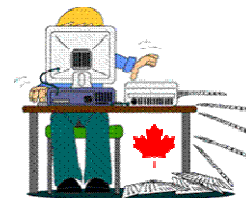


## Media Watch...

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.

9 November 2015 Edition | Issue #435



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Public knowledge: Scroll down to [Specialist Publications](#) and “What is palliative care?” Variability in content of palliative care informational web pages’ (p.7) in *American Journal of Hospice & Palliative Medicine*.

## Canada

### Community Care Access Centres likely to be dismantled

ONTARIO | *The Toronto Star* – 6 November 2015 – A major restructuring of the province’s health system is on the way, bringing big changes at the community level, says Health Minister Eric Hoskins. Insiders say this means the controversial community care access centres (CCACs) are on their way out. CCACs are charged with co-ordinating access to home and community care services, including nursing, physiotherapy and personal care. Part of the system for almost two decades, they have come under fire for delivering uneven levels of care across the province, giving big raises to their CEOs, and being too administration-heavy. Opposition politicians have long called for scrapping them. So has the Registered Nurses’ Association of Ontario. The centres also came under heavy criticism from the provincial auditor last month,<sup>1</sup> and earlier this year by an expert panel the province commissioned to study how well the home and community care system is working.<sup>2</sup> Until now, the government has steered clear of addressing structural reform. But in a speech ... Hoskins said it’s time to up-end the *status quo*, in hopes of bringing services closer to those who need them, breaking “the cycle of poor health outcomes,” and addressing inequities across the province. [http://www.thestar.com/life/health\\_wellness/2015/11/06/community-care-access-centres-likely-to-be-dismantled.html](http://www.thestar.com/life/health_wellness/2015/11/06/community-care-access-centres-likely-to-be-dismantled.html)

1. ‘Community Care Access Centres – Financial Operations & Service Delivery,’ Office of the Auditor General of Ontario, September 2015. [Noted in Media Watch, 28 September 2015, #429 (p.2)] [http://www.auditor.on.ca/en/reports\\_en/CCACs\\_en.pdf](http://www.auditor.on.ca/en/reports_en/CCACs_en.pdf)
2. ‘Bringing Care Home,’ Expert Group on Home & Community Care, March 2015. [Noted in Media Watch 21 September 2015, #428 (p.2)] [http://health.gov.on.ca/en/public/programs/ccac/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf)

**N.B.** See ‘2014 Report,’ Office of the Auditor General of Ontario, December 2014. (Extract on end-of-life care in the province, see ‘Palliative Care,’ pp.258-288), [Noted in Media Watch, 15 December 2014, #388 (p.2)] [http://www.auditor.on.ca/en/reports\\_en/en14/308en14.pdf](http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf)

### 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.19.

## Palliative care improvements are “urgent,” Moncton doctor says

NEW BRUNSWICK | CBC News (Moncton) – 2 November 2015 – The New Brunswick government must make urgent changes to improve care for dying patients and their families, according to a palliative care (PC) specialist. Dr. Pamela Mansfield, the clinical director of palliative medicine for the Moncton area with Horizon Health Network, says with doctor-assisted suicide soon to be legal in Canada it is urgent that the provincial government start making changes based on the recommendations of a June 2013 [unpublished] report. “It gives direction for how do we deliver equitable, good PC for everyone in the province no matter where you live,” Mansfield said in an interview... CBC News has contacted the Department of Health to find out what is happening with the report, but so far there has been no response. Mansfield says doctors with the Horizon Health Network regularly ask the provincial government officials when action will be taken and they are told it is being studied. <http://www.cbc.ca/news/canada/new-brunswick/pamela-mansfield-moncton-palliative-care-1.3299560>

### Selected articles, reports, etc., on the provision and delivery of palliative care in New Brunswick

- CBC NEWS (Fredericton) – 2 October 2014 – ‘**Hospice in Chaleur region could save \$2-million a year, study suggests.**’ Many patients end up spending their final days in hospital at a cost of \$1,000 a day. “To provide that care in a hospice environment costs around \$445 to \$450. At a capacity of 160 patients annually, we’re looking at over \$2 million in savings to the government’s health care bill,” said Sheraz Thomas, a researcher at the University of New Brunswick, who was commissioned by Chaleur Palliative [Services] to study the issue. [Noted in Media Watch, 6 October 2014, #378 (p.1)] <http://www.cbc.ca/news/canada/new-brunswick/hospice-in-chaleur-region-could-save-2m-a-year-study-suggests-1.2785284>
- GLOBE TV NEWS (Moncton) – 12 September 2014 – ‘**Group urges equal access palliative care strategy for New Brunswick.**’ The New Brunswick Hospice Palliative Care Association wants New Brunswick to adopt a provincial strategy for hospice palliative care that includes better training and pay for personal support workers, sustainable funding for residential hospices, and equal access to this specialist care across the maritime province. [Noted in Media Watch, 15 September 2014, #375 (p.1)] <http://globalnews.ca/news/1558829/group-urges-equal-access-palliative-care-strategy-for-new-brunswick/>
- CBC NEWS (Dalhousie) – 6 August 2014 – ‘**Dalhousie residents demand to keep palliative care beds.**’ Dalhousie-area residents are upset about the loss of four palliative care beds at the St. Joseph Community Health Centre in the northern town. The beds are closed for several months each year to save money, but the Vitalité Health Network announced it plans to shut them down permanently, reducing the number of end-of-life care spots in the region to six from 10. [Noted in Media Watch, 11 August 2014, #340 (p.2)] <http://www.cbc.ca/news/canada/new-brunswick/dalhousie-residents-demand-to-keep-palliative-care-beds-1.2729087>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News – 3 November 2015 – ‘**Doctor-assisted suicide gets green light from Sherbrooke palliative care centre.**’ A palliative care centre in Sherbrooke is poised to become the first facility to provide access to doctor-assisted suicide for terminally ill patients. The CEO of la Maison Aube-Lumière, Elizabeth Brière, said the centre will begin offering the service on 1 February 2016, five days before the ban on doctor-assisted suicide is lifted outside of Quebec. In Quebec, the right to end one’s life with a doctor’s help will take effect in December 2015. The centre’s staff voted 61% in favour of offering the service. Its board of governors voted unanimously in favour. As recently as last May, management at the centre said doctor-assisted suicide would not be permitted at the hospice. Last September, however, it pledged to revisit the subject. The decision to allow medically assisted death came from the findings of that investigation. <http://www.cbc.ca/news/canada/montreal/doctor-assisted-suicide-vote-maison-aube-lumiere-1.3302254>

## U.S.A.

### Woman faces dilemma in sending terminally ill son to school

ALABAMA | Associated Press – 3 November 2015 – An Alabama teen with a terminal heart condition has not returned to school after a spate of hospitalizations because of what his mother says is a dispute with school officials about how he might die. Alex Hoover's case presents something of a legal loophole: His mother, Rene, has drawn up legal documents known as an advance directive to ensure the 14-year-old is not revived if he goes into cardiac arrest. But officials say they can't follow that directive if his heart stops at school. Rene Hoover says she does not want her son's last days spent enduring a battery of medical procedures and medication as a result of his condition, aortic mitral valve stenosis. The condition causes the heart's mitral valve to narrow and restrict blood flow. Alex, of Athens, Alabama, was hospitalized three times over the summer and hasn't returned to class because Limestone County school board officials have said they won't recognize the advance directive. In Alabama, do-not-

resuscitate orders and similar directives apply only to people 19 and older. Alabama State Department of Education said the department has no policy on advance directives and school staff must decide whether to follow parents' orders. [http://www.salon.com/2015/11/03/woman\\_faces\\_dilemma\\_in\\_sending\\_terminally\\_ill\\_son\\_to\\_school/](http://www.salon.com/2015/11/03/woman_faces_dilemma_in_sending_terminally_ill_son_to_school/)

#### Specialist Publications

'Characterizing the hospice and palliative care workforce in the U.S.: Clinician demographics and professional responsibilities' (p.13), in *Journal of Pain & Symptom Management*.

'Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency' (p.15), *Journal of Pain & Symptom Management*.

Noted in Media Watch, 13 July 2015, #418 (p.7):

- U.K. (England) | *The Guardian* – 9 July 2015 – '**How schools support children with life-limiting illnesses.**' Although dealing with the challenges of providing education to very sick children may seem rare, 49,000 people in the U.K. under the age of 19 live with a life-threatening or life-limiting condition: that's one child in every 270, or on average one per school. <http://www.theguardian.com/teacher-network/2015/jul/09/how-schools-support-children-life-limiting-illnesses>

Noted in Media Watch, 7 July 2014, #365 (p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(6):355-361. '**Supporting children with life-threatening conditions in the schools.**' School nurses [i.e., survey participants] encountered several types of questions from children with life-threatening conditions, their classmates and families, and school staff. They had questions themselves, in such areas as gaining and disseminating information, promoting understanding of the child's condition and providing support, addressing symptoms in conjunction with school activities, and also do-not-resuscitate orders in the school setting. [http://journals.lww.com/jhpn/Abstract/2014/08000/Supporting\\_Children\\_With\\_Life\\_Threatening.8.aspx](http://journals.lww.com/jhpn/Abstract/2014/08000/Supporting_Children_With_Life_Threatening.8.aspx)

From the archives:

- *AMA JOURNAL OF ETHICS*, 2012;12(7):569-572. '**Do-not-attempt-resuscitation orders in public schools.**' Pediatric patients receiving palliative care may still be well enough to benefit from attending school, and may at the same time have a do-not-attempt-resuscitation order in place. A parent's request to honor such an order in the public school setting is an example of a situation in which personal and individual parental decisions create ethically sensitive repercussions for others, including teachers, school nurses, classmates, administrators, school systems, local governments, and the legal system. <http://journalofethics.ama-assn.org/2010/07/pfor1-1007.html>

## Are seniors getting too much medical treatment?

*FORBES* | Online – 2 November 2015 – Older adults are getting too much medical treatment. No, I am not suggesting we ration treatment for seniors or empower the mythical death panels. Rather, the health system should replace aggressive, but ultimately useless medical interventions, with more personal care. This means rethinking the way we care for older adults with chronic disease. We should organize care around the goal of improving their quality of life rather than on aggressively treating their specific medical conditions. Rather than doing that third scan on the same body part, we could better spend our dollars on home delivered meals or an adult day program for an otherwise homebound senior. Every decision should be based on the answers to two simple questions: Is it what the patient wants? Will it improve her quality of life? The idea isn't new, of course. It has been floating around the edges of medicine for years. More hospitals are developing palliative care programs. People at the end of life are increasingly relying on hospice, though still for a too-short period of time. And many are taking more control of their end-of-life care through advanced directives, do-not-hospitalize orders, and right-to-die laws. But these initiatives are either modest or focused only on people at the very end of life. Many completely miss those who will live for years with chronic conditions. As many 12 million Americans need some level of personal assistance to help with their daily activities. And recent research<sup>1</sup> ... finds that 6 million people over 65 will live an average of two years with a very high level of need for assistance, and one in seven older adults will live five years or more needing significant help. <http://www.forbes.com/sites/howardgleckman/2015/11/02/are-seniors-getting-too-much-medical-treatment/>

1. 'Long-term Services and Supports for Older Americans: Risks and Financing Research Brief,' Office of the Assistant Secretary for Planning & Evaluation, Department of Health & Human Services, July 2015. [http://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb\\_0.pdf](http://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb_0.pdf)

## International

### End-of-life care in Germany

#### **Bundestag votes for better palliative care for the terminally ill**

GERMANY | *Deutsche Welle* (Berlin) – 5 November 2015 – A new law aimed at strengthening palliative care has passed in the Bundestag with broad support. It comes a day ahead of a widely-anticipated and more controversial debate on assisted suicide. <http://www.dw.com/en/bundestag-votes-for-better-palliative-care-for-the-terminally-ill/a-18830299>

### End-of-life care in Ireland

#### **Palliative care guidelines to ease pain symptoms**

IRELAND | *The Independent* (Dublin) – 5 November 2015 – Health staff are being issued with new guidelines to help patients who are suffering the distress of pain and other symptoms while having palliative care (PC). “The guidelines will help to improve the quality, safety and cost-effectiveness across the many settings where PC is delivered in Ireland,” said Minister of State Kathleen Lynch. “The primary goal is to allow patients to live as comfortably and as pain free as possible. Cancer pain and constipation are two of the most common symptoms experienced by patients with advanced, progressive illness. Unnecessary suffering can be reduced by promoting prevention and early effective

treatment of these burdensome symptoms and this is what the guidelines intend to achieve.” <http://www.independent.ie/irish-news/health/palliative-care-guidelines-to-ease-pain-symptoms-34172103.html>

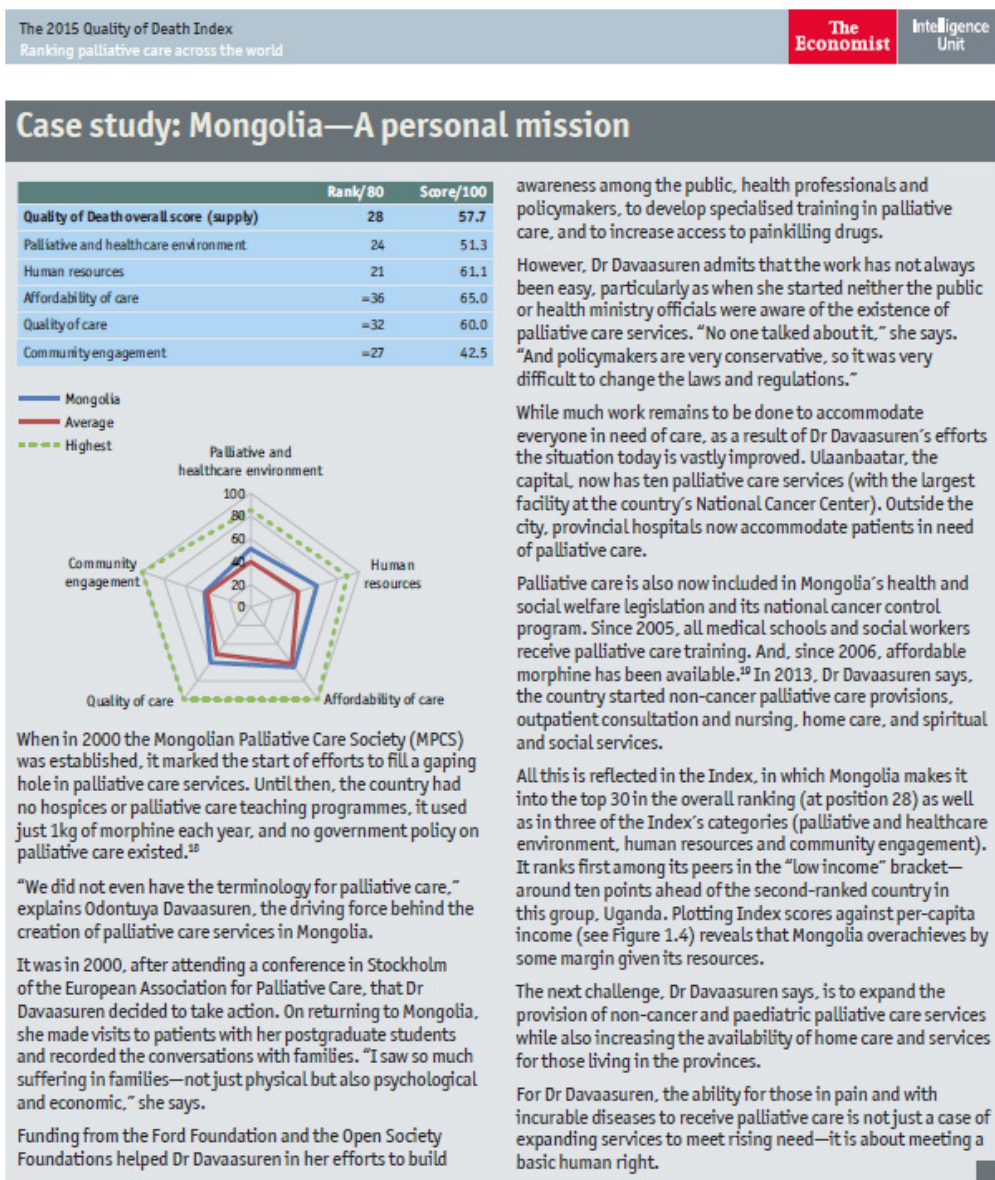
#### **Specialist Publications**

‘Current and emerging practice of end-of-life care in British prisons: Findings from an online survey of prison nurses’ (p.10), in *BMJ Supportive & Palliative Care*.



## How one woman changed the way people die in Mongolia

MONGOLIA | National Public Radio (U.S.) – 5 November 2015 – Dr. Odontuya Davaasuren has one goal: to improve the way people die in Mongolia. “My father died of lung cancer, my mother died, my mother-in-law died because of liver cancer,” she says. “Even though I was a doctor, I could do nothing.” The feeling of helplessness, and the unnecessary pain her relatives suffered, is what Davaasuren has set out to fix. She has white hair because of it, says the family doctor and professor at the Mongolian National University of Medical Sciences in Ulaanbaatar. “It’s very hard work.” Her efforts have earned her the title “the mother of palliative care in Mongolia.” And they’ve transformed the way people die. In global rankings on quality of death released this fall by the Economist Intelligence Unit, Mongolia stood out. It’s number 28 on the list. “Some countries with lower income levels demonstrate the power of innovation and individual initiative,” the report noted, citing Mongolia for “rapid growth in hospice facilities and teaching programs.” <http://www.npr.org/sections/goatsandsoda/2015/11/05/450927959/how-one-woman-changed-the-way-people-die-in-mongolia>



‘2015 Quality of Death Index’ (see p.19): [http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL\\_ARAFIL20151006\\_0002.pdf](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

## End-of-life care in Scotland

### Call for more palliative care for young people

U.K. (Scotland) | BBC News – 4 November 2015 – Bodies supporting end-of-life care for young people have called for better provision. Managed Service Network for Children & Young People with Cancer and Children’s Hospice Association Scotland (Chas) highlight a rise in young people requiring such help. This follows a study which has provided figures of young people requiring palliative care (PC) for the first time.<sup>1</sup> The University of York report says there could be more than 15,000 people with life-shortening conditions. This is an increase of around a quarter since 2009-2010, when the full data started to be collated. It is believed the increase is due to advances in medicine, with many children now living longer than before. The report calls for children aged under one to be a priority for improved PC provision, along with children who live in deprived areas. The study includes information on the numbers of babies, children and young people in Scotland who need to access PC. <http://www.bbc.com/news/uk-scotland-34716045>

1. ‘Children in Scotland Requiring Palliative Care,’ Managed Service Network for Children & Young People with Cancer and Children’s Hospice Association Scotland (Chas), October 2015. [http://www.chas.org.uk/assets/0001/5573/ChiSP\\_report.pdf](http://www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf)

Of related interest:

- U.K. (Scotland) | STV News (Glasgow) – 5 November 2015 – ‘**Nearly half of over-50s “not confident” over end-of-life care.**’ The majority of those concerned were worried that busy hospital and care home staff did not have the time to care for people with terminal illnesses. A YouGov survey for Marie Curie found just 9% of over-50s surveyed felt very confident they would get the care they needed; 43% said they were not confident they would get the care they needed toward the end of their life. <http://news.stv.tv/scotland/1332012-nearly-half-of-over-50s-not-confident-over-end-of-life-care/>

## Elder care in Wales

### Care home shortage warning in report as owners retire

U.K. (Wales) | BBC News – 4 November 2015 – Care home places could run short as owners retire and homes close with no-one to take over, a report has warned.<sup>1</sup> It found Wales less dependent than England on large firms such as Southern Cross, which collapsed in 2011. But experts said high capital costs, uncertain income and staff shortages deterred existing firms from expanding their operations, and new entrants. Health Minister Mark Drakeford said the report would help shape the debate about the provision of care. The Public Policy Institute for Wales said financial pressures on care homes had made it more difficult for new entrants to enter the market. Some existing operators were interested in expanding, but the report said they were put off by the capital costs involved, uncertainty over future demand, and the rising costs of care

as people needed more intensive support. The researchers urged the Welsh government and local councils to monitor services, ownership, financial stability, staffing and quality of care to plan for the future. <http://www.bbc.com/news/uk-wales-politics-34723524>

#### **Quote from Public Policy Institute for Wales report**

*Five years ago most of the residents at a nursing home could eat their own dinner, walk at least a short way and take themselves to the lavatory. Now hardly any patients in a care home can do that. Most require two members of staff to help them wash etc. The number of care staff needed has doubled. Nursing homes are becoming more like hospices.*

1. ‘Care Home Market in Wales: Mapping the Sector,’ Public Policy Institute for Wales, October 2015. <https://sites.cardiff.ac.uk/ppiw/files/2015/11/The-Care-Home-Market-in-Wales-mapping-the-sector.pdf>

Cont.

Related:

- U.K. (England) | *The Guardian* – 31 October 2015 – ‘**Cash crisis could close 50% of U.K. care homes.**’ Ministers are under mounting pressure to pump more money into care for the elderly as investigations by the *Observer* reveal how some of the largest providers may have to pull out of supplying services because of an escalating financial crisis. Sarah Wollaston, the Conservative chair of the all-party Commons select committee on health, is calling for the government to act, saying that social care providers are reeling from rising costs and declining fees from cash-strapped local authorities. <http://www.theguardian.com/society/2015/oct/31/half-care-homes-could-close-cash-crisis>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* (Berlin) – 6 November 2015 – ‘**Bundestag votes against “commercial” assisted suicides.**’ After a year of debate on the sensitive issue, the lower house of German parliament has voted in favor of banning assisted suicides performed by associations. <http://www.dw.com/en/bundestag-votes-against-commercial-assisted-suicides/a-18831510>

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

### “What is palliative care?” Variability in content of palliative care informational web pages

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2015 – The purpose of this study was to analyze online palliative care (PC) information pages to evaluate the breadth of their content. The authors also compared how frequently basic facts about PC appeared on the Web pages to expert rankings of the importance of those facts to understanding PC. Twenty-six pages were identified. The authors identified 22 recurring broad concepts. Each information page included, on average, 9.2 of these broad concepts... Similarly, each broad concept was present in an average of 45% of the Web pages... Significant discrepancies emerged between expert ratings of the importance of the broad concepts and the frequency of their appearance in the Web pages. This study demonstrates that PC information pages available online vary considerably in their content coverage. Furthermore, information that PC professionals rate as important for consumers to know is not always included in Web pages. The authors developed guidelines for information pages for the purpose of educating consumers in a consistent way about PC. <http://ajh.sagepub.com/content/early/2015/11/04/1049909115615566.abstract>

### [Media Watch: Back Issues](#)



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**MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care**

Download the complete issue (PDF 450 KB) 

CHEST | Online – 5 March 2015 | The tendency toward “either/or” thinking (either cure or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. [read more...](#)

Media Watch Archives

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<http://www.ipcrc.net/archive-global-palliative-care-news.php>

## Normalising advance care planning in a general medicine service of a tertiary hospital: An exploratory study

*AUSTRALIAN HEALTH REVIEW* | Online – 5 November 2015 – Advance care planning (ACP) is increasingly recognised as an important part of hospital care for older patients with advanced chronic disease. However, research indicates ACP discussions are rare in hospital settings because of various barriers that are not adequately addressed in the design of ACP programs. This study of the development, implementation and evaluation of an ACP program in a tertiary hospital general medicine service shows that program components designed to overcome specific barriers to ACP discussions was associated with a 75% completion rate of advance care plans among ACP eligible patients who participated in ACP discussions. Dedicated staff training and resources in ACP, employment of an ACP facilitator and ready access to ACP documentation forms were important enabling strategies. Hospital units caring for significant numbers of older patients with limited life expectancy can implement ACP programs that help normalise ACP discussions within routine clinical care. <http://www.publish.csiro.au/nid/270/paper/AH15068.htm>

Related:

- *BMC PALLIATIVE CARE* | Online – 3 November 2015 – **‘Evaluating the systematic implementation of the ‘Let Me Decide’ advance care planning programme in long term care through focus groups: Staff perspectives.’** The ‘Let Me Decide’ Advance Care Planning programme offers a structured approach to end-of-life (EoL) care planning in long-term care for residents with and without capacity to complete an advance care directive/plan. Key benefits of the programme included enhancing communication, changing the care culture, promoting preference-based care and avoiding crisis decision making. Establishing capacity among residents and indecision were among the main challenges reported by staff. A number of recommendations were proposed by participants and included multi-disciplinary team <http://www.biomedcentral.com/content/pdf/s12904-015-0051-x.pdf>

Noted in Media Watch, 24 March 2014, #350 (p.11):

- *NURSING RESEARCH & PRACTICE* | Online – Accessed 20 March 2014 – **‘A review of advance care planning programs in long-term care homes: Are they dementia friendly?’** Six advance care planning programs [including ‘Let Me Decide’] were included in this review, five of which could be considered more “dementia friendly.” <file:///C:/Users/Barry/Downloads/875897.pdf>

## Lesbian, gay, bisexual and transgender people’s attitudes to end-of-life decision-making and advance care

*AUSTRALASIAN JOURNAL ON AGEING*, 2015;34(Suppl S2):39-43. While limited by convenience sample, reliant on those connected to the lesbian, gay, bisexual and transgender (LGBT) communities, this study evidenced the relatively low take-up of advance care planning (ACP) options by LGBT people (although the rates of completion of enduring power of attorney and enduring guardian documents were higher than that found in the general population). This is despite their potential to promote LGBT people’s autonomy at the end of life. Similar barriers to those in the general population were found in relation to taking up these options and talking to preferred alternative decision makers about their end-of-life wishes. However, the findings also suggest that with the right promoting – creating conditions for meaningful conversations about about end-of-life car – these barriers may be overcome. Such conditions may be facilitated by health care providers or by ACP awareness campaigns targeted at LGBT people. <http://onlinelibrary.wiley.com/doi/10.1111/ajag.12268/epdf>



**N.B.** The focus of this issue of *Australasian Journal on Ageing* is on ageing and aged care in the LGBT communities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/ajag.2015.34.issue-s2/issuetoc>

Cont.



## Selected articles, reports, etc., on end-of-life care for an aging LGBT population

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE CARE*, 2015;11(2):178-201. ‘**Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective.**’ This article focuses on culturally sensitive clinical issues related to best practices with LGBT elder patients at end of life... Vital concepts, including practice evaluation and clinical skills, are presented through a cultural and oncology lens. The content of this article is designed to be adapted and used as an educational tool for institutions, agencies, graduate programs, medical professions, social work, and students. [Noted in Media Watch, 28 September 2015, #429 (p.15)] <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1074141>
- *PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 29 May 2015 – ‘**Hospice and palliative care for older lesbian, gay, bisexual and transgender adults: The effect of history, discrimination, health disparities and legal issues on addressing service needs.**’ LGBT persons are more likely to experience economic insecurity, lack health insurance, experience invisibility, and be victimized and mistreated. This is especially true of older LGBT adults who grew up in a less tolerant era when sexual minorities were criminalized and stigmatized as pathological, sinful, and immoral. Their status has led to health issues and health care disparities... [Noted in Media Watch, 20 July 2015, #419 (p.15)] [http://openventio.org/Volume1\\_Issue2/Hospice\\_and\\_Palliative\\_Care\\_for\\_Older\\_Lesbian\\_Gay\\_Bisexual\\_and\\_Transgender\\_Adults\\_The\\_Effect\\_of\\_History\\_Discrimination\\_Health\\_Disparities\\_and\\_Legal\\_Issues\\_on\\_Addressing\\_Service\\_Needs\\_PMHCOJ\\_1\\_107.pdf](http://openventio.org/Volume1_Issue2/Hospice_and_Palliative_Care_for_Older_Lesbian_Gay_Bisexual_and_Transgender_Adults_The_Effect_of_History_Discrimination_Health_Disparities_and_Legal_Issues_on_Addressing_Service_Needs_PMHCOJ_1_107.pdf)
- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 26 February 2015 – ‘**American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement.**’ This position statement addresses the vision of the Society for the care of LGBT older adults and specific steps that can be taken to ensure that they receive the care that they need. [Noted in Media Watch, 2 March 2015, #399 (p.6)] <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13297/abstract>
- *ADVOCATE* (U.S.) | Online – 27 December 2013 – ‘**End-of-life care for an aging LGBT population.**’ With the number of self-identified LGBT adults age 65 or older [in the U.S.] expected to double by 2030 – from 1.5 million to 3 million – the time has never been more urgent to discuss this silent challenge: “How do we meet the unique end-of-life care needs for an aging LGBT population?” LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care...<sup>1</sup> [Noted in Media Watch, 30 December 2013, #338 (p.2)] <http://www.advocate.com/health/2013/12/27/end-life-care-aging-lgbt-population>
  1. ‘The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults,’ National Resource Center on LGBT Aging, New York, NY, November 2011. <http://www.lgbtagingcenter.org/resources/resource.cfm?r=419>

## Paramedics’ perceptions and educational needs with respect to palliative care

*AUSTRALASIAN JOURNAL OF PARAMEDICINE*, 2015;12(5):Article 3. Paramedics [i.e., survey respondents] have a sound grasp of some important aspects of palliative care (PC) including symptom control and the holistic nature of the palliative approach. They did, however, tend to equate PC with care occurring in the terminal phase and saw it as being particularly applied to cancer diagnoses. Paramedic PC educational efforts should be focused on: 1) Ethical issues; 2) End-of-life communication; 3) Increasing understanding of the common causes of death; and, 4) Education regarding those illnesses where a palliative approach might be beneficial. <http://ajp.paramedics.org/index.php/ajp/article/viewFile/218/526>

Noted in Media Watch, 20 July 2015, #419 (p.3):

- U.S. | *New York Magazine* – 15 July 2015 – ‘**What happens when EMTs encounter dying patients – and their families.**’ When someone works as an emergency first responder for long enough, they’re going to encounter a person who is dying. While these sorts of calls aren’t necessarily common (though it varies from place to place, of course), they can naturally be jarring for emergency medical technicians and paramedics when they occur. They can be even worse when the dying person is surrounded by family members grieving, panicking, or both. Suddenly the medical emergency technician or paramedic is thrust into one of the most intimate, emotionally charged family situations imaginable... <http://nymag.com/scienceofus/2015/07/what-happens-when-emts-encounter-dying-patients.html>

## Identification of the palliative phase in people with dementia: A variety of opinions between healthcare professionals

*BMC PALLIATIVE CARE* | Online – 4 November 2015 – It is challenging for professionals to identify when a person with dementia is in need of palliative care (PC). Teams with in total 84 professionals working in 13 long-term care settings from 6 countries (France, Germany, Italy, Norway, Poland and The Netherlands) received a case-vignette concerning a person with dementia recently admitted to a nursing home. They were asked to discuss when they considered people with dementia eligible for PC. Three different time points in the disease trajectory when people with dementia were considered to be eligible for PC were extracted: 1) Early in the disease trajectory; 2) When signs and symptoms of advanced dementia are present; and, 3) From the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn't even reach consensus when considering persons with dementia eligible for PC. <http://www.biomedcentral.com/content/pdf/s12904-015-0053-8.pdf>

Noted in Media Watch, 27 July 2015, #420 (p.12):

- *BMC PALLIATIVE CARE* | Online – 25 July 2015 – ‘**Expert views on the factors enabling good end-of-life care for people with dementia: A qualitative study.**’ Four key factors ... were identified from the expert interviews: 1) Leadership and management of care; 2) Integrating clinical expertise; 3) Continuity of care: and, 4) Use of guidelines. The relationships between the four key factors are important. Leadership and management of care have implications for the successful implementation of guidelines, while the appropriate and timely use of clinical expertise could prevent hospitalisation and ensure continuity of care. A lack of integration across health and social care can undermine continuity of care. <http://www.biomedcentral.com/content/pdf/s12904-015-0028-9.pdf>

**N.B.** See the issue of Media Watch of 15 June 2015, #414 (pp.13-14), for selected articles on end-of-life care for people living with dementia noted in past issues of the weekly report.

## Current and emerging practice of end-of-life care in British prisons: Findings from an online survey of prison nurses

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 November 2015 – There are concerns about prisoners and detainees not having equal access to end-of-life care (EOLC) while in prison. There is a lack of existing literature about the standards of EOLC in U.K. prisons. The reported barriers included some prison regimes, lack of appropriate care and visiting facilities, lack of privacy and inadequate visiting hours. Respondents also reported examples of good practice, including having access to specialist palliative care and specialist equipment, and being able to receive visits from family and friends. The findings suggest there is considerable variability in the EOLC care provided to prisoners in the U.K. Further research is needed in order to reduce the health inequalities and improve the quality of end-of-life care experienced by prisoners in the U.K. <http://spcare.bmj.com/content/early/2015/11/03/bmjspcare-2015-000880.abstract>

### [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 past issues of the weekly report is available at the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/pages/view/3389845/additional-offerings>

Related:

- *MORTALITY* | Online – 5 November 2015 – ‘**A “good death” for all?: Examining issues for palliative care in correctional settings.**’ The authors identify personal, social and political concerns that influence prisoners’ ability to access a “good death” and health care providers’ potential to contribute to such an outcome. They highlight divergence between palliative care (PC) theory and practice, and the complex issues faced by dying prisoners and their families, prison officials, health care providers and other members of PC teams. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2015.1098602>

## Where do patients treated for oral cancer die? A 20-year cohort study 1992-2011

*BRITISH JOURNAL OF ORAL & MAXILLOFACIAL SURGERY* | Online – 31 October 2015 – Of 1,290 consecutive patients treated between 1992 and 2011 for primary squamous cell carcinoma of the oral cavity at a regional centre, 750 had died by August 2013. About half of them died in hospital, 113 (15%) in a hospice, 180 (24%) at home, 57 (8%) in a care home, and 22 (3%) elsewhere. Cancer was the underlying cause of death in 64%, and of them, 56% were oral cancers. The place of death was strongly associated with the age at death and cancer being the underlying cause. The percentage of people who died from cancer at home or in a hospice rose over time across all age groups and, from 2010, accounted for two-thirds. In contrast, less than 1 in 5 who did not die from cancer, died at home or in a hospice, and in this there has been no discernible change over the last 20 years. The percentage of deaths from cancer in hospital and hospice ranged from 32%-38% and 20%-29%, respectively, across age groups. An increase in the number of deaths from cancer in care homes in those aged 75 years and over was mirrored by fewer at home. Most of those who did not die from cancer, died in hospital, two-thirds were under 65 years, 85% were aged 65-84, and 56% were older. This was mirrored by fewer deaths at home in those under 85 and more in care homes in those over 75. Patients' preferences not to die in hospital are being realised. However, at the end of their lives, patients and their carers need more support at home, and more research is required. [http://www.bjoms.com/article/S0266-4356\(15\)00612-9/abstract](http://www.bjoms.com/article/S0266-4356(15)00612-9/abstract)

## Unexpected death in palliative care: What to expect when you are not expecting

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE*, 2015;9(4):369-374. Even in the palliative care (PC) setting in which death is relatively common, [in this study] up to 5% of deaths in hospice and 10% of deaths in PC units were considered to be unexpected. Unexpected death has significant impact on care, including unrealized dreams and unfinished business among patients, a sense of uneasiness and complicated bereavement among caregivers, and uncertainty in decision making among healthcare providers. Clinicians may minimize the impact of unexpected events by improving their accuracy of prognostication, communicating the uncertainty with patients and families, and helping them to expect the unexpected by actively planning ahead. Because of the emotional impact of unexpected death on bereaved caregivers, clinicians should provide close monitoring and offer prompt treatment for complicated grief. <http://www.ncbi.nlm.nih.gov/pubmed/26509862>

## Reasons for continuous sedation until death in cancer patients: A qualitative interview study

*EUROPEAN JOURNAL OF CANCER CARE* | Online – 29 October 2015 – End-of-life sedation, though increasingly prevalent and widespread, remains a highly debated medical practice in the context of palliative medicine. In-depth interviews were held with 28 physicians and 22 nurses of 27 cancer patients in Belgium who had received continuous sedation until death in hospitals, palliative care units or at home. Findings indicate that medical decision-making for continuous sedation is not only based on clinical indications but also related to morally complex issues such as the social context and the personal characteristics and preferences of individual patient and their relatives. The complex role of non-clinical factors in palliative sedation decision-making needs to be further studied to assess which medically or ethically relevant arguments are underlying daily clinical practice. In some cases continuous sedation was resorted to as an alternative option at the end of life when euthanasia, a legally regulated option in Belgium, was no longer practically possible. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12405/abstract>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2015 – ‘**A survey of hospice and palliative care physicians regarding palliative sedation practices.**’ Nearly all survey respondents indicated that palliative sedation may be used for refractory symptoms and acceptable by 26% only for imminently dying patients. Seventy-nine percent believed that opioids should not be used to induce palliative sedation, but should be continued to provide pain control. <http://ajh.sagepub.com/content/early/2015/11/04/1049909115615128.abstract>

Cont.

- *MÉDECINE PALLIATIVE* | Online – 6 November 2015 – ‘**Sedation in palliative medicine at home: Descriptive survey among general practitioners.**’ A 25-item questionnaire was sent to 110 GPs, residency supervisors from the faculté libre de médecine of Lille. All respondents had confronted end-of-life situations in the home. Most know present day guidelines and ethical considerations regarding palliative sedation. Improving professional management and training would facilitate the practice of sedation at home. <http://www.sciencedirect.com/science/article/pii/S1636652215001452>

N.B. French language article.

Noted in Media Watch, 2 November 2015, #434 (p.14):

- *MÉDECINE PALLIATIVE* | Online – 27 October 2015 – ‘**Palliative sedation for adults: Principles and best practices. Guidelines proposed by the Société québécoise des médecins de soins palliatifs.**’ Guidelines have been published by several national and international organisations to clarify the principles behind palliative sedation (PS). The Quebec society of palliative care medical doctors proposes a practical guide integrating these international recommendations... The practical aspects of the initiation and maintenance of the PS and the specific tools required for the follow-up of these patients are presented. <http://www.sciencedirect.com/science/article/pii/S1636652215001294>

N.B. French language article.

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: Analysis of international guidelines and position statements.**’ Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/32/6/660>

### **Policy on palliative care in the WHO European region: An overview of progress since the Council of Europe’s (2003) recommendation 24**

*EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 6 November 2015 – With the goal of achieving greater unity and coherence, the Council of Europe developed a national palliative care (PC) policy framework – Recommendation (2003) 24. Although directed at member states, the policy spread to the wider World Health Organisation (WHO) European Region. A cross-sectional survey was conducted in 53 European countries of the WHO European Region. Relevant data reported the ... 1) Existence of official documents concerning the provision of PC; 2) Role of health departments and policymakers in the evaluation of PC provision; and, 3) Availability of financial resources for PC provision. 46/53 (87%) EU and non-EU countries responded. PC legislation is established in 20 (71%) EU and nine (50%) non-EU countries. A total of 12 (43%) EU countries possess a PC plan or strategy in comparison with six (33%) non-EU countries. Individuals from Departments of Health and designated policymakers have established collaborative PC efforts. Quality systems have been initiated in 15 (54%) EU and four (22%) non-EU countries. Significant differences were not found in the reporting of payments for PC services between European regions. <http://eurpub.oxfordjournals.org/content/early/2015/11/05/eurpub.ckv201>

#### **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>



## Work-related experiences intensive and palliative care units and their relation to burnout

*INTENSIVE CARE MEDICINE EXPERIMENTAL*, 2015,3(Suppl):A649. Out of the 355 professionals included in this study, 27% were in burnout (this defined as being in burnout and in high risk of developing this syndrome). Higher burnout levels were significantly associated with the following work-related experiences: night shifts, conflicts, decisions to withhold treatment, decisions to withdraw treatment and implementing terminal sedation. Experiencing conflicts in the workplace was the most significant variable associated to higher burnout levels. These findings suggest that team-dynamics and conflict-management are paramount in the implementation of strategies and programs aiming at preventing or minimizing burnout. <http://www.icm-experimental.com/content/3/S1/A649>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 November 2015 – **‘Building resiliency in a palliative care team: A pilot study.’** Palliative care clinicians are vulnerable to burnout as a result of chronic stress related to working with seriously ill patients. Burnout can lead to absenteeism, ineffective communication, medical errors, and job turnover. Interventions that promote better coping with stress are needed in this population. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00577-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00577-1/abstract)

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## Characterizing the hospice and palliative care workforce in the U.S.: Clinician demographics and professional responsibilities

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 November 2015 – Palliative care (PC) services are growing at an unprecedented pace. Yet, the characteristics of the clinician population who deliver these services are not known. The authors conducted a survey of American Academy of Hospice & Palliative Medicine members. Findings revealed a current PC clinician workforce older, predominantly female, and generally with less than 10 years clinical experience in the field. Most clinicians have both clinical hospice and PC responsibilities. Many cite personal or professional growth or influential experiences during training or practice as motivations to enter the field. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00580-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00580-1/abstract)

### Media Watch: Editorial Practice

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

### Distribution

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

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



## Selected articles, reports, etc., on burnout in the context of end-of-life care

- *ONCOLOGY TIMES* | Online – 14 November 2014 – ‘**Nearly half of palliative care clinicians plan to exit the field within a decade.**’ 1 in 4 of palliative care (PC) clinicians surveyed say there is a good chance that they will leave by 2018. While retirement is the most common reason PC specialists are planning to leave, many respondents also cited burnout as another reason they are considering their exit. [Noted in Media Watch, 24 November 2014, #385 (p.11)] <http://journals.lww.com/oncology-times/blog/asco11spotlightnews/pages/post.aspx?PostID=167>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(3):219-239. ‘**Burnout and death anxiety in hospice social workers.**’ Key themes [to emerge in this study]: a) Personal interest in hospice social work; b) Although death anxiety decreased from exposure and understanding of the death process, there was increased anxiety surrounding working with certain patients; and, c) Burnout was related to workload or difficult cases. [Noted in Media Watch, 1 September 2014, #373 (p.10)] <http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.938891?journalCode=wswe20>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 November 2013 – ‘**Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota.**’ Hospice staff reported high levels of stress, with a small but significant proportion reporting moderate-to-severe symptoms of depression, anxiety, compassion fatigue, and burnout. Staff reported managing their stress through physical activity and social support, and they suggested that more opportunities to connect with co-workers and to exercise could help decrease staff burnout. [Noted in Media Watch, 11 November 2013, #331 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0202>

## Smiling through clenched teeth: Why compassion cannot be written into the rules

*JOURNAL OF MEDICAL ETHICS* | Online – 3 November 2015 – The discourse on the failings of the National Health System [in the U.K.] often cites lack of compassion as an important factor. This has resulted in proposals to enact rules which aimed at enforcing compassion in healthcare workers so as to improve the quality of healthcare and avoid future scandals. This paper argues that compassion cannot be enforced by any rule. Moreover, the contractual nature of the current doctor-patient relationship does not foster it. Experience from other service industries shows that attempts to enforce compassion in workers are futile. Rather than improving service, these attempts result in a culture of perfunctoriness and cynicism. <http://jme.bmj.com/content/early/2015/11/03/medethics-2015-102835.abstract>

Noted in Media Watch, 30 March 2015, #403 (p.14):

- *INTERNATIONAL JOURNAL OF HEALTH POLICY & MANAGEMENT*, 2015;4(4):199-201. ‘**Why and how is compassion necessary to provide good quality healthcare?**’ Recent disclosures of failures of care in the National Health Service in England have led to debates about compassion deficits disallowing health professionals to provide high quality responsive care. While the link between high quality care and compassion is often taken for granted, it is less obvious how compassion – often originating in the individual’s emotional response – can become a moral sentiment and lead to developing a system of norms and values underpinning ethics of care. In this editorial, the author argues why and how compassion might become a foundation of ethics guiding health professionals and a basis for ethics of care in health service organisations. <http://eprints.kmu.ac.ir/9083/1/IJHPM29931427830200.pdf>

### Quotable Quotes

*How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these.* **George Washington Carver (1864-1943)**

### Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the know-ledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

### **“Give sorrow words”: Working with bereavement in senior residential settings**

*JOURNAL OF NERVOUS & MENTAL DISEASE*, 2015;203(11):876-877. Bereavement and its consequent grief are frequent in senior residential settings. Failure to manage grief appropriately can have serious medical consequences, principally clinical depression. Focused talk with a grieving person can help ease the pain of grief; it can also help prevent complications that often lead to depression. Along with mental health professionals, staff members and volunteers can be important, and less expensive... [http://journals.lww.com/jonmd/Abstract/2015/11000/Give\\_Sorrow\\_Words\\_Working\\_With\\_Bereavement\\_in.10.aspx](http://journals.lww.com/jonmd/Abstract/2015/11000/Give_Sorrow_Words_Working_With_Bereavement_in.10.aspx)

### **Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 November 2015 – The authors conducted a systematic review of the literature in all available languages of six databases from 1966 to 2014. Six qualitative and four quantitative studies assessed the use of interpreters in palliative care. All studies found that the quality of care provided to limited English proficiency (LEP) patients receiving palliative services is influenced by the type of interpreter used. When professional interpreters were not used, LEP patients and families had inadequate understanding about diagnosis and prognosis during goals of care conversations, and patients had worse symptom management at the end of life, including pain and anxiety. Half of the studies concluded that professional interpreters were not utilized adequately and several suggested that pre-meetings between clinicians and interpreters were important to discuss topics and terminology to be used during goals of care discussions. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00575-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00575-8/abstract)

#### **Selected articles, reports, etc., on the role of interpreters in overcoming language barriers**

- *SMITHSONIAN* | Online – 28 September 2015 – ‘**Millions of Americans are getting lost in translation during hospital visits.**’ Unbeknownst to many patients and physicians, individuals with limited English proficiency have been guaranteed language services under federal law for decades. [Noted in Media Watch, 5 October 2015, #430 (p.4)] <http://www.smithsonianmag.com/innovation/millions-americans-are-getting-lost-translation-during-hospital-visits-180956760/?no-ist>
- *BMC HEALTH SERVICES RESEARCH* | Online – 10 September 2015 – ‘**Overcoming language barriers in healthcare: A protocol for investigating safe and effective communication when patients or clinicians use a second language.**’ The rising number of migrant patients and foreign-trained staff means that communication errors between a healthcare practitioner and patient when one or both are speaking a second language are increasingly likely. [Noted in Media Watch, 14 September 2015, #427 (pp.6-7)] <http://www.biomedcentral.com/content/pdf/s12913-015-1024-8.pdf>

#### **Pediatric palliative care**

### **Establishing feasibility of early palliative care consultation in pediatric hematopoietic stem cell transplantation**

*JOURNAL OF PEDIATRIC ONCOLOGY NURSING*, 2015;32(5):265-277. Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress, but may not be afforded timely access to palliative care (PC) services to help ameliorate the distress. This study investigated the acceptability and outcomes of early PC consultation to promote comfort in this population. Each family [i.e., participants] received 1 to 3 visits per week (ranging from 15 to 120 minutes) from the PC team. Interventions included supportive care counseling and integrative therapies. Families and providers reported high satisfaction with the nurse-led PC consultation. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT, from the child and parental perspective. Early integration of PC in HSCT is feasible and acceptable to families and clinicians. <http://jpo.sagepub.com/content/32/5/265.abstract>

Cont.

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 November 2015 – ‘**Advance care discussions: Pediatric clinician preparedness and practices.**’ Many clinicians [i.e., study participants] believe they are prepared to participate in advance care discussions (ACD), but practices are not consistent with expert recommendations for optimal ACD. Educational interventions aimed at improving clinician knowledge, attitudes, and behavior and greater clinician support may enhance health care provider ACD preparedness and skills. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00578-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00578-3/abstract)

### **What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis**

*PALLIATIVE MEDICINE* | Online – 4 November 2015 – Hospital-based specialist palliative care (SPC) services are common, yet existing evidence of inpatient generalist providers’ perceptions of collaborating with hospital-based SPC teams has never been systematically assessed. Five themes were identified as improving or decreasing effective collaboration: 1) Model of care (integrated vs. linear); 2) Professional onus; 3) Expertise and trust; 4) Skill building vs. deskilling; and, 5) SPC operations. Collaboration is fostered when SPC teams practice proactive communication, role negotiation and shared problem-solving, and recognise generalists’ expertise. Fuller integration of SPC services, timely sharing of information and mutual respect increase generalists’ perceptions of effective collaboration. Research is needed regarding the experiences of non-physician and non-nursing professionals as their views were either not included or not explicitly reported. <http://pmj.sagepub.com/content/early/2015/11/04/0269216315615483.abstract>

Noted in Media Watch, 2 November 2015, #434 (p.12):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 October 2015 – ‘**General practice and specialist palliative care teams: An exploration of their working relationship from the perspective of clinical staff working in New Zealand.**’ The findings [of this study] indicate that participants’ understanding of partnership working was informed by their identity as a generalist or specialist, their existing rules of engagement and the approach they took towards sustaining the partnership. Considerable commitment to partnership working was shown by all participating teams. However, their working relationship was based primarily on trust and personal liaison, with limited formal systems in place to enable partnership working. Tensions between the cultures of “generalism” and “specialism” also provided challenges for those endeavouring to meet PC need collaboratively in the community. <http://online.library.wiley.com/doi/10.1111/hsc.12296/abstract>

Noted in Media Watch, 11 March 2013, #296 (p.10):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 6 March 2013 – ‘**Generalist plus specialist palliative care – creating a more sustainable model.**’ Some core elements of palliative care, such as aligning treatment with a patient’s goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms. <http://www.nejm.org/doi/full/10.1056/NEJMp1215620>

### **Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 3 November 2015 – In this article, the authors describe a delicate, skilled, tailored process whereby physicians create a space in which patients feel safe enough to discuss intimate topics. Six themes are identified: 1) Developing the self: physicians describe the need to understand and be secure in one’s own spirituality and be comfortable with one’s own mortality before being able to discuss spirituality; 2) Developing one’s attitude: awareness of the importance of spirituality in the life of a patient, and the need to respect each patient’s beliefs is a prerequisite; 3) Experienced physicians wait for the patient to give them an indication that they are ready to discuss spiritual issues and follow their lead; 4) What makes it easier: spiritual discussion is easier when doctor and patient share

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spiritual and cultural backgrounds, and the patient needs to be physically comfortable and willing to talk; 5) What makes it harder: experienced physicians know that they will find it difficult to discuss spirituality when they are rushed and when they identify too closely with a patient's struggles; and, 6) An important and effective intervention: exploration of patient spirituality improves care and enhances coping. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10028620&fulltextType=RA&filed=S1478951515001236>

Related:

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE*, 2015;9(4):357-360. '**Evaluation tools for spiritual support in end-of-life care: Increasing evidence for their clinical application.**' This systematic review resulted in 45 identified studies, 14 of which were considered: five works addressed the need for development and validation of spiritual tools; three reviewed tools for spirituality assessment, interventions, or related concepts; and, three more covered the efforts to define guidelines and priorities for spiritual care and its measurement. Other topics, such as pediatric spiritual care, the use of new technologies, or nationwide surveys, also arose. Recent contributions outline usability traits such as to shorten scales and measurement protocols for maximum respect of patients' quality of life. [http://www.researchgate.net/publication/283305954\\_Evaluation\\_tools\\_for\\_spiritual\\_support\\_in\\_end\\_of\\_life\\_care\\_increasing\\_evidence\\_for\\_their\\_clinical\\_application](http://www.researchgate.net/publication/283305954_Evaluation_tools_for_spiritual_support_in_end_of_life_care_increasing_evidence_for_their_clinical_application)

Noted in Media Watch, 21 September 2015, #428 (p.14):

- *PALLIATIVE MEDICINE* | Online – 16 September 2015 – '**Spiritual history taking in palliative home care: A cluster randomized controlled trial.**' The *ars moriendi* model might be a feasible tool for spiritual history taking in palliative care (PC). A total of 245 health-care providers participated in the study (204 nurses, 41 physicians), which showed no demonstrable effect of spiritual history taking on patient scores for spiritual well-being, quality of life, health-care relationship trust or pain. Further research is needed to develop instruments that accurately assess the effectiveness of spiritual interventions in PC populations. <http://pmj.sagepub.com/content/early/2015/09/15/0269216315601953.abstract>

Noted in Media Watch, 11 May 2015, #409 (p.9):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(2):91-95. '**Spiritual care education: Results from an European Association for Palliative Care survey.**' The Association's White Paper on palliative care (PC) education states that, to adequately support patients and their families, PC professionals should be able to: 1) Demonstrate the reflective capacity to consider the importance of spiritual and existential dimensions in their own lives; 2) Integrate the patients' and families' spiritual, existential and religious needs in the care plan, respecting their choice not to focus on this aspect of care if they so wish; 3) Provide opportunities for patients and families to express the spiritual and/or existential dimensions of their lives in a supportive and respectful manner; and, 4) Be conscious of the boundaries that may need to be respected in terms of cultural taboos, values and choices."

**N.B.** Access to this article requires a subscription to the *European Journal of Palliative Care*. Journal contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2015&Edition=533](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=533); Additional articles on spirituality in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 8 June 2015, #413 (pp.10-11).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 November 2015 – '**Clinical criteria for physician aid in dying.**' More than 20 years ago, even before voters in Oregon had enacted the first aid in dying (AID) statute in the U.S., Timothy Quill and colleagues proposed clinical criteria for AID. Their proposal was carefully considered and temperate, but there were little data on the practice of AID at the time. With the passage of time, a substantial body of data on AID has developed from the states of Oregon and Washington. For more than 17 years, physicians in Oregon have been authorized to provide a prescription for AID. Accordingly, the authors have updated the clinical criteria of Quill *et al* based on the many years of experience with AID. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0092>

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- *MONASH BIOETHICS REVIEW* | Online – 27 October 2015 – ‘**Should patients in a persistent vegetative state be allowed to die? Guidelines for a new standard of care in Australian hospitals.**’ The authors argue in favour of legislating to protect doctors who bring about the deaths of persistent vegetative state (PVS) patients, regardless of whether the death is through passive means (e.g., the discontinuation of artificial feeding and respiration) or active means (e.g., through the administration of pharmaceuticals known to hasten death in end-of-life care). They discuss the ethical dilemmas doctors and lawmakers faced in the more famous PVS cases arising in the U.S. and U.K., before exploring what the law should be regarding such patients, particularly in Australia. The authors argue in favour of allowing euthanasia in the interests of PVS patients, their families, and finally the wider community, before concluding with some suggestions for how these ethical arguments could be transformed into a set of guidelines for medical practice in this area. <http://link.springer.com/article/10.1007/s40592-015-0039-6>

Noted in Media Watch, 27 January 2014, #342 (p.14):

- *MEDICAL LAW REVIEW* | Online – 12 January 2014 – ‘**Does withdrawing life-sustaining treatment cause death or allow the patient to die?**’ Traditional medical ethics and the law are mistaken to take the view withdrawal merely allows the patient to die, rather than causing the patient’s death, describing such a view as “patently false.” The law’s continued position to the contrary stems from a moral bias, resulting in the moral and legal fiction withdrawal does not cause death, but lets the patient die. <http://medlaw.oxfordjournals.org/content/early/2014/01/15/medlaw.fwt034.abstract>
- *SOUTH AFRICAN MEDICAL JOURNAL*, 2015;105(10):801-802. ‘**Euthanasia in South Africa – sacrificing one to render many vulnerable?**’ The “sacred” value of autonomy in euthanasia and assisted suicide is not absolute because people change their minds – while passing enabling laws “holds grave consequences” for both individuals and society. This was the view of Dr. Tom Angier of the University of Cape Town’s Department of Philosophy, who contended that the “sacred trilogy” of values, compassion, dignity and autonomy in the euthanasia debate would be undermined by a euthanasia-practising regime. <http://www.samj.org.za/index.php/samj/article/view/10035>

**N.B.** Click on PDF icon to access the article.

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## [Media Watch: Online](#)

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/11/media-watch/>

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](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

### **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>