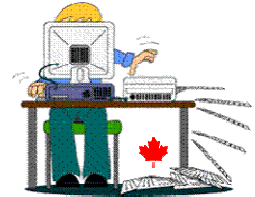


Media Watch...

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

End-of-life care in The Netherlands: Scroll down to [Specialist Publications](#) and 'GPs' recognition of death in the foreseeable future and diagnosis of a fatal condition: A national survey' (p.8), in *BMC Family Practice*.

U.S.A.

The disappearing family caregiver

FORBES | Online – 26 July 2013 – Family caregivers are the bedrock of our system of long-term supports and services. At least eight of every ten people receiving care get it at home (not in a nursing home or other residential facility), and nearly all of their assistance is provided by relatives or friends. But a forthcoming study by American Association of Retired Persons finds that huge demographic changes threaten to undermine that bedrock. Today, Baby Boomers – now in their 50s and 60s – are caring for their parents. Because there are so many Boomers, there is a relatively big pool of potential caregivers. In technical terms, the ratio of caregivers to those needing assistance is high. In human terms, there are lots of 50-somethings who are taking time off work and lots of 60-somethings spending their early retirement caring for their 80-something parents. But that pool of family caregivers will soon dry up. In a couple of decades, when all those Boomers who are now providing care will need assistance themselves, there will be many fewer adult children to help them out. <http://www.forbes.com/sites/howardgleckman/2013/07/26/the-disappearing-family-caregiver/>

N.B. The research was presented in a submission to a congressional long-term care commission. http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf

Regulations stop Jacksboro man from caring for terminally ill wife

TENNESSEE | WATE 6 News (Knoxville) – 24 July 2013 – A Campbell County woman who has less than six months to live wants permission from management at her apartment complex for her husband to be her around-the-clock caregiver. Melissa Meredith and Michael Walton were married for three years, but separated last fall about the time he was charged with a felony. Michael is not permitted now to stay with her at night in the apartment because of the felony charge. Within months of their separation, Melissa was diagnosed with a terminal illness. She can't be alone in her apartment overnight. She says she needs her husband to care for her at night in the apartment ... that's leased in her name, but the local management of the government apartment building says no. <http://www.wate.com/story/22923113/regulations-stop-jacksboro-man-from-caring-for-terminally-ill-wife>

When doctors tell patients what they don't want to hear

THE NEW YORKER | Online OpEd – 23 July 2013 – The challenge of communicating unpleasant, possibly profoundly upsetting information to patients is timeless. What has changed, however, is that physicians are now being judged, and compensated, based upon their ability to do it. In October 2012, Medicare debuted a new hospital-payment system ... which ties a portion of hospital reimbursement to scores on a host of quality measures; thirty per cent of the hospital's score is based on patient satisfaction. New York City's public hospitals recently decided to follow suit, taking the incentive scheme one step further: physicians' salaries will be directly linked to patients' outcomes, including their satisfaction. Other outpatient practices across the country have also started to

base physician pay partly on satisfaction scores, a trend that is expected to grow. But in a country that spends more per capita on health than any other, with results that remain mediocre in comparison, can we really expect that a nation of more satisfied patients will be a healthier nation over all? <http://www.newyorker.com/online/blogs/elements/2013/07/when-doctors-tell-patients-what-they-dont-want-to-hear.html>

Specialist Publications

'Advocacy at the end of life: Meeting the needs of vulnerable Latino patients' (p.13), in *Social Work in Health Care*.

Bring back the "death panel" bill

CALIFORNIA | *The Los Angeles Times* (OpEd) – 22 July 2013 – Probably nothing causes members of Congress more unease than having to talk about death. It's only been four years since healthcare reform became more about whether President Obama wanted to throw mama from a train via "death panels" than, well, how best to reform a broken healthcare system. Still, there are several representatives from both parties who want to discuss it. Since 2009, Rep. Earl Blumenauer (Democrat-Oregon) has been pushing a bill that would require Medicare coverage for an optional end-of-life consultation between a patient and a doctor every five years (more often if the patient's health declines). Even though this might be the same policy Sarah Palin termed the "death panel," it's not a conversation Congress should shy away from. There's been some support for Blumenauer's bill from across the aisle. One of the co-sponsors, Rep. Phil Roe (Republican-Tennessee.), has strong conservative credentials when it comes to healthcare, having often voted to repeal Obamacare. According to *Politico*, they make the common-sense argument that the bill doesn't force a patient to pursue a particular end-of-life treatment: "Both lawmakers noted that an advanced directive doesn't mean a do-not-resuscitate order. People can and do opt for very aggressive do-everything care."¹ In many ways, the bill is a very moderate approach. After all, it doesn't even mandate that all Medicare subscribers have an advanced directive, something the *Washington Post's* Ezra Klein argues: "The problem with Blumenauer's legislation isn't that it goes too far. It's that it doesn't go nearly far enough. Blumenauer's bill would reimburse doctors in the event that their patients want to schedule a visit to discuss end-of-life-care. But everyone on Medicare should have their end-of-life preferences clearly spelled out."² Instead, the bill simply requires that Medicare cover the consultation in the same way other (more expensive) medical procedures are covered. <http://www.latimes.com/news/opinion/opinion-la/la-ol-we-congress-death-panels-health-care20130722,0,3716779.story>

Cont. next page

Clarification

In response to a number of inquiries in recent months, the publication of Media Watch is not financially supported in any shape or form by either corporate, institutional, government or private interests. Nor is the weekly report affiliated or associated with any special interest group. Its sole purpose is to contribute to the knowledge base of those active or with a special interest in advancing hospice and palliative care. BRA

1. 'The "death panel" bill lives,' *Politico*, accessed 23 July 2013.
http://www.politico.com/story/2013/07/the-death-panel-bill-lives-94536_Page2.html
2. 'Can we please talk about death like adults?' *The Washington Post*, accessed 23 July 2013.
<http://www.washingtonpost.com/blogs/wonkblog/wp/2013/07/22/can-we-please-talk-about-death-like-adults/>

Of related interest:

- *THE NEW YORK TIMES* | Online – 25 July 2013 – '**A novel way to document end-of-life care preferences.**' Maybe we've been going about this all wrong. In the continuing campaign to get people, particularly the old and sick, to discuss their preferences for end-of-life care, we've been pushing for them to have intimate conversations with family members. Progress on this front has been slow, however. <http://newoldage.blogs.nytimes.com/2013/07/25/a-novel-way-to-document-end-of-life-preferences/?ref=health>

N.B. The author cites 'Incentivizing residents to document inpatient advance care planning,' *JAMA Internal Medicine*, 15 July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.4): <http://archinte.jamanetwork.com/article.aspx?articleid=1713506>

Noted in Media Watch, 15 July 2013, #314 (p.7):

- *THE HASTINGS REPORT*, 2013;43(4):20-28. '**Avoiding a "death panel" redux.**' If engaging in end-of-life conversations and advance care planning not only is desired by many Americans but also might significantly improve patient care at the end of life, then why was a provision that provided reimbursement for physicians to engage in end-of-life planning through Medicare removed from legislation? If ... reimbursements under Medicare "would have been a start" for encouraging these conversations, then why was the Advance Care Planning Consultation provision in the 2008 health reform effort so vehemently opposed by politicians and citizens alike? <http://onlinelibrary.wiley.com/doi/10.1002/hast.190/abstract>

Eco-friendly funerals

Green goodbyes

MASSACHUSETTS | Aljazeera – 22 July 2013 – Death is a messy business. In America alone, 1.6 million tonnes of cement and over 870,000 gallons of embalming fluid - commonly containing formaldehyde - are buried along with 2.5 million caskets every year. "What you have here is a landfill ... a toxic landfill," says Glen Ayers of the Green Burial Committee as he looks around a traditional graveyard in Massachusetts. Proponents of natural burial want to reduce the pollution and resource waste associated with funerals, which also includes burying masses of hardwood and steel. One solution is to use eco-friendly biodegradable coffins made out of cardboard or even banana leaves. Campaigners also hope to increase the number of natural burial sites, where plots blend in with the natural surroundings. There are currently fewer than 40 in the U.S. <http://www.aljazeera.com/programmes/earthrise/2013/07/2013722103321611250.html>

Noted in Media Watch, 1 April 2013, #299 (p.6):

- U.K. | *The Economist* – 30 March 2013 – '**Six feet greener.**' Unlike one of the national parks it resembles, Hinton Park has some 6,000 people buried there. It is one of over 260 eco-friendly burial sites in Britain. The ways that Britons choose to have their bodies disposed of after death are changing markedly. <http://www.economist.com/news/britain/21574514-funerals-help-environment-are-taking-six-feet-greener>

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.14.

For-profit vs. non-profit hospices

Hospice competition heats up again

WISCONSIN STATE JOURNAL (Madison) | Online – 22 July 2013 – Hospice care ... became competitive in the Madison area only recently. Fitchburg-based Agrace, formerly known as HospiceCare Inc., was the area's only hospice provider for 30 years. Saint Jude, based in a suburb of Des Moines, Iowa, opened a Madison office in 2011. Two other hospice providers opened offices in Madison in recent years, and others serve parts of Dane County or surrounding areas. Agrace, which is non-profit, has made a point of noting that Saint Jude and the other hospices new to Madison are for-profit companies. "Our focus isn't on the bottom line," Agrace spokesman Dan Chin [said] shortly after Saint Jude opened in Madison. "Our focus is on how to best use funds to provide the highest level of care possible." [Tom] Moreland, upset by what he characterized as "less than flattering comments" about Saint Jude from Agrace representatives, took out ads in *Madison Magazine* and the *State Journal* last year. In the ads, presented as a letter to the community, he said Saint Jude's for-profit status allows the organization to retain control over its Catholic mission. http://host.madison.com/wsj/news/local/health_med_fit/health-sense/health-sense-hospice-competition-heats-up-again/article_c631a57b-874a-5172-8f91-3964734d80bb.html

N.B. A representative list of articles on for-profit hospices noted in past issues of Media Watch appears in the issue of the weekly report dated 6 May 2013, #304 (pp.3-4).

Of related interest:

- *THE ATLANTIC* | Online – 26 July 2013 – '**Helping make the best of the end of life.**' Unsurprisingly, palliative care does not generate large amounts of revenue, nor is it the sort of service many hospitals choose to advertise. But when done well, it can make a huge difference. <http://www.theatlantic.com/health/archive/2013/07/helping-make-the-best-of-the-end-of-life/278039/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON STATE | *The Oregonian* (Portland, Oregon) – 22 July 2013 – '**Dilemma for hospice workers: Physician-assisted suicide.**' Hospice organizations traditionally oppose physician-assisted suicide, yet 85-95% of Oregon and Washington patients who choose to die that way also use hospice services.¹ Oregon State University researchers analyzed 33 hospice programs in Washington and found that reaction to physician-assisted death varies among hospice organizations, agencies and workers. Approaches range from opposition to non-participation or non-interference. Researchers found little consistency to questions about how, whether and when hospice workers will get involved as patients choose to end their lives. http://www.oregonlive.com/health/index.ssf/2013/07/dilemma_for_hospice_workers_ph.html

Noted in Media Watch, 15 July 2013, #314 (p.16):

1. 'Dignity, death, and dilemmas: A study of Washington hospices and physician-assisted death,' *Journal of Pain & Symptom Management*, 8 July 2013. This article sets a national and local context for the discussion of hospice involvement in physician-assisted death, summarizes the content of hospice policies in Washington State, and presents an analysis of these findings. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00270-4/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00270-4/abstract)

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

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

International

Watchdog warns elderly care still not good enough

U.K. (SCOTLAND) | *The Herald* (Glasgow) – 26 July 2013 – Continuing shortcomings in elderly care have been highlighted by Scotland's hospital watchdog which criticised staff for not treating older patients with respect and failing to comply with do not resuscitate notices.¹ The report ... said that six months on from its first overview into the treatment of older people in acute care, there were still several areas of concern, including staff risking patient confidentiality and using inappropriate language on wards. It identified 87 areas for improvement and 12 areas for continuing improvement during its most recent visits to seven units at six hospitals between September 2012 and June this year. <http://www.heraldscotland.com/news/health/watchdog-warns-elderly-care-still-not-good-enough.21706734>

1. *Care for Older People in Acute Hospitals Overview Report*, Healthcare Improvement Scotland, 2013. http://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/opah_overview_reports/opah_overview_report_july_2013.aspx

The Liverpool Care Pathway

Beecroft welcomes halt to tick-box end-of-life regime

U.K. (ISLE OF MAN) | *Isle of Man Today* – 25 July 2013 – A long-standing critic of The Liverpool Care Pathway for dying patients says she is pleased it is being abolished. The controversial "tick-box" care regime for terminally-ill patients is to be suspended in the island – after an independent review concluded it should be phased out in England.¹ The U.K. government-commissioned review ... heard harrowing stories from families who had not been told loved ones were expected to die and of cases where patients were denied fluids. In a joint statement, Hospice Isle of Man and the Department of

Health insisted there was no evidence that the Pathway had ever been used inappropriately in the Isle of Man but they acknowledged that in some hospitals in the U.K. some staff misunderstood and misused the tool. <http://www.iomtoday.co.im/news/isle-of-man-news/beecroft-welcomes-halt-to-tick-box-end-of-life-regime-1-5886560>

Specialist Publications

'The Liverpool Care Pathway: Last rites' (p.9), in *British Medical Journal*.

1. *Independent Report: Review of Liverpool Care Pathway for dying patients*, Department of Health [England], July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>



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>

Funding hospice in the U.K.

Strength in numbers: How independent hospices can raise more income from voluntary and donated sources to fund their work

U.K. | Help the Hospices – 25 July 2013 – With so much change and uncertainty over the sources and scale of hospice income, the opportunity to revisit our effectiveness at generating funds directly from the public is timely. This report ... commissioned by the Commission into the Future of Hospice Care, does just that. Its arguments are convincing, drawing on both survey data and interviews within the hospice sector, and its recommendations provide a route to improvement. While it is important to note that this it only deals with voluntary income, the data, its analysis and the authors' reflections all yield some important messages. First, there is evidence of considerable fundraising success on the part of local hospices and the sector at large. The data tells us that the hospice movement is the second largest recipient of legacy income across the charitable sector, and that retail profits for the hospice movement have risen significantly. <http://www.helpthehospices.org.uk/our-services/commission/resources/?entryid209=136261>

Palliative care falls short in Armenia

ARMENIA | Institute for War & Peace Reporting – 22 July 2013 – Doctors in Armenia are calling for radical changes to palliative care practices so as to give patients in chronic pain easier access to prescription opiates. At present, morphine is only prescribed to cancer patients in liquid form used for injection, in a process tightly controlled by the police. Other painkillers, such as methadone pills, are not available at all. Hrant Karapetyan, head of the Armenian Pain Control & Palliative Care Association, says that only one or two ampoules of morphine can be dispensed at one time, providing a maximum of eight hours of pain relief a day, and requiring regular return visits to the dispensary. "Every year, there are 80,000 to 100,000 people in need of palliative care,"

he said. "In Armenia, however, there is no programme that would allow us to help 80,000-100,000 patients at the one time." <http://iwpr.net/report-news/palliative-care-falls-short-armenia>

Specialist Publications

'Comparison of legislation, regulations and national health strategies for palliative care in seven European countries: A descriptive study' (p.8), in *BMC Health Services Research*.

'Improving palliative care outcomes for Aboriginal Australians: Service providers' perspectives' (p.8), in *BMC Palliative Care*.

Dying shame: Shock rise of paupers' funerals as recession bites hard

U.K. (ENGLAND) | *The Daily Mirror* – 22 July 2013 –The recession has bitten so hard that the number of people who have to be buried at the state's expense has doubled in some areas, shock figures reveal. A *Mirror* investigation has exposed the shameful rise in the number of people who die in such poverty that neither they nor their families can afford the funeral costs. Babies and the elderly are among those who have been given council-funded paupers' funerals, in which bodies are buried in unmarked plots. In many cases, victims have died alone and relatives cannot be traced. Dr. Kate Woodthorpe, a funerals expert from the University of Bath, said: "It's becoming increasingly expensive for poor people to die. There isn't room enough in people's budgets to plan ahead for a funeral. Local authorities are becoming the backstop for this." The findings, gathered through Freedom of Information requests, show that paupers' funerals – which cost £950 on average – have doubled in places including Liverpool, Reading and Plymouth. Cash-strapped councils are spending small fortunes burying the poor. <http://www.mirror.co.uk/news/uk-news/dying-shame-shock-rise-paupers-2073524>

Cont.

Noted in Media Watch, 2 July 2012, #260 (p.4):

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

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | RTÉ News (Dublin) – 25 July 2013 – **'Marie Fleming's lawyers applying for legal costs from assisted suicide appeal.'** The Supreme Court will be asked to exercise its "exceptional jurisdiction" to award costs in favour of Marie Fleming, the terminally ill Wicklow woman who lost her "right to die" case. Ms. Fleming lost her appeal against a High Court decision refusing her the right to assisted suicide earlier this year. She has already been awarded the costs of the High Court case despite losing because of the issues of exceptional public importance involved in the case. <http://www.rte.ie/news/2013/0725/464578-marie-fleming/>

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

- IRELAND | *The Independent* (Dublin) – 29 April 2013 – **'Marie Fleming loses Supreme Court right-to-die case.'** A full, seven-judge Supreme Court gave its ruling in the so called "right to die" action brought by Ms. [Marie] Fleming who wants to be helped to end her life at a time of her choosing. Chief Justice Susan Denham said that there is no constitutional right to commit suicide or to arrange for the termination of one's life at the time of their own choosing. <http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html>

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

Furry and feathered family members: A critical review of their role in palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 July 2013 – This article presents a comprehensive critical review of the peer-reviewed literature on palliative care and companion animals (CAs), reporting on the evidence and knowledge base regarding CAs and their role for people at end of life. The evidence for efficacy and the knowledge base about the role of CAs at end of life in hospice and palliative care is weak. Further efforts are required to study the conditions under which CAs may be beneficial for patient care, including acceptability to staff, family, and other patients, and with consideration of welfare for the animals involved. <http://ajh.sagepub.com/content/early/2013/07/25/1049909113497084.abstract>



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

12 October 2013

End-of-life care in The Netherlands

GPs' recognition of death in the foreseeable future and diagnosis of a fatal condition: A national survey

BMC FAMILY PRACTICE | Online – 22 July 2013 – The data were analysed of the 297 GPs who responded. 76% of the reported cases were cancer patients and 24% were patients with another non-sudden cause of death. The diagnosis was made only in the last week of life for 15% of the non-cancer patients and 1% of the patients with cancer. GPs were most likely to have been informed of the diagnosis by the medical specialist, although particularly in the case of non-cancer patients GPs also relied on their own assessment of the diagnosis or on other information sources. The GP remained unaware that the patient would die in the foreseeable future until the last week of life in 26% of the non-cancer group, while this was the case for only 6% of the cancer patients. <http://www.biomedcentral.com/content/pdf/1471-2296-14-104.pdf>

Of related interest:

- *SUPPORTIVE CARE IN CANCER* | Online – 26 July 2013 – '**Involvement of general practitioners in palliative cancer care: A qualitative study.**' The substantial involvement of general practitioners in end-of-life care for cancer patients pushes them to their limits because of the major time commitment required, and the need for special skills for which they have received no training. It will be a challenge to provide general practitioners with the structural and personal support they need to provide home-based palliative care for their cancer patients at end of life. <http://link.springer.com/article/10.1007/s00520-013-1904-6>

Europall Research Group

Comparison of legislation, regulations and national health strategies for palliative care in seven European countries: A descriptive study

BMC HEALTH SERVICES RESEARCH | Online – 17 July 2013 – In all countries [Belgium, England, France, Germany, The Netherlands, Poland and Spain] palliative care regulations and policies existed (either in laws, royal decrees, or national policies). An explicit right to palliative care was mentioned in the Belgium, French and German law. In addition, access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, opioids and the role of volunteers. <http://www.biomedcentral.com/content/pdf/1472-6963-13-275.pdf>

Improving palliative care outcomes for Aboriginal Australians: Service providers' perspectives

BMC PALLIATIVE CARE | Online – 23 July 2013 – Overall [study participants] reported lack of understanding of Aboriginal culture and being uncertain of the needs and priorities of Aboriginal people during end-of-life care. According to several participants, very few Aboriginal people had an understanding of palliative care. Managing issues such as anger, denial, the need for non-medical support due to socioeconomic disadvantage, and dealing with crises and conflicts over funeral arrangements were reported as some of the tensions between Aboriginal patients and families and the service providers. Early referral to palliative care is important in demonstrating and maintaining a caring therapeutic relationship. Paramount to meeting the needs for Aboriginal patients was access to appropriate information and logistical, psychological and emotional support. These were often seen as essential but additional to standard palliative care services. <http://www.biomedcentral.com/content/pdf/1472-684X-12-26.pdf>

Cont.

Noted in Media Watch, 13 May 2013, #305 (p.16):

- **RURAL & REMOTE HEALTH** | Online – 8 May 2013 – '**Considering Aboriginal palliative care models: The challenges for mainstream services.**' Currently Aboriginal people tend to not access palliative care services in mainstream facilities; and there is very little data on Aboriginal admissions to palliative care centres. Over the last two decades only two models of palliative care focusing on and developed in Aboriginal communities have been implemented. The Australian government's National Indigenous Palliative Care Needs Study indicated that Australian empirical research on Aboriginal palliative care service provision is in its infancy, and comprehensive data on the rates of Aboriginal access to palliative care services did not exist.¹ <http://www.rrh.org.au/articles/subviewaust.asp?ArticleID=2339>

1. National Indigenous Palliative Care Needs Study, Department of Health & Ageing, 2003. [http://www.health.gov.au/internet/main/publishing.nsf/Content/5619BFE763995E17CA256F410011C5C3/\\$File/needall.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/5619BFE763995E17CA256F410011C5C3/$File/needall.pdf)

The Liverpool Care Pathway

Last rites

BRITISH MEDICAL JOURNAL | Online – 24 July 2013 –The Liverpool Care Pathway [LCP] was developed in the U.K. in the late 1990s. Since then it has been adopted at national level by 20 other countries, reflecting growing efforts around the world to improve care for patients dying in hospital. But last week the pathway was given its own last rites by the U.K. government.¹ In this week's journal, Krishna Chinthapalli tells the story of the LCP from its origins in the hospice movement to its U.K. demise.² He asks where doctors, especially trainees, can now turn for necessary reminders to consider all aspects of a dying patient's care, and for specific guidance on symptom management. In an editorial, the pathway's architect, John Ellershaw, reiterates the underlying principles of good end of life care, calling for these to be applied wherever a person is dying: hospital, hospice, or home.³ <http://www.bmj.com/content/347/bmj.f4714>

1. *Independent Report: Review of Liverpool Care Pathway for dying patients*, Department of Health [England], July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>
2. 'The birth and death of The Liverpool Care Pathway,' 24 July 2013. <http://www.bmj.com/content/347/bmj.f4669>
3. 'Best care for the dying patient,' 12 July 2013. <http://www.bmj.com/content/347/bmj.f4428>

Palliative care education in Zagreb: An assessment of the effectiveness of an undergraduate course

CROATIAN MEDICAL JOURNAL, 2013;54(2):212-213. Although the Croatian Society for Hospice & Palliative Care was formed by Professor Anica Jusić in 1989 there have been limited and local developments of services – within certain cities and towns, usually as a result of local enthusiastic doctors or other professionals. However, there has been growing awareness of the need for education of medical and nursing students and when the English Course for Medical Students was started in Zagreb in 2003 it was agreed that there would be an optional course in palliative care. [Evaluations in] 2008- 2012 showed evidence of increasing confidence in all areas – talking about dying, discussing cancer, assessing symptoms, discussing psychological issues, and working as part of a multidisciplinary team – with improved scores. There also seems to be a movement to feeling less uneasy when coping with dying patients but little change is observed in discussing dying and death, which again may be related to their limited patient exposure. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3641880/>

Family grief in cross-cultural perspective

FAMILY SCIENCE, 2013;4(1):12-19. Although family systems theory challenges an individual focus on grief by providing conceptual tools for understanding the crucial importance of relational issues in bereavement, its totalizing language may seem to imply that bereavement is the same across cultures. It is not. We need to explore bereavement in families in diverse cultures – to make sense of unique aspects of grieving in those cultures, including the diverse cultures/ethnic groups in economically developed countries. Three examples of what might be gained from understanding specific relational grief phenomena from other cultures are offered: energy transfer in bereavement, the dead as active among the living, and dangerous witches as causes of death. <http://www.tandfonline.com/doi/abs/10.1080/19424620.2013.819226#.UfT6tdJwomY>

N.B This issue of the journal focuses on bereavement. Contents page: <http://www.tandfonline.com/toc/rfsc20/current#.UfT759Jwoma>

Time to define high-quality palliative care in oncology

JOURNAL OF CLINICAL ONCOLOGY | Online – 22 July 2013 – The time has come to enhance how the field of oncology assesses and manages patient and family distress, and then to integrate those efforts with ... palliative care. Ultimately, this serves to both preserve and support quality of life and to add an additional layer of support for those who are traversing through the cancer journey; curing when able, caring even when not. Furthermore, now is the time to describe through rigorous research what feasible processes of care constitute high-quality palliative care in oncology. Although this research continues to build the evidence base, oncology providers will need to simultaneously prioritize both aspects of palliative care that fall within the scope of oncology practice and those best suited for the expertise of specialty palliative care. <http://jco.ascopubs.org/content/early/2013/07/22/JCO.2013.50.2484.full.pdf+html>

Cont. next page

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

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Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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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.

Of related interest:

- *INTERNAL MEDICINE JOURNAL* | Online – 22 July 2013 – '**Administration of chemotherapy with palliative intent in the last 30 days of life: The balance between palliation and chemotherapy.**' In this study, the observed rate of death within 30 days of chemotherapy is within the range of published data. It is recommended that a standard definition be used to benchmark medical oncology centres and individual oncologists, and to allow comparison over time. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12245/abstract>

Noted in Media Watch, 13 February 2013, #240 (p.10)

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 7 February 2012 – '**Palliative care: A life-line to quality of life.**' Promoting quality of life and preventing suffering are essential aspects of practice for clinicians whose ambition it is to deliver high-quality cancer care. American Society of Clinical Oncology's Provisional Clinical Opinion offers the opportunity to bring clinicians a significant step forward in delivering truly patient-centered, family-focused care...¹ <http://jop.ascopubs.org/content/early/2012/02/07/JOP.2011.000530.full.pdf+html>

1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, February 2012. <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death

JOURNAL OF INTELLECTUAL DISABILITY RESEARCH – 21 July 2013 – There was little evidence [in this study] that staff talked with, or did things with clients to assist understanding of the end of life, both prior to and after a death. Prior to death staff assisted clients in a limited way to understand about determining wishes in preparation for death, and what dying looks like by observance of its passage. Following a death staff offered limited assistance to clients to understand the immutability of death, and how the dead can be honoured with ritual, and remembered. <http://onlinelibrary.wiley.com/doi/10.1111/jir.12065/abstract;jsessionid=F0B2C01C39B4454B1AAFA60CEDB0C348.d03t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Of related interest:

- *DEATH STUDIES* | online – 17 July 2013 – '**How adults with an intellectual disability experience bereavement and grief: A qualitative exploration.**' This qualitative study explored the lived experiences of bereavement of 13 adults with an intellectual disability and found that their experiences could be situated within the concept of disenfranchised grief. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.738772>

Noted in Media Watch, 22 April 2013, #302 (p.9):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES*, 2013;26(3):215-230. '**The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities.**' Staff [i.e., study participants] felt providing a good quality of care at the end of life was an important but unrecognised dimension of their work. This work could be broken down into several different phases, dying, death and beyond death. Bad deaths were felt to be those deaths which prevented staff from "being there" with individuals over those phases. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12024/abstract>

N.B. This issue focuses on several aspects of dying and death and people living with intellectual disabilities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>. Noted in this issue of Media Watch are additional articles on the issue.

Nurses' responses to requests for forgiveness at the end of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 22 July 2013 – Patients or family members facing serious illness often express regrets over life events or the need for forgiveness. Nurses [from courses throughout the U.S., and Belize, India, the Philippines and Romania] attending palliative care educational programs shared narratives of their experiences in caring for patients who expressed regret or the need for forgiveness. Nurses would benefit from additional education regarding how best to address these concerns. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00324-2/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00324-2/abstract)

Evaluation of the currency of the Davies & Oberle (1990) model of supportive care in specialist and specialised palliative care settings in England

JOURNAL OF CLINICAL NURSING | Online – 22 July 2013 – "Connecting" reduced emphasis in the hospital setting where specialist nurses spend limited time with patients, but diminishing time to "connect" with patients and carers as service develops could potentially become problematic across all settings. "Connecting" is being affected by pace of work and lateness of referrals. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12301/abstract>

Noted in Media Watch, 6 August 2012, #265 (p.6):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 July 2012 – '**Forgiveness, depressive symptoms, and communication at the end of life: A study with family members of hospice patients.**' Forgiveness has begun to receive empirical attention in end-of-life contexts, but primarily among patients. Although not as commonly endorsed as expressions of love and gratitude, forgiveness-related communications are seen as extremely important by many family members of hospice patients. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0138>

Public priorities and preferences for end-of-life care in Namibia

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 22 July 2013 – Being in pain was reported [in this study] as the most concerning of nine common end-of-life symptoms and problems, and the most important care-related aspect was having as much information as wanted. The majority (64%) would want their end-of-life care to focus on improving their quality of life rather than extending it, with 40% not wanting to know if they had limited time left to live. Hospital and home were the most preferred places of death. The most important end-of-life priority was keeping a positive attitude. Having had a close relative or friend diagnosed with a serious illness was associated with a 2.3 increase in the odds of preference for a hospital death. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00317-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00317-5/abstract)

The pediatric surgeon and palliative care

SEMINARS IN PEDIATRIC SURGERY, 2013;22(3):154-160. Palliative care is now a core component of pediatric care for children and families who are confronting serious illness with a low likelihood of survival. Pediatric surgeons, in partnership with pediatric palliative care teams, can play a pivotal role in assuring that these patients receive the highest possible quality of care. This article outlines a variety of definitions and conceptual frameworks, describes decision-making strategies and communication techniques, addresses issues of interdisciplinary collaboration and personal self-awareness, and illustrates these points through a series of case vignettes, all of which can help the pediatric surgeon perform the core tasks of pediatric palliative care. [http://www.sempedsurg.org/article/S1055-8586\(13\)00039-5/abstract](http://www.sempedsurg.org/article/S1055-8586(13)00039-5/abstract)

Cont.

Of related interest:

- *JOURNAL OF SURGICAL RESEARCH* | Online – 24 June 2013 – **'Palliative and end-of-life care training during the surgical clerkship.'** Early training in end-of-life communication is feasible during the surgical clerkship in the third-year of medical school. Of all the scenarios [discussed in this study], 'Conducting a Family Conference' proved to be the most challenging. [http://www.journalofsurgicalresearch.com/article/S0022-4804\(13\)00583-0/abstract](http://www.journalofsurgicalresearch.com/article/S0022-4804(13)00583-0/abstract)

Advocacy at the end of life: Meeting the needs of vulnerable Latino patients

SOCIAL WORK IN HEALTH CARE, 2013;52(6):558-577. Limited research exists regarding patient advocacy from the perspectives of health care providers working with vulnerable Latino populations utilizing a public sector health care system. Although roles and responsibilities vary among health providers, it is imperative that all providers become aware of the need for patient advocacy. Doing so is not only in the best interest of vulnerable Latino populations but also has overarching financial benefits and positive outcomes for patients, administrators, and public health care systems. Social workers are the ideal professionals to assume leadership roles and share their knowledge of how to advocate effectively for the most vulnerable populations. <http://www.tandfonline.com/doi/abs/10.1080/00981389.2013.779359#.Ue6VkdJwomY>

Of related interest:

- *JOURNAL OF CANCER EDUCATION* | Online – Accessed 26 July 2013 – **'Examining cultural factors that influence treatment decisions: A pilot study of Latino men with cancer.'** Latino men's limited knowledge of cancer diagnosis and treatment options coupled with their fear led them to immediately believe that they were going to die. Knowledge gaps regarding diagnosis-related communication, treatment decisions, and advance care planning varied among the men. The forthright diagnosis communication and the expectation to engage in decision making are contrary to Latinos men's beliefs of reliance on health providers' decisions. <http://link.springer.com/article/10.1007/s13187-013-0522-9#>

Noted in Media Watch, 18 February 2013, #293 (p.2):

- NBC LATINO | Online – 18 February 2013 – **'Nine tips for caring for the family caregiver.'** For Latinos where "la familia" is everything, providing care to someone who is ill, disabled or aged is a huge issue. According to a 2008 survey of Latino caregivers, a third of Latino households report having at least one family caregiver resulting in approximately 8.147 million Latino caregivers in the U.S. <http://nbclatino.com/2013/02/18/9-tips-for-caring-for-the-family-caregiver/>

Noted in Media Watch (under 'Worth Repeating'), 10 September 2012, #270 (p.11):

- *PALLIATIVE MEDICINE*, 2010;24(4):427-434. **"The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with U.S.-born White, non-Latino cancer caregivers.'** This study identifies a significant dilemma: how to discuss hospice with a patient and family who prefer not to discuss a terminal prognosis. <http://pmj.sagepub.com/content/24/4/427.short>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HELLENIC JOURNAL OF SURGERY*, 2013;85(2):105-108. **'Terminal cancer patients and euthanasia: The church's position.'** Seventy-six percent of patients [in this literature review] were in favour of euthanasia but only at terminal disease stage, 15% of patients said they would most likely sanction it, 7% were against, and 2% did not respond. In the event that the patient was not in a position to give their consent, 62% of relatives would permit euthanasia. The difference presented by patients and their relatives (and from the bibliography) appears to be related to religious beliefs. <http://link.springer.com/article/10.1007/s13126-013-0019-3#>

Worth Repeating

Vigilant at the end of life: Family advocacy in the nursing home

JOURNAL OF PALLIATIVE MEDICINE, 2010;13(5):573-579. An important interview theme revealed families [i.e., study participants] often felt the need to advocate for their dying relative because of low expectations or experiences with poor quality nursing home care. They noted staff members who did not fully inform them about what to expect in the dying process. Respondents reported burden and gratification in care they themselves provided, which sometimes entailed collaboration with staff. Interviews also identified ways hospice care impacted families, including helping to relieve family burden. End-of-life advocacy takes on increased urgency when those close to the dying resident have concerns about basic care and do not understand the dying course. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2009.0398>

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)

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