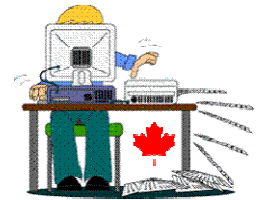


## Media Watch...

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.

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Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Sheffield Profile for Assessment & Referral for Care: Scroll down to [Specialist Publications](#) and 'A pilot randomized controlled trial of a holistic needs assessment questionnaire in a supportive and palliative care service' (p.13), in *Journal of Pain & Symptom Management*.

## Canada

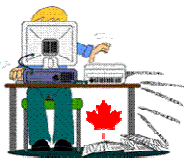
### Health Quality Council of Alberta

#### Health quality council survey shows little progress in long-term care

ALBERTA | *The Calgary Herald* – 29 October 2015 – Long-term care across the province has improved little over the past five years, as concerns around staffing levels, timely help, and supervision continue to be raised by families, according to a new survey released by the Health Quality Council of Alberta.<sup>1</sup> The health care watchdog also provided ratings on individual facilities for the first time ever, hoping the public availability of the data will result in more efforts to improve. Andrew Neuner, chief executive of the council, said that while most facilities scored well in a variety of areas ... not much has changed or improved since the survey was done last in 2010. <http://calgaryherald.com/health/seniors/health-quality-council-releases-results-of-long-term-care-survey>

1. 'Long Term Care Family Experience Survey Report,' Health Quality Council of Alberta, October 2015. [https://d10k7k7mywg42z.cloudfront.net/assets/562fabf3d4c9610610181c2c/HQCA\\_LTC\\_Provincial\\_Report\\_2015.pdf](https://d10k7k7mywg42z.cloudfront.net/assets/562fabf3d4c9610610181c2c/HQCA_LTC_Provincial_Report_2015.pdf)

**N.B.** A brief reference is made in the report to the need for continuing education and professional development, for example, in palliative care (p.86).



### 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>

## Right-to-die debate ignites calls for better palliative care

CBC NEWS | Online – 29 October 2015 – Religious leaders from several faiths are calling on Canadian legislators to improve palliative care (PC) and respect human life as the contentious debate over doctor-assisted dying heats up. The Canadian Conference of Catholic Bishops and the Evangelical Fellowship of Canada, along with other faith leaders, held a news conference on Parliament Hill to release a declaration on physician-assisted death.<sup>1</sup> “We urge federal, provincial and territorial legislators to enact and uphold laws that enhance human solidarity by promoting the rights to life and security for all people; to make good-quality home care and PC accessible in all jurisdictions; and to implement regulations and policies that ensure respect for the freedom of conscience of all health-care workers and administrators who will not and can not attempt suicide or euthanasia as a medical

solution to pain and suffering,” the declaration reads. The statement is endorsed by more than 30 Christian denominations, as well as Jewish and Muslim leaders from across the country. <http://www.cbc.ca/news/politics/canada-assisted-dying-laws-religious-leaders-1.3293919>

### Specialist Publications

‘Quality of care and satisfaction with care on palliative care units’ (p.13), in *Journal of Pain & Symptom Management*.

‘Palliative sedation for adults: Principles and best practices. Guidelines proposed by the Société québécoise des médecins de soins palliatifs’ (p.14), in *Médecine Palliative*.

1. ‘Canadian Conference of Catholic Bishops and The Evangelical Fellowship of Canada – Declaration on Euthanasia and Assisted Suicide,’ October 2015. <http://www.euthanasiadeclaration.ca/declaration/>

## Canadian Institute for Health Information

### Health-care spending growth slows, but reaches \$6,105 per Canadian

CBC NEWS | Online – 29 October 2015 – Health spending in Canada is expected to reach \$219.1 billion this year, according to a new 40-year report.<sup>1</sup> This amounts to \$6,105 per person, the Canadian Institute for Health Information said ... in its report on national health expenditure trends from 1975 to 2015. The pattern of growth in expenditures is expected to continue to slow and is forecast at an annual 1.6%. “A new period has emerged, with health spending growth not keeping pace with inflation and population growth [combined],” the report’s authors said. “It reflects, in large part, Canada’s modest economic growth and fiscal restraint as governments focus on balancing budgetary deficits.” Out-of-pocket health expenditure per person increased from \$278 in 1988 to \$844 in 2013. Private health insurance expenditure per person increased from \$139 to \$720 over the same period. <http://www.cbc.ca/news/health/cihi-health-expenditures-1.3293294>

### Extracts from Canadian Institute for Health Information report

While Canadians age 65 and older account for about 15% of the Canadian population, they consume more than 45% of all public sector health care dollars spent by provinces and territories.

Overall, population aging is a modest driver of increasing health care costs, estimated at 0.9% per year. The share of public sector health care dollars spent on Canadian seniors has not changed significantly over the past decade – from 44% in 2000 to 45.4% in 2013. During the same time period, the percentage of seniors in the population grew from 12.6% to 15.3%.

1. ‘National Health Expenditure Trends, 1975 to 2015,’ Canadian Institute for Health Information, October 2015. <https://www.cihi.ca/en/spending-and-health-workforce/spending/national-health-expenditure-trends>

**N.B.** There is no specific mention in the Institute’s report of the cost of end-of-life care.

## Privacy lacking for palliative-care patients at Parkwood

ONTARIO | *The London Free Press* – 28 October 2015 – London’s Parkwood Hospital places some palliative care patients in crowded wards where they spend their final days watching roommates die, a situation a leading advocate for seniors calls “institutionalized elder abuse.” A lack of privacy for dying patients and their families was one of a number of problems flagged by experts hired by the hospital to produce a report three years ago that wasn’t made public. Dr. Jose Pereira and Dr. Robin Fainsinger, who led palliative care in Ottawa and Edmonton, questioned why Parkwood places eight palliative patients in rooms with four beds each, calling the practice a “significant source of distress for patients, families, staff and referral sources.” “It is very difficult, and one could argue inappropriate, to have four terminally-ill patients in the same room with limited privacy and limited space for family members to visit,” they wrote. “Patients who are at the end of life are also subjected to witnessing the deaths of their roommates; sometimes multiple deaths are witnessed.” Asked ... about the report, those who oversee Parkwood at St. Joseph’s Health Care defended their record in a statement placed on the home page of its website that revealed plans to replace wards with private rooms in the spring. <http://www.lfpress.com/2015/10/27/privacy-lacking-for-palliative-care-patients-at-parkwood>

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

- *JOURNAL OF CLINICAL NURSING* | Online – 4 May 2015 – ‘**Finding privacy from a public death: A qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families.**’ Dying in hospital is a common outcome for people across the world. However, noise and activity in acute environments present barriers to quality end-of-life care. This is of concern because care provided to dying patients has been shown to affect both the patients and the bereaved families. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12845/abstract>

### Institute for Clinical Evaluative Sciences

## Seniors in private nursing homes more likely to die within 6 months

ONTARIO | CTV News – 24 October 2015 – Seniors living in private nursing homes are more likely to die within six months of their stay than those living in non-profit facilities, a group of researchers has found. A recent study by the Institute for Clinical Evaluative Sciences found that for-profit seniors’ homes have a 16% higher death rate for seniors within six months of arrival, and that there is a 33% greater likelihood that they’ll end up in hospital.<sup>1</sup> “Those are not trivial numbers,” said Dr. Peter Tanuseputro, a researcher behind the study. “If there’s a way that we can get to the bottom of this and correct it, we could potentially be preventing many, many hospitalizations and potentially many deaths.” The figures are particularly concerning for Ontario, where nearly 60% of seniors’ facilities are privately run. The difference in numbers calls into question why both long-term care facilities receive the same subsidy from the provincial government, and how both must meet the same guidelines for care. <http://www.ctvnews.ca/health/seniors-in-private-nursing-homes-more-likely-to-die-within-6-months-study-1.2626416>

1. ‘Hospitalization and mortality rates in long-term care facilities: Does for-profit status matter?’ *JAMDA, Journal of Post Acute & Long Term Care*, 2015;16(10):874-883. [http://www.jamda.com/article/S1525-8610\(15\)00414-4/pdf](http://www.jamda.com/article/S1525-8610(15)00414-4/pdf)

**N.B.** See the issues of Media Watch of 26 October 2015, #433 (p.10) and 15 December 2014, #388 (p.12) for selected articles on the quality of end-of-life care in nursing homes and long term care facilities noted in past issues of the weekly report.

### [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.16.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **THE GLOBE & MAIL** | Online – 27 October 2015 – ‘**What the top court left out in judgment on assisted suicide.**’ A central question in legalizing physician-assisted suicide is where the balance between respecting individual rights to autonomy and protection of the “common good” (protection of others and society, including its important values) should be struck. In this case, there was almost no such balancing. Rather, both the trial court and the Supreme Court focused almost exclusively on the rights of individual persons, so that the factual findings and legal reasoning were intensely individualistically based. There was heavy emphasis on the suffering of people who had “bad deaths” and both courts ruled that the potential risks and harm to people of legalizing physician-assisted dying – that is, what is required to protect them and the common good – was a “theoretical or speculative fear” that could not outweigh the individual’s right to autonomy with respect to deciding what should happen to his or her own body and life. Both courts adopted a narrow definition of Parliament’s purpose in prohibiting assisted suicide (namely, that it was to protect a vulnerable person in moments of weakness from acting on suicidal ideation) and concluded that an absolute prohibition was not needed to achieve this. <http://www.theglobeandmail.com/globe-debate/what-the-top-court-left-out-in-assisted-suicide-ruling/article26995241/>
- **THE NATIONAL POST** | Online – 22 October 2015 – “‘**What is it with these doctors?’ Medical regulators playing God on euthanasia rules, ethicists warn.**’ Alberta’s medical regulator says it’s a doctor’s role to help determine whether assisted death is in a person’s “best interests.” Quebec says suffering, fundamentally, is what the patient says it is. Manitoba wants psychiatric assessments of most anyone who isn’t terminal. As the provinces wrestle with who decides when a patient is ready to depart this world, ethicists say the regulators are playing God. It’s not a role any of them want. But with legalized assisted suicide and euthanasia looming early next year, the medical colleges are scrambling to draft rules for doctor-prescribed death. <http://news.nationalpost.com/health/medical-regulators-playing-god-on-euthanasia-rules-ethicists-warn>

## U.S.A.

### New Medicare rule authorizes “end-of-life” consultations

**THE NEW YORK TIMES** | Online – 30 October 2015 – Six years after legislation to encourage end-of-life planning touched off a furor over “death panels,” the Obama administration issued a final rule [effective January 2016] ... that authorizes Medicare to pay doctors for consultations with patients on how they would like to be cared for as they are dying. [http://www.nytimes.com/2015/10/31/us/new-medicare-rule-authorizes-end-of-life-consultations.html?\\_r=0](http://www.nytimes.com/2015/10/31/us/new-medicare-rule-authorizes-end-of-life-consultations.html?_r=0)

**Media Watch: Back Issues**



The screenshot shows the IPCRC.NET website. The header includes the logo and navigation links: Home, About IPCRC, CIA, NCI, Partners, Contact, Acknowledgements. Below the header, there is a section for 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A small box on the right side of the screenshot lists the 'Media Watch Archives' with a list of years and months: 2014, July - December; 2014, January - June; 2013, July - December; 2013, January - June; 2012, July - December; 2012, January - June; 2011, July - December; 2011, January - June; Current.



**Media Watch Archives**

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

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

## The silver tsunami is actually silver-brown. How does end-of-life care differ for minorities?

*THE WASHINGTON POST* | Online – 28 October 2015 – Due to the unprecedented advances in medicine, Americans are living longer – but we’re not necessarily living better. Currently, 45% of Americans have at least one chronic illness and 70% will eventually die from one. Heart disease, cancer or stroke, in particular, will claim one in two lives. By 2030, sixty-nine million Americans will be seniors, a number more than double what it was in 2000. While this growing wave of older adults has been called the “silver tsunami,” most Americans don’t know that it is actually “silver-brown.” The U.S. is poised to become a majority-minority nation by 2044, and the population of minority seniors is growing exponentially in turn. The silver-brown tsunami includes rapidly aging seniors from ethnic and racial minority groups, aging baby boomers and Gen-X Americans as well as immigrants who joined the U.S. workforce a few decades ago. Health disparities that plague ethnic minorities throughout their youth and middle age doggedly pursue them through the end of life. Minorities are less likely to enroll in, more likely to revoke and less likely to report satisfaction with hospice care. They are also more likely to be subjected to burdensome treatments at the end of life that do not necessarily increase lifespan or quality of life but instead prolong the dying process. Though a third of total Medicare spending is on care in the last two years of life, higher spending has not been associated with better health outcomes. <http://www.washingtonpost.com/news/in-theory/wp/2015/10/28/the-silver-tsunami-is-actually-silver-brown-how-does-end-of-life-care-differ-for-minorities/>

Noted in Media Watch, 24 August 2015, #424:

- NATIONAL PUBLIC RADIO | Online – 20 August 2015 – ‘**Can health care be cured of racial bias?**’ Even as the health of Americans has improved, disparities in treatment and outcomes between white patients and black and Latino patients are almost as big as they were 50 years ago. A growing body of research suggests doctors’ unconscious behavior plays a role in these statistics, and the Institute of Medicine of the National Academy of Sciences has called for more studies looking at discrimination and prejudice in health care.<sup>1</sup> <http://www.npr.org/sections/health-shots/2015/08/20/432872330/can-health-care-be-cured-of-racial-bias>

1. ‘Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,’ Institute of Medicine of the National Academy of Sciences, 2003. <http://www.nap.edu/catalog/12875/unequal-treatment-confronting-racial-and-ethnic-disparities-in-health-care>

### **Death rates, declining for decades, have flattened, study finds**

*THE NEW YORK TIMES* | Online – 27 October 2015 – Gains in the American life span have slowed in recent years, according to a new report,<sup>1</sup> with average annual death rates flattening for the first time since researchers started measuring them in the late 1960s. Death rates (measured as the number of deaths per 100,000 people in a given year) in the U.S. have been declining for decades, an effect of improvements in health care, disease management and medical technology. The researchers had expected to find more of the same. Instead, they stumbled upon a disturbing development. The declines in death rates flattened in the most recent period, from 2010 to 2013, dropping by an average of 0.4% annually, a rate so slight that it was not statistically significant. The rate had slowed in previous periods, but never this substantially. <http://www.nytimes.com/2015/10/28/health/death-rates-declining-for-decades-have-flattened-study-finds.html?ref=health&r=0>

1. ‘Temporal trends in mortality in the U.S...,’ *Journal of the American Medical Association*, 2015;314(16):1731-1739. <http://jama.amanetwork.com/article.aspx?articleid=2466136>

### **Specialist Publications**

**‘Impact of provider level, training and gender on the utilization of palliative care and hospice in neuro-oncology: A North American survey’** (p.13), in *Journal of Neuro-Oncology*.

## Dying inmates don't need to be in jail

MASSACHUSETTS | *The Boston Globe* – 26 October 2015 – It's no wonder state legislators aren't anxious to establish a way to release prison inmates who are dying or severely incapacitated. What politician wants to be on record expressing sympathy for criminals, even grievously ill ones? But that's how legislation under consideration ... has been framed in public discussion – as a “compassionate release” law. It's a key reason why the bill ... has languished. Take compassion out of the equation, however, and the proposal appears practical and fiscally smart. The state already spends about \$100 million annually on inmate health care. With prisons overcrowded and their populations aging, that figure is increasing every month. A small percentage of those inmates have a terminal disease, are so disabled they can barely function, or require regular treatment ... outside of jail. If they were released to a hospital, hospice, nursing home, or family member, spending on inmates' health care could be reduced: Those allowed out ... could qualify for MassHealth insurance coverage, which is partially subsidized by the federal government. <https://www.bostonglobe.com/opinion/editorials/2015/10/26/dying-inmates-don-need-jail/lnZKtssOjIMbiDctGF8NEL/story.html>

**N.B.** 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 selected 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>

## End-of-life care vastly more expensive for dementia patients than for others

*THE WASHINGTON POST* | Online – 26 October 2015 – Care in the last five years of life costs much more for patients with dementia than for those who die of heart disease, cancer or other causes, a new study shows.<sup>1</sup> In addition to costing more across the board, out-of-pocket spending for patients with dementia is 81% higher than for people with other diseases, according to the study conducted by the Icahn School of Medicine at Mount Sinai, Dartmouth College, and the University of California ... and funded by the National Institute on Aging. The burden is disproportionately high when the patients are black, have less than a high school education or are widowed or unmarried women, said the study, which looked at patient and family expenses as well as Medicare and Medicaid spending. One reason for the discrepancy is the fact that patients with dementia often require care for many years, and much of the care they need is not covered by insurance. Medicare does not cover health-related expenses such as homecare services, equipment, and non-rehabilitative nursing care. [https://www.washingtonpost.com/local/social-issues/end-of-life-care-vastly-more-expensive-for-dementia-patients-than-for-others/2015/10/26/747dd8ee-7c15-11e5-beba-927fd8634498\\_story.html](https://www.washingtonpost.com/local/social-issues/end-of-life-care-vastly-more-expensive-for-dementia-patients-than-for-others/2015/10/26/747dd8ee-7c15-11e5-beba-927fd8634498_story.html)

1. 'The burden of health care costs for patients with dementia in the last 5 years of life,' *Annals of Internal Medicine*, 27 October 2015. <http://annals.org/article.aspx?articleid=2466364>

## Selected articles, reports, etc., on end-of-life care for people living with advanced dementia

Noted in Media Watch, 14 September 2015, #427 (p.15):

- *PALLIATIVE MEDICINE* | Online – 9 September 2015 – '**Development of a model for integrated care at the end of life in advanced dementia...**' There are few evidence-based interventions to improve end-of-life care in advanced dementia. Twenty-nine statements [from people with dementia, carers and health and social care professionals in England, from expert opinion and existing literature] were agreed and mapped to individual, group, organisational and economic/political levels of health-care systems. The resulting main intervention components are: 1) Influencing local service organization through facilitation of integrated multi-disciplinary care; 2) providing training and support for formal and informal carers; and. 3) Influencing local healthcare commissioning and priorities of service providers. <http://pmj.sagepub.com/content/early/2015/09/08/0269216315605447.abstract>

Cont.

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.

### How Nevada deals with end-of-life spending

NEVADA | *The Las Vegas Review-Journal* – 25 October 2015 – Federal statistics show legions of Nevadans ... go all-out in the last few months of life, taking desperate medical measures even though death is unavoidable. In the process, patients, their families, their providers and even the medical system suffer immense financial and emotional costs. From hospital invoices that run in the six figures to guilt that can last a lifetime, the final bill is in every way the costliest of all. Nevada, and Las Vegas in particular, have end-of-life spending issues. In Nevada, 19.6% of residents spent seven or more days in intensive care in the last six months of life in 2012, well above the national average of 14.7%, according to the Dartmouth Atlas of Health Care.<sup>1</sup> And local hospitals receive well-above the average Medicare reimbursements for those patients. <http://www.reviewjournal.com/news/death-las-vegas/how-nevada-deals-end-life-spending>

1. ‘Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness,’ A Report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, Hanover, New Hampshire, 12 April 2011. [Noted in Media Watch, 18 April 2011, #197 (p.3)] [http://www.dartmouthatlas.org/downloads/reports/EOL\\_Trend\\_Report\\_0411.pdf](http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf)

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | CBS News (Boston) – 26 October 2015 – ‘**Lawmakers weigh bill to allow doctor-assisted suicide.**’ Legislation in Massachusetts that would let doctors prescribe life-ending drugs to terminally ill patients is heading to a public hearing... The bill would require the patient has a terminal illness or condition that can reasonably be expected to cause death within six months. The patient must self-administer the drugs. The legislation would also require before prescribing the drugs the doctor must inform the patient about the diagnosis, prognosis, risks associated with taking the medication and other treatment options, including palliative care. <http://www.cbsnews.com/news/massachusetts-lawmakers-weigh-bill-to-allow-doctor-assisted-suicide/>
- NEW MEXICO | *Courthouse News Service* – 26 October 2015 – ‘**Aid in dying ban heads to New Mexico High Court.**’ A challenge by two oncologists and a patient to the ban against physician-assisted suicide in New Mexico goes before the state Supreme Court... The State adopted the law in question ... in 1963 making it a fourth-degree felony to help others end their lives. Though a Bernalillo County judge found the law trampled a terminally ill, mentally competent patient’s “fundamental right to choose aid in dying,” a divided three-judge panel of the State Court of Appeals reversed [the ruling] in August. <http://www.courthousenews.com/2015/10/26/aid-in-dying-ban-heads-to-n-m-high-court.htm>

### [Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com)

The website promotes education amongst health care providers in places around the world where the knowledge 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>

## International

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

#### ***Is Britain fairer? The state of equality and human rights 2015***

U.K. | Equality & Human Rights Commission – 30 October 2015 – The Commission produced its first report on equality in 2010 and a separate report on human rights in 2012. ‘Is Britain Fairer?’ is the Commission’s follow-up report on both equality and human rights. It outlines its findings and sets out the challenges for the future. On end-of-life and palliative care (pp.55-58), the Commission points to evidence of inequality in outcomes at the end of life for people sharing particular characteristics; one study<sup>1</sup> indicates overall a larger portion of men die at home and in hospital compared with women, while a larger proportion of women die in care homes; evidence suggests that children with cancer who need palliative care often do not receive it owing to a lack of provision, and a lack of awareness and acceptance; a review of U.K.-based literature<sup>2</sup> found that studies reported

lower access to palliative and end-of-life care for ethnic minorities; and, specific challenges face lesbian, gay, bisexual and transgender people. [http://www.equalityhumanrights.com/sites/default/files/uploads/IBF/Final-reports/EHRC\\_IBF\\_MainReport\\_acc.pdf](http://www.equalityhumanrights.com/sites/default/files/uploads/IBF/Final-reports/EHRC_IBF_MainReport_acc.pdf)

#### Specialist Publications

‘Comparing palliative care provision in India and the U.K.’ (p.11), in *British Journal of Nursing*.

‘The cost of providing end-of-life care for nursing care home residents: A retrospective cohort study’ (p.11), in *Health Services Management Research*.

1. ‘Geographical and Temporal Understanding in Place of Death in England (1984-2010): Analysis of Trends and Associated Factors to Improve End-of-Life Care (GUIDE\_Care) Primary Research,’ *Health Services & Delivery Research*, 2014;2(42). [Noted in Media Watch, 26 January 2015, #394 (p.11)] <http://www.journalslibrary.nihr.ac.uk/hshr/volume-2/issue-42#abstract>
2. ‘Palliative and End-of-Life Care for Black, Asian and Minority Ethnic Groups in the U.K.,’ The Cicely Saunders Institute at King’s College, June 2013. [Noted in Media Watch, 1 July 2013, #312 (p.7)] <http://www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf>

Related:

- U.K. | *The Daily Telegraph* – 29 October 2015 – **“Shocking” end of life care in National Health Service boosting support for assisted suicide – MPs.** ‘Shocking’ standards of end-of-life care in the National Health Service (NHS) are fuelling support for the legalisation of assisted dying, the chairman of an inquiry by MPs into palliative care in the U.K. has warned. Bernard Jenkin, chairman of the Commons Public Administration & Constitutional Affairs Committee, said a fear of “finishing up on some hospital trolley, dying in some forgotten corner” was helping drive support among the public for a change in the law. The committee is calling for an urgent overhaul of training and the working culture in hospitals to address “systemic” failings in caring for people in the final days and hours of their lives. It follows a highly critical report by the Parliamentary & Health Service Ombudsman ... which concluded that too many people in Britain are being forced to die without dignity because staff are too busy or unsure of how to care for dying people.’ <http://www.telegraph.co.uk/news/politics/11961554/Shocking-end-of-life-care-in-NHS-boosting-support-for-assisted-suicide-MPs.html>
1. ‘Dying with Dignity: Investigations by the Parliamentary & Health Service Ombudsman into Complaints About End-of-Life Care,’ May 2015. [Noted in Media Watch, 25 May 2015, #411 (p.6)] [http://www.ombudsman.org.uk/data/assets/pdf\\_file/0019/32167/Dying\\_without\\_dignity\\_report.pdf](http://www.ombudsman.org.uk/data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf)

**N.B.** The Commons Public Administration & Constitutional Affairs Committee “follow-up” to the Parliamentary & Health Service Ombudsman’s report. <http://www.parliament.uk/business/committees/committees-a-z/commons-select/public-administration-and-constitutional-affairs-committee/news-parliament-2015/report-published-dying-without-dignity-15-16/>

Cont.



- U.K. | *The Economist* – 26 October 2015 – ‘**The new palliative care gold standard.**’ Coordinate My Care (CMC) coordinates the care of patients [across the City of London] and provides them with choice and the assurance that all the healthcare professional teams involved in their care are connected and mindful of these choices, whenever they are treated. A digital, personalised urgent care plan underpins the service. This documents a patient’s views and wishes, and can be seen by the entire multidisciplinary team involved in their care, 24/7. The priority of CMC is to support and facilitate the provision of integrated health and social care by bridging the divide between community, acute and urgent care settings, with integration of the voluntary sector. CMC integrates care across London both in and out-of-hours, including GPs, community nurses, community palliative care teams, hospitals, hospices, social workers, the London Ambulance Service, National Health Service 111 [i.e., non-emergency number], and nursing/care homes. The service is clinician-led, with clinical governance embedded into its framework. <http://www.economistinsights.com/opinion/new-palliative-care-gold-standard>

Noted in Media Watch, 26 October 2015, #433 (p.6):

U.K. (England) | Pan-London End of Life Alliance – 19 October 2015 – ‘**Is London the worst place to die?**’ A report by the Economist Intelligence Unit recently ranked the U.K. as the best country in the world for end-of-life care (EOLC) services.<sup>1</sup> However, the quality of EOLC received in London currently underperforms against national averages.<sup>2</sup> The London Assembly Health Committee will examine end-of-life care in the capital and the barriers certain groups face. <http://www.london.gov.uk/media/assembly-press-releases/2015/10/is-london-the-worst-place-to-die>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] [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)
2. ‘A review of specialist palliative care provision and access across London,’ London Cancer Alliance, PallE8 & Marie Curie, 18 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.5)] <https://www.mariecurie.org.uk/globalassets/media/documents/research/london-spc-provision-report.pdf>

### **Elderly home care services in Northern Ireland “at breaking point”**

U.K. (Northern Ireland) | BBC News (Belfast) – 29 October 2015 – Home care services across Northern Ireland’s five health trusts are at breaking point, the outgoing commissioner for older people has said. Claire Keatinge told the BBC that care being provided is failing to meet older people’s needs due to under investment. Her office has carried out a wide-ranging report on home care services. It asks why many people have to be assessed as “critical” before receiving any care, and also queries the pay and training of domiciliary staff. The report<sup>1</sup> ... calls on the government to match need with resources. It is the first time Northern Ireland’s domiciliary care services, including the commissioning, regulation, inspection and delivery of care, have been held to scrutiny. <http://www.bbc.com/news/uk-northern-ireland-34660009>

1. ‘Domiciliary Care in Northern Ireland,’ Commissioner for Older People for Northern Ireland, 2015. [http://www.copni.org/images/publications/Domiciliary\\_care\\_in\\_Northern\\_Ireland\\_-\\_A\\_report\\_of\\_the\\_Commissioners\\_Summit.pdf](http://www.copni.org/images/publications/Domiciliary_care_in_Northern_Ireland_-_A_report_of_the_Commissioners_Summit.pdf)

**N.B.** No mention is made of meeting the needs of people living with a terminal illness.

### **End-of-life care in Australia**

#### **More New South Wales patients spend their final days at home after introduction of care program**

AUSTRALIA (New South Wales) | ABC News (Sydney) – 22 October 2015 – Two years after it was introduced, a program to help terminally ill people die in the familiar surrounds of home is improving the final days of hundreds of patients in New South Wales. Fewer than 20% of Australians are able to die at home, despite studies consistently showing that between 70% and 80% would like to. In a consortium with Sacred Heart Health Service and Calvary Health Care, the program is being run in seven local health

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districts in New South Wales. Two years into its operation, more than 650 people have accessed the services, 76% of whom are managing to die at home. The program provides a free package of end-of-life care for people who are in the deteriorating or terminal phase of their illness – with services ranging from overnight care, to domestic support and basic nursing. The program was designed to overcome some of the obstacles that often prevented terminally ill patients from being able to die in their own homes. <http://www.abc.net.au/news/2015-10-25/hundreds-access-program-of-end-of-life-care-at-home/6883162>

Noted in Media Watch, 26 January 2015, #394 (p.6):

- AUSTRALIA | *Business Insider* (Sydney, New South Wales) – 19 January 2015 – **‘Most Australians want a good death at home, but only 14% get it.’** Dying in Australia is highly institutionalised with 54% [of Australians] ending their days in hospital and 32% in residential care. However, most (60-70%) would prefer to die at home.<sup>1</sup> <http://www.businessinsider.com.au/doctors-when-the-end-comes-most-australians-want-a-good-death-at-home-2015-1>

1. ‘What can we do to help Australians die the way they want?’ *The Medical Journal of Australia*, 2015;202(1):10-11. A different service mix could better meet end-of-life care needs for little additional cost. <https://www.mja.com.au/journal/2015/202/1/what-can-we-do-help-australians-die-way-they-want>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FRANCE | *The Daily Telegraph* (U.K.) – 24 October 2015 – **‘French “ethanasia” doctor gets symbolic suspended sentence.’** A French doctor who gave lethal injections to seven terminally ill patients was given a two-year suspended sentence... The lenient sentence, announced after nearly seven hours of jury deliberations, reflected public sympathy for Nicolas Bonnemaison, a 54-year-old former emergency room doctor, who remained impassive, with his head lowered, as the verdict and sentence were announced. Relatives of his patients testified in his favour and some were tearful but obviously relieved by the lenient sentence. He was acquitted by a lower court last year, but stood trial again after prosecutors appealed. <http://www.telegraph.co.uk/news/worldnews/europe/france/11952971/French-ethanasia-doctor-gets-symbolic-suspended-sentence.html>

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

#### **“I wanted to communicate my feelings freely”: A descriptive study of creative responses to enhance reflection in palliative medicine education**

*BMC MEDICAL EDUCATION* | Online – 23 October 2015 – The teaching of communication in palliative medicine is challenging and the opportunity to enable medical students to talk with patients at end-of-life although pragmatically difficult to arrange has proven to be an effective learning opportunity. Educationally, it is important to ensure students gain as much as they can in processing this experience. The introduction of an option to use creative media in a reflective response has been of value to the students in achieving this, particularly for those who are thus able to find a medium that suits their learning style. This approach would be suitable to use in other areas that have similar sensitive responses, such as maternity and fertility, aging, disability and mental health. <http://www.biomedcentral.com/content/pdf/s12909-015-0465-4.pdf>

Noted in Media Watch, 25 February 2013, #294 (p.13, under ‘Worth Repeating’):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2011;1(2):193-197. **‘Overcoming the challenges of bedside teaching in the palliative care setting.’** Bedside teaching is the process of active learning in the presence of a patient and is one of the most traditional teaching techniques used in undergraduate medicine. Students and patients both appear to benefit from the experience. However, bedside teaching with medical students and palliative care patients presents a number of challenges for the patient, the learner, and also the educator. <http://spcare.bmj.com/content/1/2/193.abstract?sid=68a10cdd-e64a-4b9a-b17e-947fe2be9bab>

## End-of-life care in The Netherlands

### **Comparison of end-of-life care for older people living at home and in residential homes: A mortality follow-back study among GPs in The Netherlands**

*BRITISH JOURNAL OF GENERAL PRACTICE*, 2015; 65(640):e724-e730. Despite similar treatment goals, care in residential homes seems more successful in avoiding transfers and hospitalisation at the end of life. Especially since older people are encouraged to stay at home longer, measures should be taken to ensure they are not at higher risk of transfers and hospitalisations in this setting. Controlling for the differences between the populations in home settings and residential homes, no differences were found in treatment goals, communication about end-of-life care, or use of specialised palliative care between the two settings. However, people living in a residential home were more likely to have received palliative care from a GP than people living at home... In residential homes, people more often experienced no transfer between care settings ... and no hospitalisations ... in the last 3 months of life, and died in hospital less often ... than those people living at home. <http://bjgp.org/content/65/640/e724>

### **Comparing palliative care provision in India and the U.K.**

*BRITISH JOURNAL OF NURSING* | Online – 24 October 2015 – The Prince & Princess of Wales Hospice in Glasgow is committed to developing culturally competent, sensitive services to meet the needs of local ethnic minority communities. The clinical nurse specialist for widening access travelled to India funded by a travel scholarship from the Florence Nightingale Foundation. The main rationale for this visit was to observe and compare palliative care (PC) practice in India in community, hospice and hospital settings with the current service provision by the hospice/hospital PC teams in Glasgow. A second focus was to study the cultural differences and potential challenges of providing PC to a diverse Indian population from multi-faith communities and different socio-economic classes. Throughout the visit the barriers to accessing PC services in India were observed as well as cultural norms that might impact on clinical practice in the U.K. <http://www.magonlinelibrary.com/doi/abs/10.12968/bjon.2015.24.19.962>

**N.B.** India was ranked 67th and the U.K. 1st of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [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)

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 29 October 2015 – **'Spirituality as an ethical challenge in Indian palliative care: A systematic review.'** Since spiritual well-being greatly impacts quality of life, and because of the substantial presence of people of Indian origin living outside the subcontinent, the findings of the review have international relevance. Moreover, this review illustrates spirituality can be an ethical challenge and that more ethical reflection on provision of spiritual care is needed. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10022179&fulltextType=RV&fileId=S147895151500125X>

## End-of-life care in England

### **The cost of providing end-of-life care for nursing care home residents: A retrospective cohort study**

*HEALTH SERVICES MANAGEMENT RESEARCH* | Online – 27 October 2015 – The proportion of people dying in long-term care institutions is predicted to increase in future years. Thirty-eight nursing care homes took part, comprising 2,444 individual residents. End of life was defined as the last six months of life, or from time of residency if this was less than six months. The total mean healthcare cost per resident was £3,906. Hospital stays accounted for two-thirds (67%) of these costs; 56% of these occurred in the final month of life. Death in hospital vs. in the nursing care home was associated with an average increase in costs of £4,223. Death in hospital is costly, and is seldom identified as a preferred place of death. Therefore, interventions are needed which help nursing care home staff to identify when an individual is dying, and have the skill and confidence to make difficult decisions regarding care provision at the end of life. <http://hsm.sagepub.com/content/early/2015/10/26/0951484815607541.abstract>

## **General practice and specialist palliative care teams: An exploration of their working relationship from the perspective of clinical staff working in New Zealand**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 October 2015 – With the future focus on palliative and end-of-life care provision in the community, the role of the general practice team and their relationship with specialist palliative care (PC) providers is key to responding effectively to the projected increase in PC need. Studies have highlighted the potential to improve co-ordination and minimise fragmentation of care for people living with PC need through a partnership between generalist services and specialist PC. However, to date, the exact nature of this partnership approach has not been well defined and debate exists about how to make such partnerships work successfully. 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://onlinelibrary.wiley.com/doi/10.1111/hsc.12296/abstract>

**N.B.** New Zealand was ranked 3rd of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [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)

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.**' The demand for palliative care (PC) specialists is growing rapidly, since timely PC consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity. Some core elements of PC, 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>

### **End-of-life care in Israel**

#### **Preparedness for end of life: Survey of Jerusalem district nursing homes**

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2015;63(10):2114-2119. Most staff members reported that end-of-life (EOL) preferences were unknown for more than 90% of residents and that fewer than 10% had a healthcare proxy. Most staff members recalled conducting fewer than five EOL conversations over the past year with residents or family members and could recall fewer than five cases in which a resident was allowed to die in the nursing home. According to staff opinions the prevalence of tube feeding was estimated at greater than 10%, initiated because of aspiration, malnutrition, and understaffing, often against family's preferences. More than 25% of staff members believed pain management was inadequate. Knowledge about management of chronic pain was poor in half of nurses and nearly one-third of physicians. Most staff would rather not receive the treatments they administered to residents. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13645/abstract;jsessionid=D55EAE05ADBABC248958CF95BF25E1C.f01t04?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Noted in Media Watch, 29 October 2012, #277 (p.8):

- *JOURNAL OF SUPPORTIVE ONCOLOGY* | Online – 22 October 2012 – '**Initiating palliative care conversations: Lessons from Jewish bioethics.**' The principle that we can derive from Jewish bioethics teaches that the medical staff has a responsibility to help our patients live in a way that is consistent with how they understand their task or responsibility in life. For some patients, the best way to preserve a meaningful life in which they can fulfill their sense of purpose in the time that remains is to focus on palliation. <http://www.sciencedirect.com/science/article/pii/S154467941200170X>

## **Impact of provider level, training and gender on the utilization of palliative care and hospice in neuro-oncology: A North American survey**

*JOURNAL OF NEURO-ONCOLOGY* | Online – 30 October 2015 – The utilization patterns of palliative care (PC) in neuro-oncology are unknown. Forty-seven percent [of survey respondents] were medical or neuro-oncologists, 31% neurosurgeons and 11% radiation oncologists. Forty percent had no formal training in PC, 57% had some formal training, and 3% completed a PC fellowship. Seventy-nine percent practiced in an academic setting. Of the respondents, 57% referred patients to PC when symptoms required treatment and 18% at end of life. Only 51% of all providers felt comfortable dealing with end-of-life issues and symptoms, while 33% did not. Fifty-one percent preferred a service named “Supportive Care” rather than “Palliative Care,” and 32 % felt that patient expectations for ongoing therapy hindered their ability to make PC referrals. <http://www.ncbi.nlm.nih.gov/pubmed/26518539>

### **Sheffield Profile for Assessment & Referral for Care**

## **A pilot randomized controlled trial of a holistic needs assessment questionnaire in a supportive and palliative care service**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2015;50(5):587-598. Results identify a potential negative effect of the Sheffield Profile for Assessment & Referral for Care (SPARC) in specialist palliative care services, raising questions that standardized holistic needs assessment questionnaires may be counterproductive if not integrated with a clinical assessment that informs the care plan. It may raise expectations that are not subsequently met. We can, however, conclude that a larger trial with more power to detect an effect is highly unlikely to be positive. A larger trial in specialist outpatient or home care services using the same design and outcome measures is unlikely to demonstrate any benefit. It is nevertheless possible that SPARC has utility for the original purpose for which it was designed, as a screening tool, in primary care or general medical care for selection of patients who may benefit from a referral to specialist palliative care. It is also possible that, were SPARC to be included in the routine clinical assessment that informs a care plan within a specialist service, then immediate benefit might follow within an effective supportive or palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00255-9/pdf](http://www.jpmsjournal.com/article/S0885-3924(15)00255-9/pdf)

Noted in Media Watch, 25 February 2013, #294 (p.5):

- *HEALTH EXPECTATIONS* | Online – 18 February 2013 – ‘**Sheffield Profile for Assessment & Referral for Care (SPARC): A survey of self-help support groups in health care.**’ SPARC was developed in response to concerns that palliative care may not be reaching all people who could benefit from it. <http://onlinelibrary.wiley.com/doi/10.1111/hex.12058/abstract>

### **End-of-life care in Canada**

## **Quality of care and satisfaction with care on palliative care units**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 October 2015 – There is little research on quality of care specific to palliative care units (PCUs). Qualitative interviews and focus groups were conducted across four Toronto [Ontario] PCUs, with a total of 46 patient/caregiver interviews and eight staff focus groups. Key elements of quality care and patient satisfaction on a PCU were grouped into six domains: 1) Interprofessional team: a team of experts comprising multiple disciplines functioning as a unit; 2) Communication: developing rapport, addressing expectations, providing information, listening actively and facilitating end-of-life discussions; 3) Attentive, personalized care: anticipatory and responsive compassionate care with tailored management of physical and nonphysical symptoms; 4) Family-centered: support of patients and caregivers within a family; 5) Accessible and consistent: appropriate resources and adequate staff to provide consistent care; and, 6) Supportive setting: a bright non-institutionalized setting allowing both privacy and socialization. The elements identified support the delivery of quality care. They may act as a guide for those planning to develop PCUs and form the basis for measures of satisfaction with care. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00567-9/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00567-9/abstract)

## **Palliative sedation for adults: Principles and best practices. Guidelines proposed by the Société québécoise des médecins de soins palliatifs**

*MÉDECINE PALLIATIVE* | Online – 27 October 2015 – Palliative sedation (PS) can be useful to insure the comfort of patients experiencing severe distress at the end of their lives, when no other treatments are effective in doing so. Guidelines have been published by several national and international organisations to clarify the principles behind 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...**’ Published guidelines: 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/early/2014/05/06/1049909114533002.abstract>

## **Closing the casket: Professionalism and care amongst funeral directors in the Republic of Ireland**

*MORTALITY* | Online – 25 October 2015 – This article explores the experiences of funeral directors and ways in which they position themselves in relation to the ritual of the funeral, social and religious values and family structures. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2015.1100160>

## **Death Cafe: What is it and what we can learn from it**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 29 October 2015 – This article explains the meaning of the phrase Death Cafe (DC) and describes what typically occurs at a DC gathering. The article traces the history of the DC movement, explores some reasons why people take part in a DC gathering, and gives examples of what individuals think they might derive from their participation ... [and] ... notes similarities between the DC movement and three other developments in the field of death, dying, and bereavement. The authors identify provisional lessons that can be drawn from DC gatherings and the DC movement itself. <http://ome.sagepub.com/content/early/2015/10/25/0030222815612602.abstract>

## **The potential therapeutic value for bereaved relatives participating in research: An exploratory study**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 29 October 2015 – The results [of this study] center around six recurring concepts identified as adaptive in current bereavement theory: 1) An opportunity to share the narrative accounts of the final hours of their relative's life; 2) A search for sense and meaning in loss; 3) An ongoing bond/attachment with the deceased; 4) Altruistic motivations; 5) Oscillation between loss and restorative orientations; and, 6) A sense of resilience. Overall, the participants found that taking part in the research was valuable and that it could be described as offering therapeutic benefits. The need for bereaved relatives to take part in research studies should be encouraged, as they provide an accurate proxy for the patient's experience of end-of-life care while also providing a valuable account of their own perspective as family member and carer. In addition, the authors highlight the need for ethics committees to be aware of the potential benefits for bereaved relatives participating in research of this kind. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10022173&fulltextType=RA&fileId=S1478951515001194>

## Trends in end-of-life care in pediatric hematology, oncology, and stem cell transplant patients

*PEDIATRIC BLOOD & CANCER* | Online – 29 October 2015 – The authors evaluated associations of demographic variables (race, ethnicity, language, religion, and diagnosis) with end-of-life characteristics (Phase I enrollment, do-not-resuscitate (DNR) orders, hospice utilization, location of death), and trends in palliative care (PC) services delivered to pediatric hematology, oncology, and stem cell transplant patients. Of the 445 patients [included in this study], 64% had relapsed disease, 45% were enrolled in hospice, and 16% had received PC consultation. Patients with brain or solid tumors enrolled in hospice ... and died at home more frequently than patients with leukemia/lymphoma... Patients who received Phase I therapy or identified as Christian/Catholic religion enrolled in hospice more frequently ... When patient deaths were analyzed over quartiles, the frequency of DNR orders ... and PC consultation ... increased over time. Hospice enrollment, location of death, and Phase I trial enrollment did not change significantly. Despite increases in PC consultation and DNR orders over time, utilization remains sub-optimal. No increase in hospice enrollment or shift in death location was observed. These data will help target future initiatives to achieve earlier discussions of goals of care and improved PC for all patients. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25822/abstract>

The Economist

Intelligence Unit

The 2015 Quality of Death Index  
Ranking palliative care across the world

### Children's palliative care

The 2015 Quality of Death Index ranks countries by their provision of palliative care to adults, principally for reasons of data availability. The lack of comparable data on the provision of such care to children reflects that their needs are too often ignored in this area.

"This group has been marginalised over the years and there's no reason for them to be left out," says Joan Marston, chief executive of the South Africa-based International Children's Palliative Care Network. "But people are starting to realise that you can't exclude children—it's a human rights issue."

A number of obstacles hamper the development of children's palliative care. Their needs are diverse because of the widely different age groups, from babies to young people, and the complexity of their conditions demands more sophisticated services. Also, most of the deaths take place in low-income countries and the developing world, with few being identified as in need of care—particularly in countries with a high HIV burden.

Even in developed countries, there are challenges, communication being one. For while it is relatively easy to talk to an adult or a young person about symptoms and pain levels, this is harder with, say, a three-year-old and impossible with a baby, demanding sophisticated diagnostic skills.

Mrs Marston points to other barriers. "A lot of clinicians are afraid of looking after children, because children's care needs are so complex and because of the emotions that surround the family," she says.

Many are hesitant to dispense appropriate painkillers, too. "We know you can give morphine to a newborn but you have to work out that dose very carefully," she says. "So there's a fear of using opioids."

This has led to severe shortfalls in the availability of palliative care for children. "The UK has the best spread of children's hospice and palliative care services but they're only reaching 25% of the children who need it," Mrs Marston says.

Encouragingly, however, some developing countries are moving ahead rapidly in developing children's palliative care services. In Malawi, for example, children's palliative care is now part of national policy and the government has committed to rolling out training in the regions. In the Indian state of Maharashtra, children's palliative care is also included in state policy and its government is setting aside money for care provision.

In many of these countries—as well as in some Eastern European nations such as Belarus, Latvia and Poland—progress on developing children's palliative care is happening due to the efforts of one or several passionate individuals. "If you look at children's palliative care, you'll always find that right at the beginning, there was someone who said, 'We need to do something about the children,'" says Mrs Marston.

She adds that listening to children themselves is also critical. "Having the child and the young person talk about their needs—that's really powerful."

2015 Quality of Death Index' (see p.44): [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)

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Noted in Media Watch, 10 August 2015, #422 (p.12):

- *BMC PALLIATIVE CARE* | Online – 4 August 2015 – ‘**Priorities for global research into children’s palliative care: Results of an International Delphi Study.**’ The top five research priorities identified were: 1) Children’s understanding of death and dying; 2) Managing pain in children where there is no morphine; 3) Funding; 4) Training; and, 5) Assessment of the WHO two-step analgesic ladder for pain management in children. This information is important for policy makers, educators, advocates, funding agencies, and governments and provides a much needed starting place for the allocation of funds and building research infrastructure. <http://www.biomedcentral.com/content/pdf/s12904-015-0031-1.pdf>

Noted in Media Watch, 22 September 2014, #376 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 September 2014 – ‘**Reported availability and gaps of pediatric palliative care in low- and middle-income countries: A systematic review of published data.**’ The majority of young people in need of palliative care (PC) live in low- and middle-income countries, where curative treatment is less available. The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Comprehensive pediatric PC provision is possible even in markedly impoverished settings. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0095>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/10/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>



## Worth Repeating

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

*BMC HEALTH SERVICES RESEARCH* | Online – 17 July 2013 – In all countries [Belgium, England, France, Germany, The Netherlands, Poland and Spain] palliative care regulations and policies existed (either in laws, royal decrees, or national policies). An explicit right to palliative care was mentioned in the Belgium, French and German law. In addition, access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, opioids, and the role of volunteers. [Noted in Media Watch, 29 July 2013, #316 (p.8)] <http://www.biomedcentral.com/content/pdf/1472-6963-13-275.pdf>

**Figure 2.2: Presence and effectiveness of government-led national palliative care strategy**

5		4		3		2		1	
There is a comprehensive strategy for the development and promotion of national palliative care. It has a clear vision, clearly defined targets, an action plan and strong mechanisms in place to achieve targets. In federal-structure countries, there are strong and clearly defined strategies that individual states must follow. These mechanisms and milestones are regularly reviewed and updated.		There is a well-defined, government-led strategy for the development and promotion of national palliative care. It has a clear vision and specific milestones. There are mechanisms in place and guidelines on implementation. It is mostly well implemented, even in federal-structure countries.		There is a government-led strategy for the development and promotion of national palliative care. This has a broad vision, and loosely defined milestones (no specific targets). There are limited mechanisms in place that aim to achieve milestones. In federal-structure countries, states are not mandated to follow the national strategy; i.e. it is only prescriptive in nature		There is a government-led strategy for the development and promotion of national palliative care. However, it is merely a statement of broad intent. It does not contain a clear vision or specific milestones to achieve. There are no clear mechanisms in place to achieve the strategy.		There is no government-led strategy for the development and promotion of national palliative care.	
Australia	Singapore	Austria	Japan	Brazil	Portugal	Argentina	Iran	Bulgaria	Guatemala
Ireland	Taiwan	Belgium	Mongolia	Canada	Puerto Rico	Bangladesh	Kazakhstan	Dominican	Iraq
Netherlands	UK	Chile	Norway	Costa Rica	Russia	Botswana	Lithuania	Republic	Philippines
New Zealand		Finland	Panama	Cuba	South Africa	China	Morocco	Egypt	Romania
		France	South Korea	Denmark	Sri Lanka	Colombia	Myanmar		
		Germany	Spain	Ecuador	Sweden	Czech	Nigeria		
		Hong Kong	Switzerland	Ghana	Tanzania	Republic	Saudi Arabia		
		Israel	US	India	Thailand	Ethiopia	Slovakia		
		Italy		Indonesia	Turkey	Greece	Ukraine		
				Jordan	Uganda	Hungary			
				Kenya	Uruguay				
				Malawi	Venezuela				
				Malaysia	Vietnam				
				Mexico	Zambia				
				Peru	Zimbabwe				
				Poland					

'2015 Quality of Death Index' (see p.24): [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)

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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.

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### Something Missed or Overlooked?

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

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