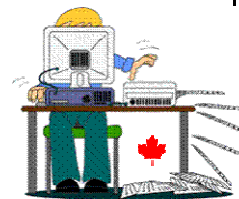


Media Watch...

is intended as an advocacy, research and teaching 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.

16 February 2015 Edition | Issue #397



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Compiled & Annotated by Barry R. Ashpole

End-of-life care for vulnerable populations: Scroll down to [International](#) and 'Research reveals experiences of disabled people with a terminal illness' (p.7), online posting by Marie Curie in the U.K.

Canada

Crisis in Ontario health-care system deepens: Hepburn

ONTARIO | *The Toronto Star* – 11 February 2015 – A bitter strike by 3,000 nurses and other health professionals now dragging into its third week is providing a rare and disturbing glimpse into Ontario's home- and community-health sector. What the strike by workers at 10 Community Care Access Centres [CCAC] across the province has exposed is clear evidence that this increasingly critical part of our health care system is grossly underfunded and inefficient, with underpaid and overworked employees scrambling – and too often failing – to keep up with growing demand for services. The result of this worsening mess is that tens of thousands of patients across the province, ranging from seniors to young schoolchildren, often receive too little or no care at home, in nursing homes... It's especially true for patients pushed quickly out of hospitals

in an effort to save money and turned over to CCAC, which oversee home- and community-care... At the same time, the stresses and demands being placed on community health professionals have created a group of dedicated workers who rightly feel frustrated, disillusioned and underappreciated. <http://www.thestar.com/opinion/commentary/2015/02/11/crisis-in-ontario-health-care-system-deepens-hepburn.html>

Extract from *The Toronto Star* article

For years, successive governments have talked boldly about the need to focus more resources on community care. However, barely 5% of the province's health care budget goes to home- and community-health care.

Noted in Media Watch, 24 November 2014, #385 (p.2):

- ONTARIO | *The Toronto Star* – 19 November 2014 – **'Home-care system in free fall after more cuts.'** While home and community care are "the cornerstones" of a major health-system transformation, nurses are furious with a wave of cuts in home- and community-care services. http://www.thestar.com/opinion/commentary/2014/11/19/homecare_system_in_free_fall_after_more_cuts_hepburn.html

Government spends 3 times more on seniors: Study

THE TORONTO STAR | Online – 11 February 2015 – Seniors are receiving three times more government money than those under 45, according to a new study, the first to tabulate total public spending by age group.¹ <http://www.thestar.com/news/gta/2015/02/11/government-spends-3-times-more-on-seniors-study.html>

1. 'Measuring the Age Gap in Canadian Social Spending,' Generation Squeeze, February 2015: http://gensqueeze.ca/wp-content/uploads/2015/02/Measuring-the-Age-Gap-in-Social-Spending_Final_6Feb2015.pdf

Aboriginal children receive poorer health care, suffer delays

THE GLOBE & MAIL | Online – 10 February 2015 – A study suggests aboriginal children often get poorer health care than other kids while governments argue over who pays the bill.¹ Co-author Vandna Sinha, a professor at McGill University, says the problem persists despite the federal government's position that there are no violations of the so-called Jordan's principle. "You get children and First Nations families caught in the middle," she said. Jordan's principle holds that no aboriginal child should suffer denials, delays or disruptions of health services available to other children due to jurisdictional disputes. Jordan Anderson was a Cree boy from Norway House, Manitoba, who died in hospital

in 2005 after such disagreements kept him from spending his last years in home care. <http://www.theglobeandmail.com/news/national/aboriginal-children-receive-poorer-health-care-suffer-delays/article22905265/>

Extract from The Jordan's Principle Working Group report

...many communities "are unable to provide access to the necessary supportive service elements such as respite, rehabilitative services, and home-based palliative care."

1. 'Without denial, delay, or disruption: Ensuring First Nations children's access to equitable services through Jordan's principle,' The Jordan's Principle Working Group, Assembly of First Nations, 2015: http://www.afn.ca/uploads/files/jordans_principle-report.pdf

Family caregivers need support

THE TORONTO STAR (OpEd) | Online – 8 February 2015 – Four years ago, Michael Ignatieff presented himself as a smart, sophisticated patriot, eminently qualified to lead the nation. Voters perceived him as an aloof, self-absorbed academic who didn't understand the country or its people. His political career was mercifully brief. But the former Liberal leader got one thing right: he recognized unpaid caregivers as the backbone of Canada's health-care system and offered them support. His "family care plan" would have given workers caring for a seriously ill family member six months of paid leave and offered those outside with no earnings a monthly allowance of \$1,350. Ignatieff's proposal sank with him in the last federal election. The Liberals have not resurrected it. The only vestige that remains is a modest Conservative tax break. Seeking to undercut the Liberals on the eve of the 2011 campaign, Prime Minister Stephen Harper announced a family caregiver tax credit of less than \$1 a day. It applies to just 18% of the 2.7 million Canadians who sacrifice their income, career prospects and sometimes their health to care for loved ones. <http://www.thestar.com/opinion/commentary/2015/02/08/family-caregivers-need-support-goar.html>

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.13.

Assisted (or facilitated) death

Representative sample of news media coverage post the Supreme Court of Canada's ruling on decriminalizing "assisted suicide and euthanasia":

- *THE GLOBE & MAIL* | Online – 13 February 2015 – '**Time for a quick compromise on assisted suicide.**' The Supreme Court's one-year period of grace is not as generous as it sounds. The next general election is scheduled for 19 October, which means parliament would normally be dissolved in early to mid-September. Parliament, moreover, usually takes a summer break of about two or three months. The ideal would be for all parties to co-operate to pass legislation by June, thus not disturbing the normal timetable of summer holidays and the fixed election date. Second-best would be to sit well into the summer, using pressure of time to force passage of a bill. Worst would be to go into the election campaign in September without having passed anything at all... <http://www.theglobeandmail.com/globe-debate/time-for-a-quick-compromise-on-assisted-suicide/article22964155/>
- *THE TORONTO STAR* | Online – 13 February 2015 – '**Most Canadians support assisted death ruling, poll shows.**' A new Forum Research poll finds that 78% of Canadians support the Supreme Court's ruling on physician-assisted suicide. <http://www.thestar.com/news/canada/2015/02/13/most-canadians-support-assisted-death-ruling-poll-shows.html>
- *THE NATIONAL POST* | Online – 10 February 2015 – '**In wake of assisted-suicide ruling, a huge question looms: Who does the killing?**' The Canadian Society of Palliative Care Physicians says a survey conducted in January, one month before the high court ruling, shows a majority – 74% – of its members would not help their patients commit suicide when the act becomes legal. "It is just anathema to us," said president Dr. Susan MacDonald, an associate professor of medicine and family medicine at Memorial University in St. John's, Newfoundland "How would I ever inspire trust when people already have this terrible fear of what it is I do already?" <http://news.nationalpost.com/2015/02/10/in-wake-of-assisted-suicide-ruling-a-huge-question-looms-who-does-the-killing/>

N.B. The Canadian Society of Palliative Care Physicians revised this month its position statement on "euthanasia and assisted suicide." The Society states "if legalized, [it] should not be provided by palliative care services or palliative care physicians": <http://www.cspcp.ca/wp-content/uploads/2014/10/CSPCP-Position-on-Euthanasia-and-Assisted-Suicide-Feb-6-2015.pdf>.
- *THE TORONTO STAR* | Online – 10 February 2015 – '**Feds will not override the court's ban on assisted suicide, MacKay hints.**' After the Supreme Court struck down Canada's ban on doctor-assisted suicide, the justice minister says there are no plans to override that ruling. Peter MacKay said the Conservatives will solicit a range of views on doctor-assisted suicide, including from the medical profession and those living with disabilities. <http://www.thestar.com/news/queenspark/2015/02/10/feds-will-not-override-the-courts-ban-on-assisted-suicide-mackay-hints.html>

[Back Issues of Media Watch](#)

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

U.S.A.

2015 AARP Caregiving Survey

Opinions of Iowa Registered Voters ... on Support for The Caregiver Advise, Record, Enable (CARE) Act

IOWA | *AARP News* – 12 February 2015 – More than 80% of Iowa registered voters age 45 and older supports measures in The Caregiver Advise, Record & Enable (CARE) Act... The bill features three important provisions that require hospitals to provide instructions on the medical tasks the family caregiver may need to perform at home, keep a family caregiver informed of major decisions, like transferring or discharging the patient, and to engage with caregivers by recording the name of the family caregiver when a loved one is admitted into a hospital. <http://www.aarp.org/research/topics/care/info-2015/iowa-caregiving-care-act.html>

N.B. See Media Watch dated 12 January 2015, #392 (pp.4-5) for a listing of selected articles on the need to train family caregivers noted in past issues of the weekly report.

Cancer patients and doctors struggle to predict survival

NATIONAL PUBLIC RADIO | Online – 10 February 2015 – When a doctor tells a patient that she has cancer and has just a year left to live, that patient often hears very little afterward. It's as though the physician said "cancer" and then "blah, blah, blah." Anxiety makes it difficult to remember details – and the worse the prognosis, the less the patient tends to remember. Studies have found that cancer patients retain less than half of what their doctors tell them. So it's not surprising, perhaps, that a patient with advanced cancer can leave her oncology appointment thinking she has a set amount of time left to live. "The doctor gave me a year," she'll say, as though she were a half-gallon of milk with a "sell-by" date printed on her head. But prognoses are almost never that clear-cut, despite the fact patients need to make big

decisions based on those numbers. <http://www.npr.org/blogs/health/2015/02/10/384011538/cancer-patients-and-doctors-struggle-to-predict-survival>

Specialist Publications

'**Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective, longitudinal cohort study**' (p.9), in *Cancer*.

'**Teaching colleagues how to discuss prognosis as part of a hospital-wide quality improvement project: The positive impact of a 90-minute workshop**' (p.9), in *Journal of Pain & Symptom Management*.

Selected articles on prognoses noted in past issues of Media Watch:

- *JOURNAL OF SOCIOLOGY* | Online – 14 August 2014 – '**When they don't die: Prognosis ambiguity, role conflict, and emotion work in cancer caregiving.**' Analysis indicates a clearly terminal (negative) prognosis facilitates clear priorities, unambiguous emotion management, and improved social bonds. A more ambiguous (positive) prognosis, that includes a greater chance of survival, fosters role conflict, clashing feeling rules, and ongoing guilt within spousal carers. [Noted in Media Watch, 25 August 2014, #372 (p.13)] <http://jos.sagepub.com/content/early/2014/08/14/1440783314544996.abstract>
- *JAMA INTERNAL MEDICINE* | Online Commentary – 14 October 2013 – '**How long do I have?'** Aside from the difficulty of prognosis, there also seems to be a reluctance by many physicians to wade into the murkiness of prognostication, even though patients and families desperately want to know. [Noted in Media Watch, 21 October 2013, #328 (p.11)] <http://archinte.jamanetwork.com/article.aspx?articleid=1748833>

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- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;26(368):2448-2450. **'Uncertainty – the other side of prognosis.'** Prognoses will always have inherent uncertainty, which is often difficult for patients, their families, and even physicians to deal with. But there are ways clinicians can communicate more effectively to help patients and families manage uncertainty. [Noted in Media Watch, 1 July 2013, #312 (p.11)] <http://www.nejm.org/doi/full/10.1056/NEJMp1303295>

Care planning

When "doing everything" is way too much

THE NEW YORK TIMES | Online – 7 February 2015 – Nursing homes typically highlight advance directive completion rates as a point of pride, a metric to prove that they are concerned about the patients' preferences. But the advance directives that we receive from nursing homes are cookie-cutter similar. Almost all indicate that a patient has stated that all attempts to prolong life should be pursued. No treatment is considered unacceptable, regardless of prognosis. There are neat signatures from two witnesses, usually the admissions clerk and the social worker. Almost never the physician. Discussing values, preferences and personal goals in the event of debilitation is difficult,

time-consuming and often harrowing. It is an ambitious load. And since nursing homes are paid to care for patients in perpetuity, are their employees really the right people to oversee the completion of these forms? http://opinionator.blogs.nytimes.com/2015/02/07/when-doing-everything-is-way-too-much/?_r=0

Specialist Publications

'Easing the burden of surrogate decision making: The role of a do-not-escalate-treatment order' (p.11), in *Journal of Palliative Medicine*.

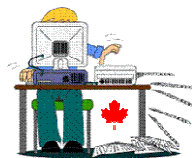
Of related interest:

- PUBLIC BROADCASTING SERVICE | Frontline – 13 February 2015 – **'Prolonging life or prolonging death?'** For doctors, there are rarely easy decisions to be made when it comes to the care of someone critically ill. In some cases, a bleak prognosis may require them to advise a patient against continuing their treatment. Other times, they may see cause for optimism, however remote it may seem. Knowing how or when to make that determination is the tricky part. <http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/prolonging-life-or-prolonging-death-two-doctors-on-caring-for-the-critically-sick/>
- *THE NEW YORK TIMES* | Online – 9 February 2015 – **'Know the hard choices prolonging life entails.'** Most people are aware of advance directives ... assignment of health care agents to speak for patients when they cannot speak for themselves. As of 2010, only 26.3% of American adults had prepared such a document, according to a survey of 7,946 participants.¹ http://well.blogs.nytimes.com/2015/02/09/know-the-hard-choices-prolonging-life-entails/?ref=health&_r=0

1. 'Completion of advance directives among U.S. consumers,' *American Journal of Preventive Medicine*, 2014;46(1):65-70. The authors analyzed data in 2013 from adults aged 18 years and older who had participated in the 2009 or 2010 HealthStyles Survey. [http://www.ajpmonline.org/article/S0749-3797\(13\)00521-7/abstract](http://www.ajpmonline.org/article/S0749-3797(13)00521-7/abstract)

Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



International

Facebook rolls out feature for users when they die

BBC NEWS | Online – 13 February 2015 – Facebook has added a new setting that gives users the option of having their account permanently deleted when they die. Or, if they wish, they can choose to appoint a friend or family member to take control of some aspects of the account after their death. Facebook's legacy contact feature will initially only be available in the U.S. <http://m.bbc.com/news/technology-31438707>

Noted in Media Watch, 10 March 2014, #348 (p.11):

- *BULLETIN OF SCIENCE TECHNOLOGY SOCIETY* | Online – 5 March 2014 – '**Virtual mourning and memory construction on Facebook: Here are the terms of use.**' This article investigates the online information practices of persons grieving and mourning via Facebook. <http://bst.sagepub.com/content/early/2013/12/18/0270467613516753.abstract>

Dying on their own time: China's elite push for right to die

CHINA | *The Malay Mail* (Kuala Lumpur) – 12 February 2015 – Failure to take every measure to keep a person alive is seen as shameful and sometimes confused with euthanasia in China. So, senior officials are often given every treatment by the government to prolong their lives. That can leave these patients battling gruelling therapies right to the end, rather than spending their final weeks and months more peacefully. [The goal of "a group of princelings – children of the nation's highest-ranking officials": to help patients say no to certain medical interventions toward the end and seek palliative care for comfort. For the past nine years it has promoted living wills. This year they are widening their mission to train doctors and volunteers to provide end-of-life support for terminally ill patients <http://www.themalaymailonline.com/features/article/dying-on-their-own-time-chinas-elite-push-for-right-to-die>

N.B. See Media Watch dated 26 January 2015, #394 (pp.8-9) for a listing of selected articles on the end-of-life care in China noted in past issues of the weekly report.

Living and Dying with Dementia in Wales: Barriers to Care

U.K. (Wales) | Online – Accessed 12 February 2015 – The number of people affected by dementia in Wales stands at 45,000, with around 95% of those people aged over 65. By 2030, the proportion of the U.K. aged 85 or over is expected to double. As a result we are likely to see a significant increase in the number of people with dementia – currently the leading cause of death in women and the third leading cause of death in men. Marie Curie and Alzheimer's Society joined forces to compile this report to address the often overlooked final stage of dementia. The report highlights that dementia is often not recognised as a terminal diagnosis, which can lead to poor access to care, inconsistent quality of care and inadequate pain management. The report draws on research from across the U.K., as well as find-

ings from health and social care services. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf>

Specialist Publications

'What should we know about dementia in the 21st Century? A Delphi consensus study' (p.11), in *BMC Geriatrics*.

'An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper' (p.11), *International Psychogeriatrics*.

N.B. See Media Watch dated 9 February 2015, #396 (p.9) for a listing of selected articles on end-of-life care for people living with dementia noted in past issues of the weekly report.

Palliative care severely neglected in South Africa

SOUTH AFRICA | Voice of American – 10 February 2015 – [Jack] Kieser and [Peter] Cunningham are two of the few terminally ill South Africans who have access to palliative care. Thousands don't receive it, despite the country's high death rates from infectious diseases, cancer and heart disorders. "Most of these people, because they're poor, die in pain and despair, without receiving the benefits of palliative care that would have prolonged their lives and allowed them to live with a measure of joy and peace and even productivity in their last days," said Rian Venter, director of West Gauteng Hospice. The government doesn't fund palliative care; it's almost exclusively available at privately funded institutions. What the state does fund, at a cost of many millions of dollars, are drug programs to combat tuberculosis and the more virulent multidrug resistant TB, and the world's largest antiretroviral therapy rollout, giving medicines to almost three million people living with HIV. Venter commented: "I understand that governments should prioritize keeping people alive. What I don't understand is why, given South Africa's massive disease burden, there's not one cent given by the state towards helping people to die in the best possible way." <http://www.voanews.com/content/palliative-care-pt-5-south-africa/2636569.html>

Noted in Media Watch, 1 December 2014, #386 (p.6):

- SOUTH AFRICA | *Business Day* (Johannesburg) – 24 November 2014 – '**Dwindling donations threaten hospices.**' Hospice and palliative care centres have less than half of the 1 billion Rand [equal to approximately \$91 million U.S.] they need to function annually and "a fair percentage" of their 4,300 staff members are facing retrenchment. Funding has dried up from sources such as the National Lottery Distribution Trust Fund and corporate South Africa... <http://www.bdlive.co.za/national/health/2014/11/24/dwindling-donations-threaten-hospices>

N.B. South Africa was ranked 30th of forty countries studied in *The Quality of Death: Ranking End-of-life-care Across the World*, Economist Intelligence Unit, July 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

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

Research reveals experiences of disabled people with a terminal illness

U.K. | Marie Curie – 10 February 2015 – Only 22% of those surveyed by charity Disability Rights UK ranked end of life care services as "very good." This compares unfavourably with the 43% of bereaved people who, in the most recent VOICES survey, described care in the last three months of life as either outstanding or excellent.¹ One of the main challenges for disabled people with a terminal illness was communication. Some found it difficult to talk about the end of life as a disabled person, with some feeling that healthcare professionals assumed that their quality of life was already poor and probably not worth living. And most of those surveyed said they weren't supplied with information in a format appropriate to their disability. Some respondents said that professionals often didn't understand how best to support disabled people when they were terminally ill. The professionals who took part in the survey agreed this was an issue, but were keen to do more, providing examples of where they were trying to provide better support. The work included online surveys, a focus group and phone interviews. Most of the people who took part had cared for a disabled person at the end of life. Key findings are summarised in the graphic at right. <http://blog.mariecurie.org.uk/2015/02/10/research-reveals-experiences-of-disabled-people-with-a-terminal-illness/>

1. 'National Survey of Bereaved People (VOICES),' Office for National Statistics, July 2014. [Noted in Media Watch, 14 July 2014, #366 (p.5)] <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html>

Cont.

Noted in Media Watch, 28 October 2013, #329 (p.12, under 'Worth Repeating'):

- *JOURNAL OF PALLIATIVE CARE*, 2006;22(3):166-174. **'Vulnerability, disability, and palliative end-of-life care.'** Palliative care has paid exceedingly little attention to the needs of disabled people nearing the end of life. It is often assumed these individuals, like all patients with little time left to live, arrive at palliative care with various needs and vulnerabilities that by and large, can be understood and accommodated within routine standards of practice. However, people with longstanding disabilities have lived with and continue to experience various forms of prejudice, bias, disenfranchisement and devaluation. Each of these impose heightened vulnerability, requiring an honest, thoughtful, yet difficult revisiting of the standard model of palliative care. A Vulnerability Model of Palliative Care¹ attempts to incorporate the realities of life with disability and how a contextualized understanding of vulnerability can inform how we approach quality, compassionate palliative care for marginalized persons approaching death. <http://europepmc.org/abstract/MED/17058755/reload=0;jsessionid=8v6LkYzNhjoT6DGQkiW5.42>

1. 'Revised Vulnerability Model of Palliative Care,' Vulnerable Persons and End of Life New Emerging Team, University of Manitoba, Canada. (Website accessed 02.11.2015): <http://www.umanitoba.ca/outreach/vpnet/lpv-concepts-model.htm>

Elder and home care in the U.K.

Care workers are underpaid by £130 million a year, according to new study

U.K. | *The Guardian* – 9 February 2015 – About 160,000 care workers are paid less than the minimum wage – meaning that they miss out on £815 a year on average.¹ The thinktank said the "wage theft" totalled £130 million a year and employers were failing to meet legal requirements to pay employees the minimum wage, and depriving the exchequer of an additional £9 million of employer national insurance contributions. <http://www.theguardian.com/society/2015/feb/09/care-workers-underpaid-resolution-foundation-minimum-wage>

1. 'Scale of minimum wage underpayment in social care,' Resolution Foundation, February 2015: <http://www.resolutionfoundation.org/wp-content/uploads/2015/02/NMW-social-care-note1.pdf>

Of related interest:

- U.K. (England) | BBC News – 7 February 2015 – **'One in five care homes "failing standards."** One in five care homes for older people in England fail to meet set national standards for safety and care, a report by [BBC's] 5 Live Investigates suggests. Research by healthcare analysts LaingBuisson examined inspection records for almost 10,000 care homes, and found 20% had failed to meet at least one key quality measure. <http://www.bbc.com/news/health-31173451>

N.B. Researchers at the International Longevity Centre forecast that across the U.K. nearly 3.1 million people live with serious illness and this is set to potentially rise to between 3.4-4 million by 2025: http://www.ilcuk.org.uk/images/uploads/publication-pdfs/Serious_illness_in_the_over_50s.pdf

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

Hospice palliative care volunteers: A review of commonly encountered stressors, how they cope with them, and implications for volunteer training/management

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 February 2015 – Hospice palliative care volunteer work ... has the potential to take an emotional toll on volunteers. The aim of this review article is to examine the types of stressors hospice palliative care volunteers typically experience in their work and how they cope with them. The results of this literature review suggest that hospice palliative care volunteers do not generally perceive their volunteer

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work as highly stressful. Nonetheless, a number of potential stressors and challenges were identified in the literature, along with some strategies that volunteers commonly employ to cope with them. The implications for volunteers and volunteer training/management are discussed. <http://ajh.sagepub.com/content/early/2015/02/10/1049909115571545.abstract>

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 12 February 2015 – **'The lived experience of volunteering in a palliative care biography service.'** [The results of this study] indicated that volunteering gave the volunteers [i.e., study participants] a deeper appreciation of existential issues, and helped them to be more appreciative of their own lives and gain a deeper awareness of the struggles other people experience. They also suggested volunteers felt that their involvement contributed to their own personal development, and was personally rewarding. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9556756&fulltextType=RA&fileId=S1478951515000152>

Selected articles on hospice volunteers noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 November 2014 – **'Motivations, satisfaction, and fears of death and dying in residential hospice volunteers...'** Motivations to volunteer [among survey respondents] remained stable over time while volunteer satisfaction increased with time. [Noted in Media Watch, 1 December 2014, #386 (p.8)] <http://ajh.sagepub.com/content/early/2014/11/24/1049909114559830.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained, and learning from their patients' experiences/listening to their patients' life stories. [Noted in Media Watch, 23 July 2012, #263 (p.6)] <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.'** Volunteers said that feeling appreciated by the patients/families they support gave them great satisfaction. [Noted in Media Watch, 16 January 2012, #236 (p.5)] <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>

Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective, longitudinal cohort study

CANCER | Online – 9 February 2015 – Five highly specific physical signs associated with death within 3 days among cancer patients were recently reported that may aid in the diagnosis of impending death. In this study, the frequency and onset of another 52 bedside physical signs and their diagnostic performance for impending death were examined. Eight physical signs that were highly diagnostic of impending death were identified. These signs occurred in 5% to 78% of the patients within the last 3 days of life, had a late onset, and had a high specificity and a high positive likelihood ratio for death within 3 days. They included non-reactive pupils, a decreased response to verbal stimuli, a decreased response to visual stimuli, an inability to close eyelids, drooping of the nasolabial fold, hyperextension of the neck, grunting of vocal cords, and upper gastrointestinal bleeding. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29048/abstract>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 February 2015 – **'Teaching colleagues how to discuss prognosis as part of a hospital-wide quality improvement project: The positive impact of a 90-minute workshop.'** Physicians identified several reasons why discussions of prognosis are hard: "I am not sure of the actual prognosis," "I worry I will take away hope," and "I worry the patient is not ready to hear the information." Physicians who attended this short workshop reported that they could apply what was learned to their work immediately. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00069-X/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00069-X/abstract)

What constitutes a good and bad death?: Perspectives of homeless older adults

DEATH STUDIES | Online – 12 February 2015 – The themes for a good death were: 1) dying peacefully; 2) not suffering; 3) experiencing spiritual connection; and, 4) making amends with significant others. Themes for a bad death were: 1) experiencing death by accident or violence; 2) prolonging life with life supports; 3) becoming dependent while entering a dying trajectory; and, 4) dying alone. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629>

N.B. Several articles on end-of-life care for the homeless are noted in Media Watch, 3 February 2014, #343 (p.4). In the U.K., Marie Curie Cancer, with St. Mungo's Broadway, published 'Homelessness and End-of-Life Care.' <http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf> [Noted in Media Watch, 20 May 2013, #306 (p.7)]. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: http://www.sophie-project.eu/pdf/ENHW_2014.pdf

Planning for the end of life in prison

EARLY CAREER ACADEMIC NETWORK BULLETIN (Howard League for Penal Reform) | Online – January 2015 – New research currently underway at Lancaster University is investigating how palliative and end-of-life care is provided for prisoners who are likely to die from natural causes whilst still in custody. This article will explore some of the complexities inherent in providing palliative care in a prison setting, and consider some early findings from the research which suggests ways to improve end-of-life care for this group of prisoners. End-of-life care in prisons raises a wide range of ethical, political, policy and practical questions, not least of which is whether prison can even be an appropriate setting for dying. Political decisions about sentencing policies have resulted in more people being imprisoned for longer, at a time when crime rates are falling; these changes have directly led to a

rapid increase in the numbers of people dying in prison. The continuing challenge for prison staff is to ensure that those who are going to die in prison can approach the end of their lives with dignity and compassion. https://d19ylpo4aovc7m.cloudfront.net/fileadmin/howard_league/user/pdf/Research/ECA/ECAN_bulletin_25.pdf#page=10

[Prison Hospice Backgrounder](#)

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

Islam and palliative care

GLOBAL BIOETHICS | Online – 9 February 2015 – Palliative care is experiencing an upsurge in interest and importance. This is driven, paradoxically, by modern medicine's increased ability to provide effective pain relief on the one hand and an acknowledgement of its limitation in delivering a cure for certain diseases on the other. With many Muslims suffering from such incurable diseases worldwide, they too are now faced with the decision of whether to avail themselves of pain relief offered within the framework of scientific medicine. However, while the general ethos of palliative care, which is to promote the quality of life of those facing life-limiting illnesses is consistent with Islamic values, this paper explores whether the same can be submitted for modern methods of pain control. The investigation will be steered by... First, if pain and suffering could, as highlighted in the primary sources of Islamic Law, lead to the expiation of sins, can pain relief be taken? Second, is it religiously permissible to choose pain treatment options that could bring about iatrogenic addiction, the hastening of death and the impairment or obliteration of consciousness? http://www.tandfonline.com/doi/abs/10.1080/11287462.2015.1008752#.VOCMaebF_YQ

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Noted in Media Watch, 12 January 2015, #392 (p.7):

- *AMERICAN JOURNAL OF BIOETHICS*, 2015;15(1):3-13. 'Ethical obligations and clinical goals in end-of-life care: Deriving a quality-of-life construct based on the Islamic concept of accountability before God (*Taklif*).' End-of-life medical decision making presents a major challenge to patients and physicians alike. In order to determine whether it is ethically justifiable to forgo medical treatment in such scenarios, clinical data must be interpreted alongside patient values, as well as in light of the physician's ethical commitments. Though much has been written about this ethical issue from religious perspectives (especially Christian and Jewish), little work has been done from an Islamic point of view. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.974769>

N.B. This issue of the *American Journal of Bioethics* includes several articles on end-of-life care from the Islamic perspective. Contents page: <http://www.tandfonline.com/toc/uajb20/current>. Additional articles on the subject are noted in Media Watch, 15 December 2014, #388 (pp.11-12), 16 June 2014, #362 (p.11), and 28 March 2011, #194 (p.10).

An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper

INTERNATIONAL PSYCHOGERIATRICS | Online – 13 February 2015 – Although palliative care was not explicitly referred to in eight of the 14 countries [reviewed], and only to a limited extent in three countries, a number of domains from the Association's white paper were well represented, including "person-centered care, communication, and shared decision making"; "continuity of care"; and "family care and involvement."¹ Three countries that referred to palliative care did so explicitly, with two domains being well represented: "education of the health care team"; and "societal and ethical issues." The strategies all lacked reference to ... "prognostication and timely recognition of dying" and to spiritual caregiving. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9557793&fulltextType=RA&fileId=S1041610215000150>

What should we know about dementia in the 21st Century? A Delphi consensus study

BMC GERIATRICS | Online – 6 February 2015 – This study identified information about dementia that experts consider essential for a contemporary understanding of the condition. While expert consensus supports a diverse range of domains as critical in understanding dementia, information about the provision of care was prominent. The findings may assist clinicians and academics to convey information about dementia to colleagues, health workers, and the general public, as well as facilitate the development of education and knowledge-evaluation products. <http://www.biomedcentral.com/content/pdf/s12877-015-0008-1.pdf>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, published online 4 July 2013. [Noted in Media Watch, 8 July 2013, #313 (p.8)] <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

N.B. Selected articles on end-of-life care for people living with dementia listed in past issues of Media Watch are noted in the issue of the weekly report of 9 February 2015, #396 (p.9).

Easing the burden of surrogate decision making: The role of a do-not-escalate-treatment order

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 February 2015 – The authors illustrate the common problem of a surrogate decision maker who is psychologically distressed over the medical team's recommendation to withdraw life-sustaining treatment. They suggest how a do-not-escalate-treatment (DNET) order can be helpful in such situations when the usual approaches to withholding or withdrawing care are not acceptable to the surrogate. The authors define a DNET order, explain when it might be useful, and discuss how it can facilitate a humane, negotiated resolution of differences. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0295>

Care planning

Forty years of work on end-of-life care – from patients' rights to systemic reform

NEW ENGLAND JOURNAL OF OF MEDICINE, 2015;372(7):678-682. Nearly 40 years of work to improve end-of-life care has revealed the difficulty of aligning care with patients' needs and preferences to ease the dying process. The problem must be attacked at all levels, from individual rights to relationships to systemic reform. <http://www.nejm.org/doi/full/10.1056/NEJMms1410321>

Of related interest:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 11 February 2015 – '**Consensus views on advance care planning for dementia: A Delphi study.**' The panel agreed on 11 different areas for discussion. They concurred that advance care planning was best addressed after the person has come to terms with the diagnosis when the individual feels ready to do so. There was a consensus view that the process should be couched in terms of "certain possibilities." <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12191/abstract>
- *NEW ENGLAND JOURNAL OF OF MEDICINE*, 2015;372(7):598-599. '**Should we practice what we profess? Care near the end of life.**' Vast majorities of U.S. physicians and other Americans say they'd like to avoid high-intensity care at the end of life, but these wishes are frequently overridden. <http://www.nejm.org/doi/full/10.1056/NEJMmp1413167>
- *NEW ENGLAND JOURNAL OF OF MEDICINE*, 2015;372(7):595-598. '**Finding the right words at the right time – high-value advance care planning.**' Advance care planning discussions are difficult, and evidence suggests that targeting everyone for them might dilute our efforts. <http://www.nejm.org/doi/full/10.1056/NEJMmp1411717>
- *PALLIATIVE MEDICINE* | Online – 13 February 2015 – '**Patients' preferences in palliative care: A systematic mixed studies review.**' 13 qualitative and 10 quantitative studies identified included participants with different illnesses in various settings. Four themes emerged representing patient preferences ... 'living a meaningful life' illustrated what patients strived for. The opportunity to focus on living required the presence of 'responsive healthcare personnel,' 'responsive care environment' and 'responsiveness in the organization of palliative care.' <http://pmj.sagepub.com/content/early/2015/02/11/0269216314557882.abstract>
- *TIDSSKRIFT FOR DEN NORSKE LEGEFORENING* (The Journal of the Norwegian Medical Association), 2015;135:233-235. '**Advance care planning discussions with geriatric patients.**' Of the 58 [patients] interviewed, 54 wanted complete transparency of information and 47 wanted their families to participate when important information was to be imparted and crucial decisions on treatment were to be made. A total of 11 wanted no involvement of their families in these processes. All of them wanted their doctor to participate in important decisions. <http://tidsskriftet.no/article/3290842>

N.B. English language article.

Association of actual and preferred decision roles with patient-reported quality of care: Shared decision making in cancer care

JAMA ONCOLOGY | Online – 12 February 2015 – Physician-controlled decisions regarding lung or colorectal cancer treatment were associated with lower ratings of care quality and physician communication. These effects were independent of patients' preferred decision roles, underscoring the importance of seeking to involve all patients in decision making about their treatment. <http://oncology.jamanetwork.com/article.aspx?articleid=2108850>

Pediatric palliative care

Novel legislation for pediatric advance directives: Surveys and focus groups capture parent and clinician perspectives

PALLIATIVE MEDICINE | Online – 10 February 2015 – The authors explored pediatric clinicians' experiences with life-sustaining treatments prior to the Medical Orders for Life-Sustaining Treatment [MOLST] mandate. A minority of clinicians, but all parents [i.e., survey respondents] supported universal pediatric MOLST. Prior to the MOLST mandate, many clinicians had felt unprepared to lead [treatment] limitation discussions... Communication training is perceived essential to successful MOLST conversations. Parents felt that universal MOLST would decrease the stigma of limitation discussions ... [and] ... clarify decision making and increase utilization of palliative care. <http://pmj.sagepub.com/content/early/2015/02/10/0269216315571020.abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/02/media-watch/#CHINESE>

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]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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>

End-of-life care in Norway

Palliative sedation at the end of life – revised guidelines

TIDSSKRIFT FOR DEN NORSKE LEGEFORENING (The Journal of the Norwegian Medical Association), 2015;135:220-221. Palliative sedation of patients at the end of life involves a number of medical, ethical and legal challenges. As a support to doctors who provide this treatment to patients who cannot be helped in any other way, the Norwegian Medical Association prepared a set of guidelines in 2001. These have now been revised and adopted by the national board in June 2014. This work and some key points in the new guidelines will be presented here. <http://tidsskriftet.no/article/3290661>

N.B. English language article.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 February 2015 – **'Pediatric euthanasia and palliative care can work together.'** Most rejections of pediatric euthanasia fall into one or more of three categories, each of which has problems. This article shows how several recent arguments against pediatric euthanasia fail to prove that pediatric euthanasia is unacceptable. It does not follow from this that the practice is permissible, but rather that if one is to reject such a practice, stronger arguments will need to be made, especially in countries where adult euthanasia or assisted suicide is already permitted. <http://ajh.sagepub.com/content/early/2015/02/06/1049909115570999.abstract>

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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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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 February 2015 – '**Legalizing physician-assisted suicide and/or euthanasia: Pragmatic implications.**' Despite the availability of palliative care in many countries, legalization of euthanasia and physician-assisted suicide (EAS) continues to be debated – particularly around ethical and legal issues – and the surrounding controversy shows no signs of abating. Responding to EAS requests is considered one of the most difficult healthcare responsibilities. In the present paper, the authors highlight some of the less frequently discussed practical implications for palliative care provision if EAS were to be legalized. Their aim was not to take an explicit anti-EAS stance or expand on findings from systematic reviews or philosophical and ethico-legal treatises, but rather to offer clinical perspectives and the potential pragmatic implications of legalized EAS for palliative care provision, patients and families, healthcare professionals, and the broader community. The authors believe that these issues, many of which are encountered at the bedside, must be considered in detail so that the pragmatic implications of EAS can be comprehensively considered. Increased resources and effort must be directed toward training, research, community engagement, and ensuring adequate resourcing for palliative care before further consideration is given to allocating resources for legalizing euthanasia and physician-assisted suicide. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9555508&fulltextType=RA&fileId=S1478951515000176>

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