardian* – 4 January 2013 – Hospice care extends beyond just the treatment of physical symptoms. We also consider the emotional, social and practical needs of seriously ill people and their families, friends and carers, providing care that is tailored and personal for each person. Many families affected by terminal illness have worries about issues such as employment, finances, housing, their children, practical matters, or future care. I work in a team of experienced social workers at St Joseph's hospice to help people address these issues, working across all clinical areas at the

Specialist Publications

Of related interest:

Latin America: 'Atlas de cuidados paliativos de Latinoamérica' (p.8), in *European Association for Palliative Care*.

Japan: 'What influences the willingness of community physicians to provide palliative care for patients with terminal cancer? Evidence from a nationwide survey' (p.10), in *Japanese Journal of Clinical Oncology*.

Republic of Korea: 'Current status of end-of-life care in Korean hospitals' (p.12), in *Journal of the Korean Medical Association*.

Turkey: 'Palliative care in last 48 hours of terminally period: Review' (p.11), in *Journal of Anesthesiology & Reanimation*.

hospice, including day care, the in-patient unit and out in the community. <http://www.guardian.co.uk/social-care-network/2013/jan/04/day-in-life-hospice-social-worker>

Specialist Publications

Of related interest:

'Hearing the voices of people with high support needs' (p.10), in *Journal of Aging Studies*.

Cont.

Noted in Media Watch, 23 July 2012:

- **COMMUNITY CARE** | Online – 19 July 2012 – **'Social work 'too often missing from end-of-life care.'** Social workers have a vital role in end-of-life care but they often struggle to perform it because of cuts, workloads and a lack of confidence, says a report from the National End of Life Care Programme.¹ <http://www.communitycare.co.uk/Articles/19/07/2012/118394/Social-work-39too-often-missing-from-end-of-life.htm>

1. 'The route to success in end of life care – achieving quality for social work,' National End of Life Care Programme, The College of Social Work & National Health Service, July 2012. http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoL.C_Social_Work_Route_to_Success_web.pdf

"Pressures of an ageing population"

Neglectful Britons blamed for forcing elderly into care homes

U.K. | *The Daily Telegraph* – 2 January 2013 – Britain has become a "neglectful society" where the elderly are driven into care homes unnecessarily because they lack support from their families and communities, the care minister has claimed. [Secretary of State for Health] Norman Lamb told *The Daily Telegraph* that older people were being let down by their friends and neighbours who should help them to live independently at home. Local councils needed to help rebuild "neighbourly resilience" to stop pensioners leading dismal, lonely lives, he said, which would also reduce the burden on the state by avoiding the need for as many people to be moved into residential care. Mr. Lamb added that the care system would only cope with the pressures of an ageing population if individuals contributed to a "partnership between state and society." Mr. Lamb confirmed that a government deal to cap spending on care fees will be announced in the coming weeks. The funding deal is likely to limit lifetime spending on care costs at £75,000, and ease means-testing rules. <http://www.telegraph.co.uk/news/uknews/9773652/Neglectful-Britons-blamed-for-forcing-elderly-into-care-homes.html>

Noted in Media Watch, 27 February 2012:

- U.K. | *The Daily Mail* – 21 February 2012 – **'Code that makes dignity and respect a right for our elderly is launched.'** <http://www.dailymail.co.uk/news/article-2104670/Dignity-Code-makes-respect-right-elderly-launched.html?ito=feeds-newsxml>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | *The New Zealand Herald* – 6 January 2013 – **'Polls: Gay marriage, right to die get the tick.'** New polls show New Zealanders support the terminally ill's right to die, think same-sex marriages should be legal and are largely happy with the current number of people immigrating. http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10857496



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

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

Promoting volunteer capacity in hospice palliative care: A narrative review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 December 2012 – A substantial body of evidence exists describing the roles, stresses and rewards of hospice volunteering. Less is known about how to adequately recruit, prepare and retain volunteers. A small but intriguing body of evidence exists around volunteers' contributions to family satisfaction and patient longevity. Although the evidence around hospice volunteers continues to grow, there is an urgent need for further research. Findings indicate that volunteers make important contributions to high quality end of life care. However, more focused research attention is required to better understand how to maximize this contribution while providing better support for volunteers.

<http://ajh.sagepub.com/content/early/2012/12/28/1049909112470485.abstract>

Noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – '**Hold on to what you have got: Keeping hospice palliative care volunteers volunteering.**' <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2012 – '**Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.**' <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>

Narratives of 'terminal sedation' and the importance of the intention-foresight distinction in palliative care practice

BIOETHICS, 2013;27(1):1-11. The moral importance of the 'intention-foresight' distinction has long been a matter of philosophical controversy, particularly in the context of end-of-life care. Previous empirical research in Australia has suggested that general physicians and surgeons may use analgesic or sedative infusions with ambiguous intentions, their actions sometimes approximating 'slow euthanasia.' The authors report findings from a qualitative study of 18 Australian palliative care medical specialists, using in-depth interviews to address the use of sedation at the end of life. The majority of subjects were agnostic or atheistic. In contrast to their colleagues in acute medical practice, these Australian palliative care specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia. While some respondents acknowledged that there are difficult cases that require considered reflection upon one's intention, and where there may be some 'mental gymnastics,' the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms. They present four narratives of 'terminal' sedation – cases where sedation was administered in significant doses just before death, and may well have hastened death. Considerable ambiguities of intention were evident in some instances, but the discussion around these clearly exceptional cases illustrates the importance of intention to palliative care specialists in maintaining their professional roles.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01895.x/abstract>

Corrections & Clarifications

In the 17 December 2012 issue of Media Watch (#284), the article 'Medical specialists' motivations for referral to specialist palliative care: A qualitative study' (p.6) was wrongly indicated as published in the *American Journal of Hospice & Palliative Medicine*. The article was in fact published in *BMJ Supportive & Palliative Care*. Sincere apologies for any confusion.
BRA

Cont.

Of related interest:

- *GERIATRIC NURSING* | Online – 2 January 2013 – '**Justifying continuous sedation until death: A focus group study in nursing homes in Flanders, Belgium.**' Refractory suffering, limited life expectancy and respecting patient autonomy are considered essential elements in deciding for CSD [Continuous Sedation until Death] . However, multiple factors complicate the care of nursing home residents at the end of life, and often hinder clinicians from putting these elements into practice. [http://www.gnjournal.com/article/S0197-4572\(12\)00344-8/abstract](http://www.gnjournal.com/article/S0197-4572(12)00344-8/abstract)

Noted in Media Watch, 17 December 2012:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 December 2012 – '**Intentional sedation to unconsciousness at the end of life: Findings from a national physician survey.**' [http://www.jpmsjournal.com/article/S0885-3924\(12\)00748-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00748-8/abstract)

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

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

Atlas de cuidados paliativos de Latinoamérica

(Atlas of palliative care in Latin America)

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – Accessed 2 January 2013 – The main objective of the Atlas is to evaluate the development of CP [cuidados paliativos] in Latin America. Secondary objectives include among others, facilitate access to information and communication between regional institutions and associations dedicated to the CP, identify the key people involved in the development of CP in each country, and promote the development of CP in Region. The Atlas includes a regional summary, the list of participants and reports by country. <http://www.cuidadospaliativos.org/article.php?id=62>

N.B. Spanish language posting.

Patient and family members' perceptions of palliative care in heart failure

HEART & LUNG: THE JOURNAL OF ACUTE & CRITICAL CARE | Online – 18 December 2012 – [In this study], participants: 1) were generally ill-prepared for the PC [palliative care] consult; 2) pursued a plan that reflected their own understanding of patient prognosis, rather than that of the clinician; 3) described a primarily supportive role for PC; and, 4) often rejected or deferred PC services if they viewed hospice and PC as synonymous. Lack of awareness of PC and the conflation of PC and hospice were barriers to PC, and many participants felt that PC services are needed to fill the gaps in their care. A collaborative model of care may best meet the complex needs of this group. [http://www.heartandlung.org/article/S0147-9563\(12\)00398-6/abstract](http://www.heartandlung.org/article/S0147-9563(12)00398-6/abstract)

Cont.

Of related interest:

- *HOME HEALTHCARE NURSE*, 2013;31(1):29-36. **'Uncertainties of the heart: Palliative care and adult heart failure.'** Eleven of 16 articles reviewed indicated that palliative care is underused. http://journals.lww.com/homehealthcareonline/Abstract/2013/01000/Uncertainties_of_the_Heart_Palliative_Care_and.6.aspx

Noted in Media Watch, 1 October 2012:

- *EUROPEAN JOURNAL OF AGEING* | Online – 22 September 2012 – **"Who is going to explain it to me so that I understand?" Health care needs and experiences of older patients with advanced heart failure.** <http://www.springerlink.com/content/4001j18092105526/>

The promise and paradox of cultural competence

HEC FORUM,¹ 2012;24(4):279-291. Cultural competence has become a ubiquitous and unquestioned aspect of professional formation in medicine. It has been linked to efforts to eliminate race-based health disparities and to train more compassionate and sensitive providers. In this article, the author questions whether the field of cultural competence lives up to its promise. She argues that it does not because it fails to grapple with the ways that race and racism work in U.S. society today. Unless we change our theoretical apparatus for dealing with diversity to one that more critically engages with the complexities of race, the author suggests that unequal treatment and entrenched health disparities will remain. If the field of cultural competence incorporates the lessons of critical race scholarship, however, it would not only need to transform its theoretical foundation, it would also need to change its name. <http://link.springer.com/article/10.1007/s10730-012-9200-2>

1. HealthCare Ethics Committee Forum

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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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.

A retrospective review of specialist palliative care involvement in motor neurone disease

IRISH MEDICAL JOURNAL, 2012;105(10). The provision of specialist palliative care to Irish patients suffering from motor neurone disease has not been described in the literature. The purpose of this study was to characterize the care provided at a Dublin hospice. Consecutive referrals between 1st January 1999 and 31st December 2008 were reviewed. At the time of data collection, 61 (84.7%) were deceased, 9 (12.5%) were alive and the status of 2 (2.7%) was unknown. Median survival from the point of referral was 7 months (95%). Of the 61 deceased patients, 22 (36%) died at home, 22 (36%) died in the inpatient unit, 9 (15%) died in hospital and 8 (13%) died in a nursing home. <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=9704>

Noted in Media Watch, 5 November 2012:

- *GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT*, 2012;15(2):32-35. '**Motor neurone disease and palliative care.**' This paper explores the progression of motor neurone disease in order to outline the complex needs and care requirements with respect to symptoms, suffering, grief and loss, and the potential for early referral to palliative care... <http://search.informit.com.au/documentSummary;dn=828691005476536;res=IELHEA>

Noted in Media Watch, 27 August 2012:

- *PALLIATIVE MEDICINE* | Online – 20 August 2012 – '**A 10-year literature review of family caregiving for motor neurone disease: Moving from caregiver burden studies to palliative care interventions.**' <http://pmj.sagepub.com/content/early/2012/08/17/0269216312455729.abstract>

What influences the willingness of community physicians to provide palliative care for patients with terminal cancer? Evidence from a nationwide survey

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 4 January 2013 – The majority of respondents expressed a willingness (92.4%) to provide palliative care if they encountered patients with terminal cancer. However, they would limit their services to consultation (83.4%) and referral (86.8%), and were less likely to see patients and prescribe medicine (62.0%), to provide phone follow-ups (45.6%), to provide home visits (42.2%) or to offer bereavement care for the family (35.1%). The results of stepwise logistic regression analysis for the willingness to provide home visits showed that 'less perception of barriers,' 'family medicine specialist' and 'older than 50 years' significantly predicted higher willingness, while 'female' predicted lower willingness. <http://jjco.oxfordjournals.org/content/early/2013/01/03/jjco.hys222.abstract>

Noted in Media Watch, 26 November 2012:

- *JAPANESE JOURNAL OF CLINICAL ONCOLOGY* | Online – 19 November 2012 – '**Past, present, and future of palliative care in Japan.**' <http://jjco.oxfordjournals.org/content/43/1/17.abstract>

Hearing the voices of people with high support needs

JOURNAL OF AGING STUDIES, 2013;27(1):52-60. The study explored the personal aspirations of a small diverse sample of hitherto un-researched people living in different parts of the U.K. Most were over 85 years of age, with varied ethnicity, health status, social care needs, financial status and lifestyle. Many participants were receiving input from statutory health and social care services and were perceived by others and often themselves to have high support needs. Accessible research methods were used to enable participants to specify those factors for well-being most central to their own lives and preferences. The study found commonalities of aspiration in relation to physical, social and psychological aspects of their lives, but also unique descriptions of their individual concerns. In striving to maintain a sense of self worth, participants accepted that some choices were not realistic for them personally. Positive relationships with care-givers were an essential enabler for some. In many cases negotiation has the potential to produce simple and cost-effective ways of addressing individual aspirations and improving quality of life. <http://www.sciencedirect.com/science/article/pii/S0890406512000795>

End-of-life care in Turkey

Palliative care in last 48 hours of terminally period: Review

JOURNAL OF ANESTHESIOLOGY & REANIMATION, 2012;10(3):168-76. A good death should be pain free and dignified for every human being. The goal of palliative care is to relieve the suffering of patients and their families by the treatment of physical, psychosocial, and spiritual symptoms in fatal, incurable diseases. In terminally period (last 6 month), symptoms require more aggressive palliation. The last 48 hours of palliative care is a period that shows all the processes of privilege. Control of symptoms and family support take priority, and the nature of the primary illness become less important in terminally 48 hours. During the final 48 hours of terminally period, patients experience increasing weakness and immobility, pain, nausea and vomiting, loss of interest in food and drink, difficulty swallowing, and drowsiness. This last period can usually be anticipated, but sometimes sudden deterioration can be distressing for health professionals. For this reason, the last 48 hours of terminally care requires physicians to utilize a multifaceted and special dynamic treatment. <http://anestezi.turkiyeklinikleri.com/abstract.php?id=63847>

Noted in Media Watch, 11 June 2012:

- *ANNALS OF ONCOLOGY*, 2012;23(Suppl.3):76-78. **'Turkish community-based palliative care model: A unique design.'** http://annonc.oxfordjournals.org/content/23/suppl_3/76.abstract

Noted in Media Watch, 11 April 2011:

- *JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY*, 2011;30(Suppl.1). **'Palliative care in Middle-Eastern countries.'** Focus is on palliative care in Cyprus, Egypt, Israel, Pakistan, the Palestinian Authority and Turkey. Other articles focus on opioid use in pain management. Contents page: <http://journals.lww.com/jpho-online/toc/2011/04001>

N.B. Turkey was rated 34th (of forty countries surveyed) in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Care planning

Stability over time in the preferences of older persons for life-sustaining treatment

JOURNAL OF BIOETHICAL INQUIRY | Online – 4 January 2012 – Eighty-six percent of the patients [i.e., study participants] did not change preferences. Sex, age, marital status, hospitalisation, and self-perception of health and pain did not affect preferences. Morbidity and the death of a relative did. Stability of preferences of older persons in relation to end-of-life decisions seems to be more probable than instability. Some factors, such as the death of a relative or the increase in morbidity, can change preferences. These findings have implications for advance directives and advance care planning. <http://link.springer.com/article/10.1007/s11673-012-9417-4>

Of related interest:

- *JOURNAL OF COMMUNITY HEALTH* | Online – 25 December 2012 – **'Advance directives and HIV: A current trend in the Inner City [of New York].'** The majority of HIV infected patients hospitalized lacked an AD [advance directive]. With longer years with an HIV diagnosis, the number of ADs did not increase. Results would indicate that a different approach is necessary to adequately address ADs with this specific population... <http://link.springer.com/article/10.1007/s10900-012-9645-x>
- *JOURNALS OF GERONTOLOGY* (Series B) | Online – 4 January 2013 – **'Family relationships and advance care planning: Do supportive and critical relations encourage or hinder planning?'** <http://psychsocgerontology.oxfordjournals.org/content/early/2013/01/03/geronb.gbs161.abstr act>

End-of-life care in Republic of Korea

Current status of end-of-life care in Korean hospitals

JOURNAL OF THE KOREAN MEDICAL ASSOCIATION, 2012;55(12):1171-1177. The level of end-of-life (EOL) care quality in the Republic of Korea has been regarded as inferior to more advanced countries. The EOL care delivered has varied depending on physicians' perceptions and patients' family requests for care. A consensus guideline on withdrawing life-sustaining therapies, which has been endorsed by the Korean Medical Association, Korean Academy of Medical Sciences, and Korean Hospital Association, was published on 13 October 2009. However, the guideline seems to be still not widely applied in our hospitals. The acknowledgment of patient wish, reflected by such as an advance directives (AD) is the most important ethical and legal requirement in EOL care decisions. However, there are barriers to adopting the AD as a solely legitimate tool of EOL decision making even in Western societies. Advance care planning depending on a patient's condition seems to be a more reasonable approach for better EOL care. For an appropriate advance care planning, open communications between physicians and patients or their surrogates is crucial. The lack of an open approach to discussing EOL care with patients results in inappropriate prolongation of patients' dying process. In summary, physicians, who know the clinical significance of treatments to be delivered to EOL patients, should play a central role based on the 2009 consensus guideline to help patients and their families make good decisions on EOL care. <http://synapse.koreamed.org/DOIx.php?id=10.5124/jkma.2012.55.12.1171>

N.B. This issue of the *Journal of the Korean Medical Association* includes several articles on life-sustaining treatment. Contents page: <http://jkma.org/>. Republic of Korea (i.e., South Korea) was rated 32nd (of forty countries surveyed) in The Quality of Death: Ranking End-of-life-Care Across the World, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Experience as a prelude to disaster: American philosophy and the fear of death

MORTALITY | Online – 24 December 2012 – This article addresses the existential problem of the fear of death. Drawing on the experiences and philosophies of Ralph Waldo Emerson, William James, and Jane Addams as a theoretical framework, a prescriptive claim regarding how to confront human mortality is advanced. It is suggested that embracing the notion of experience as a prelude to the disaster of death can be – despite appearances to the contrary – a useful approach to navigating exigencies connected with mortality and, in particular, fear of death. The essay contributes to a small but growing body of literature on the topic of death in American philosophy scholarship, while addressing a perennial problem receiving treatment in contemporary popular discourse. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.753871>

Pediatric palliative care

End-of-life care decisions in the PICU: Roles professionals play

PEDIATRIC CRITICAL CARE MEDICINE | Online – 17 December 2012 – The results of this study describe a framework for healthcare professionals' roles in parental end-of-life care decision making in the pediatric ICU that includes directive, value-neutral, and organizational roles. More research is needed to validate these roles. Actively ensuring attention to these roles during the decision-making process could improve parents' experiences at the end of a child's life. http://journals.lww.com/pccmjournal/Abstract/publishahead/End_of_Life_Care_Decisions_in_the_PICU_Roles.99274.aspx

Cont.

Of related interest:

- *JOURNAL OF CLINICAL ETHICS*, 2012;23(3):224-230. **'Stories and the longitudinal patient relationship: What can clinical ethics consultants learn from palliative care?'** Particularly in centers where palliative care services are not available, it can be important for care providers and clinical ethics consultants to focus on alliance-building and a longitudinal relationship with patients and families. http://www.clinicalethics.com/single_article/r0adiunluwA.htm

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *CHEST*, 2013;143(1):279a-279. **'Premature termination of life is not palliative care.'** Attorney Kathryn Tucker's guidance ... for physician aid in dying is troubling.¹ A citation error was apparent in a reference to the Expert Consensus Statement of the Heart Rhythm Society (HRS) regarding withdrawal of cardiovascular implantable electronic devices (CIEDs). Tucker wrote, "Provision of aid in dying does not constitute assisting a suicide or euthanasia." The HRS statement reads, "Ethically, CIED deactivation is neither physician-assisted suicide nor euthanasia." CIED deactivation is not aid in dying, and the HRS statement said why: "The clinician's intent is to discontinue the unwanted treatment and allow the patient to die naturally of the underlying disease – not to terminate the patient's life." <http://journal.publications.chestnet.org/article.aspx?articleid=1512547>

1. 'Aid in dying: Guidance for an emerging end-of-life practice,' *CHEST*, 2012;142(1):218-224. <http://journal.publications.chestnet.org/article.aspx?articleid=1206626#Abstract>

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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>

- *IRISH MEDICAL TIMES* | Online – 3 January 2013 – '**Court ruling on assisted suicide due in new year.**' A three-judge High Court will hand down judgment on the challenge to the absolute ban on assisted suicide brought by a woman terminally ill with multiple sclerosis. After the Court heard evidence and legal submissions in the case, the President of the High Court Mr. Justice Nicholas Kearns ... said they had many issues to consider and would give their judgment in the matter next month. Fifty-eight-year-old Marie Fleming of County Wicklow claims the ban on assisted suicide in Section 2.2 of the Criminal Law Suicide Act is unconstitutional, on the grounds it breaches her personal rights to equality, privacy and autonomy under the Constitution and European Convention on Human Rights. Counsel for the State argued that there was no right to suicide under the Constitution and the policy outlawing assisted suicide was justified to protect vulnerable people from involuntary death. <http://www.imt.ie/news/latest-news/2013/01/court-ruling-on-assisted-suicide-due-in-new-year.html>
- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 29 December 2012 – '**Different trends in euthanasia acceptance across Europe. A study of 13 western and 10 central and eastern European countries, 1981-2008.**' The authors examined how acceptance of euthanasia among the general public has changed between 1981 and 2008 in western and central and eastern European (CEE) countries using data of the European Values Surveys. Data were collected in 1981, 1990, 1999 and 2008 for 13 western European countries and in 1990, 1999 and 2008 for 10 CEE countries. Euthanasia acceptance increased each decade up until 2008 in 11 of 13 western European countries; in CEE countries, it decreased or did not increase between 1999-2008 in 8 of 10 countries. A number of explanations for and implications of this apparent east-west polarization are suggested. <http://eurpub.oxfordjournals.org/content/early/2012/12/28/eurpub.cks186.abstract>

Noted in Media Watch, 3 December 2012:

- SWITZERLAND | ISO Public – Accessed 28 November 2012 – '**Assisted suicide in the view of Europeans.**' Report: <http://www.worldrtd.net/sites/default/files/newsfiles/Isopublic%20Engels.pdf>

Worth Repeating

In most published remembrances, loved ones dance around death – but does that really help anyone?

CALIFORNIA | *Sacramento Bee* – 21 January 2010 – Death is hard to find in death notices. This is the time of year – January and February – when death rates are generally highest, according to the National Vital Statistics System. *The Bee* and other newspapers tend to run more paid death notices at this time of year, too. If you read those notices carefully, however, you'll find many people in them didn't exactly die. Most of them "passed away." Some "entered into rest." Others "left the world in God's hands." In a few cases, there isn't even a verb, only a date and location to indicate the death. "Death is hard to deal with," said University of California, Berkeley, linguist Geoffrey Nunberg, explaining why people avoid the four-letter word that starts with 'd' – died. <http://www.sacbee.com/livinghere/story/2471062.html>

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