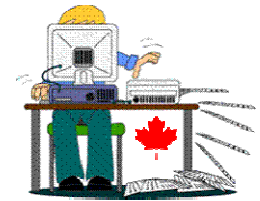


Media Watch...

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.

19 October 2015 Edition | Issue #432



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Expressions of loss and separation: Scroll down to [Specialist Publications](#) and ‘Teenagers’ reasoning about a parent’s recent death in cancer’ (p.14), in *Palliative & Supportive Care*.

Canada

Home care in Ontario

Stress load on family caregivers in Ontario doubles in four years

ONTARIO | CTV News – 14 October 2015 – A new report says the stress load on people helping to care for an elderly or sick family member or friend has more than doubled in Ontario in the past four years.¹ Health Quality Ontario says 33% of people who care for loved ones at home reported feeling distress, anger or depression in 2013-2014, up from 16% in 2008-2009. The government advisory group says almost all home care patients rely on an informal caregiver for everything from shopping and transportation to managing medications and helping with personal care. However, one third of those caregivers say they are too stressed out to do it any longer. The annual report from Health Quality Ontario also found patients in hospitals are waiting an average of 69 days to get into long-term care homes – an increase of nearly three weeks from four years earlier. People at home who need a long-term care bed have seen the wait reduced by 74 days, but they’re still waiting an average of 116 days, or just under four months. <http://www.ctvnews.ca/health/stress-load-on-family-caregivers-in-ontario-doubles-in-four-years-1.2609256>

1. ‘Measuring Up: A Yearly Report on How Ontario’s Health System is Performing,’ Health Quality Ontario, October 2015. <http://www.hqontario.ca/portals/0/Documents/pr/measuring-up-2015-en.pdf>

N.B. Discussion of home care services and family caregivers begins on p.62. There is no mention of the needs of patients or families living with a terminal or life-threatening illness.

Reports on Ontario’s home care system

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
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

Cont.

3. 'The Care We Need: Ontarians Speak Out on the State of Home Care – A Proposal for Reforming Home Care in the Public Interest,' Ontario Health Coalition, March 2015. [Noted in Media Watch, 16 March 2015, #401 (p.1)] <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>

Related:

4. 'Factors associated with not receiving homecare, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study,' *Health Policy*, 3 December 2014. [Noted in Media Watch, 15 December 2014, #388 (p.11)] [http://www.healthpolicyjrnl.com/article/S0168-8510\(14\)00334-0/abstract](http://www.healthpolicyjrnl.com/article/S0168-8510(14)00334-0/abstract)
5. '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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) – 15 October 2015 – **'Manitoba College of Physicians & Surgeons releases draft statement on doctor-assisted dying.'** The College ... is asking its members and the public for feedback.¹ Among other things, the statement outlines how patients will be able to request and access physician-assisted dying (the term the college prefers), what role a doctor will play in the process, or if he or she refuses to participate what at a minimum should be expected of a doctor. <http://www.cbc.ca/news/canada/manitoba/manitoba-college-of-physicians-and-surgeons-releases-draft-statement-on-doctor-assisted-dying-1.3271796>
1. Manitoba College of Physicians & Surgeons draft statement on doctor-assisted dying: <http://cpsm.mb.ca/cjj39alckF30a/wp-content/uploads/PAD/DraftStatementPAD.pdf>

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.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.

U.S.A.

Bring back house calls

THE NEW YORK TIMES | Online – 14 October 2015 – Rehospitalization is a huge and costly problem in this country, where the rate has increased 50% over the past three decades. Today, about 1 in 5 Medicare patients discharged from the hospital is rehospitalized within a month. A third of those patients are rehospitalized within a week. Removing elderly patients from their homes and sending them back to the alien environment of the hospital is often traumatizing. Neither doctors nor hospitals have tried very hard to tackle this problem. We don't ensure patients released from the hospital obtain their medications and know how to take them. We don't secure timely medical follow-ups. Most of the time we don't communicate with patients' primary care physicians. And, of course, we almost never visit them at home. This goodbye-and-good-luck attitude costs us a lot of money. The price tag of unplanned readmissions is \$17 billion a year for Medicare alone. Given the huge costs, it is no surprise that the Obama administration has been penalizing hospitals with higher-than-average readmission rates. Last year about 2,600 hospitals across the country were docked up to 3% their total Medicare revenue, for a total of \$420 million. You would think such penalties would have a big impact on the

discharge planning at most hospitals, which operate with narrow profit margins. They don't. <http://www.nytimes.com/2015/10/15/opinion/bring-back-house-calls.html?action=click&pgtype=Homepage&module=opinion-c-col-right-region®ion=opinion-c-col-right-region&WT.nav=opinion-c-col-right-region&r=0>

Specialist Publications

'The myth regarding the high cost of end-of-life care' (p.12), in *American Journal of Public Health*.

'Palliative care: Continued progress, but gaps remain' (p.12), in *Health Affairs*.

'Hospice services for complicated grief and depression: Results from a national survey' (p.15), in *Journal of the American Geriatrics Society*.

'Palliative care in the U.S. Military Health System' (p.13), in *Military Medicine*.

'Toward evidence-based end-of-life care' (p.14), in *New England Journal of Medicine*.

Noted in Media Watch, 5 October 2015, #430 (p.5):

- *THE WALL STREET JOURNAL* | Online – 27 September 2015 – '**How house calls can cut medical costs.**' Evidence has mounted that primary care at home, though not inexpensive to provide, can be more economical than a constant cycle of emergency-room visits and hospital stays. According to a study published last year¹ ... Medicare costs for patients in a home-based primary-care program in Washington DC, were 17% lower than those for a control group, averaging \$8,477 less per beneficiary over two years. Another study in the same journal, of Veterans Affairs home-based care, showed it not only reduced costs but also led to higher patient satisfaction.² <http://www.wsj.com/articles/how-house-calls-can-cut-medical-costs-1443407612>

1. 'Effects of home-based primary care on Medicare costs...', *Journal of the American Geriatrics Society*, 2014;62(10):1825-1831. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12974/abstract>

2. 'Better access, quality, and cost for clinically complex veterans with home-based primary care,' *Journal of the American Geriatrics Society*, 2014;62(10):1954-1961. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13030/abstract>

Cont.

California Governor denies terminally ill access to potentially life-saving drugs

CALIFORNIA | *The Washington Free Beacon* – 12 October 2015 – Californians who are terminally ill will not be able to access drugs with the potential to save or prolong their lives as a result of Governor Jerry Brown's veto of the Right to Try Act, AB 159, the California Right to Try Act, passed the state assembly and senate with overwhelming bipartisan support. "It's disappointing that Governor Brown couldn't see the need to allow Californians the right to fight to save their own lives," said [Democratic] Assemblyman Ian Calderon, who sponsored the legislation. "Both Democrats and Republicans wanted this for our California's terminally ill." In his veto message Brown wrote that "Patients with life-threatening conditions should be able to try experimental drugs, and the U.S. Food & Drug Administration's compassion use program allows this to happen." <http://freebeacon.com/issues/california-governor-denies-terminally-ill-access-to-potentially-life-saving-drugs/>

Noted in Media Watch, 5 October 2015, #430 (p.7):

- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – '**Right-to-try laws: Hope, hype, and unintended consequences...**' Most right-to-try laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. <http://annals.org/article.aspx?articleid=2443961>

N.B. Selected articles, reports, etc., on right-to-try laws noted in past issues of Media Watch are listed in this issue of the weekly report.

International

End-of-life care in Australia

Palliative care knowledge increasing in residential, but concerns community care behind

AUSTRALIA | *Australian Ageing Agenda* – 16 October 2015 – An initial evaluation of training delivered to aged care workers by Decision Assist, the national initiative to enhance palliative care and advanced care planning, has shown significant increases in their knowledge and confidence. But the early data also suggests that community care lags behind residential in some areas of implementation. Decision Assist is a federally-funded initiative between health and aged care organisations, including Leading Age Services Australia and Aged & Community Services Australia, that provides advice and training to improve the palliative care and advance care planning expertise of aged care staff, practice nurses and GPs. <http://www.australianageingagenda.com.au/2015/10/16/palliative-care-knowledge-increasing-in-residential-but-concerns-community-care-behind/>

N.B. Australia was ranked 2nd 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

End-of-life care in Ireland

Irish Hospice Foundation says midlands is "end of life" blackspot

IRELAND | *Shannon Side* – 12 October 2015 – The Irish Hospice Foundation is calling for urgent action at government and Health Service Executive (HSE) level to provide adequate end of life care services for the midlands region. It says the region comprising of Longford, Westmeath, Offaly and Westmeath, is currently an "end of life" blackspot, with no inpatient hospice unit, and the lowest level of investment in palliative care nationally. Chief Executive Officer of the Irish Hospice Foundation, Sharon Foley, says

Cont.

without a hospice and the resultant specialist care that comes with it, patients are being denied the best possible care on their final journey. She says the fact there is no inpatient hospice in the region, means that patients have no option but to be admitted to the acute hospitals for care. As a result, 41% of cancer patients in Longford, Westmeath, Offaly and Laois die in an acute hospital, compared to only 21% in the Mid West. <http://www.shannonside.ie/news/irish-hospice-foundation-say-midlands-is-end-of-life-blackspot/>

Noted in Media Watch, 17 August 2015, #423 (pp.7-8):

- IRELAND | *The Irish Times* (Dublin) – 14 August 2015 – **‘Terminally ill need not die in hospital, says study.’** The study,¹ which looked at palliative care services in the HSE midlands, mid-west and southeast, found not all areas had access to specialist palliative care inpatient units, daycare centres or hospice care. Services varied from 24 hours a day, seven days a week, to office hours only. <http://www.irishtimes.com/news/health/terminally-ill-need-not-die-in-hospital-says-study-1.2316486>
 1. ‘Economic Evaluation of Palliative Care in Ireland,’ from Trinity College Dublin and the Economic and Social Research Institute, August 2015. The report was prepared for The Atlantic Philanthropies. <http://www.esri.ie/UserFiles/publications/BKMNEXT295.pdf>

Noted in Media Watch, 28 October 2013, #329 (p.5):


- IRELAND | *The Irish Times* (Dublin) – 22 October 2013 – **‘Lack of hospice beds leaves terminal patients out in the cold.’** More than a decade ago a report from the National Advisory Committee on Palliative Care recommended that there should be one hospice bed per 10,000 of the population. However, according to the latest report from the Irish Hospice Foundation,¹ just “just two regions – the mid-west and northwest – come close to fulfilling government policy.” <http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194>
 1. *Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us,* Irish Hospice Foundation, *Perspectives No. 2*, May 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

N.B. Ireland was ranked 4th of the 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

2015 Quality of Death Index: The Philippines

Government vows to improve health care system

THE PHILIPPINES | *The Philippines Star* (Manila) – 12 October 2015 – Malacañang [the Office of the President] said the [Benigno] Aquino administration is doing its best to improve the country’s health care system, which it hopes will translate into better services and remove the Philippines’ derogatory tag as one of the worst places to die in the world [78th of the 80 countries surveyed]. According to the 2015 Quality of Death study index [see sidebar], the Philippines lacks government-led strategy for development and promotion of national palliative care services – making Manila as the worst place to die, next to war-torn Iraq and Bangladesh. Deputy presidential spokesperson Abigail Valte said although the government has programs for palliative care, its major thrust is having universal health care. <http://www.philstar.com/headlines/2015/10/12/1509814/government-vows-improve-health-care-system>



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

http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

N.B. For additional coverage in Media Watch of the 2015 Quality of Death Index see the issue of the weekly report of 12 October 2015, #431 (pp.3, 6, 15 & 19).

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.18.

Cont.

Noted in Media Watch, 5 April 2010, #143 (p.5):

- THE PHILIPPINES | *The Manila Bulletin* – 29 March 2010 – ‘**Palace taps “hospice” as ... conduit for morphine.**’ President Gloria Macapagal-Arroyo designated the National Hospice & Palliative Care Council of the Philippines (Hospice Philippines) as one of the major conduits of the Department of Health in the distribution of morphine. The proclamation cited the progress it has achieved in forming, uniting and networking with hospice and palliative care institutions in the country as well as networking with similar institutions abroad, cooperating with the Philippine Cancer Society in its cancer program. <http://www.mb.com.ph/articles/250083/palace-taps-hospice-doh-conduit-morphine>

2015 Quality of Death Index: The U.K.

Is the U.K. really the best place in the world to die?

U.K. | *The Conversation* – 12 October 2015 – This is the second time in a row the U.K. has taken out the top spot – it topped the last index in 2010. The report attributes the U.K.’s success to its comprehensive national policies, the integration of palliative care into the National Health Service, a strong hospice movement, and deep community engagement. Yet based on experience ... many deaths in the U.K. have been poorly managed. Hundreds of frail elderly patients died prematurely at the Mid-Staffordshire hospital. The Liverpool Care Pathway – intended to improve patients’ last hours – came under fire for degenerating into a tick-box exercise – where staff seemed more concerned with meeting guidelines than administering appropriate care – and was abandoned. And the health service ombudsman is disturbed by the regularity of complaints received about poor end-of-life care. An EIU spokesperson said there is still work to do in the U.K., such as “ironing out occasional

problems with communication or symptom control.” But we believe the problems go much deeper. The U.K.’s palliative care services ... are indeed excellent. But they are based on experiences with cancer care, when in fact more of us will die, not of cancer, but of multiple conditions ... in an extended, vulnerable, frail old age. This results in a very different kind of dying, often implicated in care scandals. So although the U.K.’s palliative care services are excellent, the quality of death can still be poor for many citizens – particularly for those who aren’t dying of cancer. <http://theconversation.com/is-the-uk-really-the-best-place-in-the-world-to-die-48766>

Specialist Publications

‘The best place in the world to die: But could still be better’ (p.10), in the *British Medical Journal*.

Related:

- U.K. (England) | *Crowborough Life* – 16 October 2015 – ‘**Hospice propose “cottage hospices” to care for terminally ill patients.**’ Hospice in the Weald based at Pembury is proposing to open a string of Cottage Hospices to give terminally ill patients access to expert specialist care within their own local community. The new Cottage Hospice is intended as a community hub, with drop-in daycare facilities for patients as well as ground-breaking training courses to teach volunteers, families and carers the skills to look after patients themselves. It will provide residential suites for terminally ill patients where relatives or carers will have the chance to stay with their loved ones round the clock and care for them through their final days with the help of nursing staff. <http://crowboroughlife.com/hospice-propose-cottage-hospices-to-care-for-terminally-ill-patients-13482/>

Cont. next page

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>

- U.K. (England) | *The Guardian* – 15 October 2015 – ‘**Care Quality Commission: Two-thirds of hospitals offering sub-standard care.**’ Two-thirds of hospitals are offering sub-standard care, according to the National Health Service (NHS) regulator, which warns pressure to cut costs could lead to further worsening of health services in the coming years.¹ The Care Quality Commission also said levels of safety are not good enough in almost three-quarters of hospitals, with 1 in 8 being rated as inadequate. England’s health and social care regulator raises concerns patients could suffer as the service seeks to make £22 billion of efficiency savings by 2020 NHS England has offered and health secretary Jeremy Hunt is pressing it hard to start delivering. <http://www.theguardian.com/society/2015/oct/15/two-thirds-hospitals-substandard-care-care-quality-commission>

Extract from Care Quality Commission report

The quality of care in the hospices ... that we have rated has been good. Up to the end of 31 May 2015, eight out of 27 hospices rated outstanding, and 17 were good.

1. ‘The State of Health Care & Adult Social Care in England, 2014-2015,’ Care Quality Commission, October 2015. http://www.cqc.org.uk/sites/default/files/20151013_CQC_State_of_Care_Report_WEB.pdf

- U.K. (England) | Department of Public Health – 15 October 2015 – ‘**End-of-life care: Response to Health Select Committee’s report.**’ The government’s response sets out what has been done recently to improve end-of-life care, including: 1) The 5 priorities for the care of the dying person; 2) The Care Quality Commission’s inspection regime; and, 3) Publication of the choice review and ambitions for palliative and end-of-life care. The Department of Health published response was produced by the government in partnership with National Health Service England, Health Education England and the Care Quality Commission. <https://www.gov.uk/government/publications/end-of-life-care-response-to-health-select-committees-report>
- U.K. (England) | National End-of-Life Care Intelligence Network – Accessed 15 October 2015 – ‘**New report: Developing data and intelligence for end-of-life care.**’ This report summarises the priorities for future improvements to end-of-life care data and intelligence that were identified by over 700 participants across nine strategic clinical networks. <http://www.endoflifecare-intelligence.org.uk/news/>
- U.K. (England) | National Council for Palliative Care – 13 October 2015 – ‘**Getting serious about prevention: enabling people to stay out of hospital at the end of life.**’ Healthcare commissioners and service providers need to do more to avoid unnecessary and costly hospital stays at the end of life and to enable dying people to be cared for in the place of their choice, according to a new report. The report, from the National Council for Palliative Care, Hospice UK and Marie Curie, warns that the National Health Service is paying too much to care for people approaching the end of life in hospitals, where they often don’t want or need to be. The report makes a number of recommendations for commissioners, service providers and health and social care staff. <http://www.ncpc.org.uk/news/getting-serious-about-prevention>
- U.K. (England) | *The Henley Standard* – 12 October 2015 – ‘**Don’t come here to die.**’ Patients who are terminally ill will not be allowed to go to the new Townlands Hospital to die. The hospital’s new rapid access care unit will be able to refer patients to one of up to 14 National Health Service beds at the neighbouring care home but refuse those who require end of life care. These patients will have to stay at home, be admitted to a hospice such as the Sue Ryder home in Nettlebed or travel to hospital beds in Wallingford or Abingdon. <http://www.henleystandard.co.uk/news/news.php?id=105049>

2015 Quality of Death Index: Chile

Chile ranks Latin America’s best for treatment of the dying

CHILE | *PanAm Post* (Miami, Florida) – 9 October 2015 – Chile is the best country in which to die in Latin America, according to a study conducted by the Economist Intelligence Unit (EIU). The EIU 2015 Quality of Death Index ... evaluates the quality of palliative care offered in 80 different countries. Coming in near the bottom of the list, the report ranks Guatemala and the Dominican Republic at 74th and 75th, respectively. Puerto Rico [46th], Peru [49th], and Colombia [68th] also received low scores. According to the

Cont.

report, local governments in these countries have introduced strategies for the development of palliative care – but, there are no clear mechanisms for its implementation. At the top of the list of regional countries, Chile [at 27th] is followed by Costa Rica [29th] and Panama [31st] as the best places to die in Latin America. The EIU highlights the Chilean government’s efforts to “incorporate palliative care into health care services and to develop policies for that purpose.” The report also notes that there are sufficient specialized palliative care professionals in Chile, as well as access to medication, yet the latter is “restricted by bureaucratic red tape.” <http://panampost.com/sabrina-martin/2015/10/09/chile-ranks-latin-america-best-for-treatment-of-the-dying/>

Noted in Media Watch, 9 February 2015, #396 (p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 February 2015 – ‘**Palliative care in Latin America from the professional perspective: A SWOT analysis.**’ A Strengths, Weaknesses, Opportunities, and Threats analysis may contribute to the identification of barriers and successful strategies. A total of 577 expert statements were provided. Among the strengths were integration into health systems and increasing number of professionals with palliative care (PC) training. Among weaknesses were lack of national PC programs, limited connection between policymakers and professionals, and barriers in the availability of opioids. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0120>

N.B. See also ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)] Spanish language edition: <http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20en%20Latinoamerica.pdf>; Portuguese: <http://cuidadospaliativos.org/uploads/2014/1/Atlas%20Portuques.pdf>; English: <http://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf>

2015 Quality of Death Index: South Africa

Signs of life in palliative care

SOUTH AFRICA | *Times Live* (Johannesburg) – 8 October 2015 – The index ... ranks South Africa 34th [of the 80 countries surveyed] – a six-place rise since the first report in 2010. Liz Gwyther, CEO of the Hospice Palliative Care Association of South Africa, said while great strides had been made, only 4% of people received palliative care at the end of their lives. This was because ... palliative care courses had started only recently at South African medical schools. Ironically, said Gwyther, South Africans on medical aid were unlikely to get good palliative care because doctors would rather treat a patient medically even if there was little chance of survival. <http://www.timeslive.co.za/thetimes/2015/10/09/Signs-of-life-in-palliative-care#>

Noted in Media Watch, 16 February 2015, #397 (p.7):

- SOUTH AFRICA | Voice of America News – 10 February 2015 – ‘**Palliative care severely neglected in South Africa.**’ Thousands don’t receive it, despite the country’s high death rates from infectious diseases, cancer and heart disorders. “Most of these people, because they’re poor, die in pain and despair, without receiving the benefits of palliative care that would have prolonged their lives and allowed them to live with a measure of joy and peace and even productivity in their last days,” said Rian Venter, director of West Gauteng Hospice. The government doesn’t fund palliative care; it’s almost exclusively available at privately funded institutions. <http://www.voanews.com/content/palliative-care-pt-5-south-africa/2636569.html>

Noted in Media Watch, 7 July 2014, #365 (pp.11-12):

- *SOUTH AFRICAN MEDICAL JOURNAL*, 2014;104(7):505-506. ‘**Paediatric palliative medicine.**’ Even though an underestimate, 800,000 children in South Africa are in need of generalised palliative care, and 300,000 in need of specialised palliative care.¹ It is estimated only 5% of children requiring specialised care were being reached. <http://www.samj.org.za/index.php/samj/article/view/8428>

1. ‘Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe.’ International Children’s Palliative Care Network and the United Nations Children’s Fund. November 2013. [Noted in Media Watch, 11 November 2013, #331 (p.15)] http://www.unicef.org/aids/files/Palliative_Care_Three_Country_Report_Nov13.pdf

2015 Quality of Death Index: India

India one of worst places to die: U.K. report

INDIA | *Outlook India* – 7 October 2015 – India has been ranked as one of the worst places in the world to die, but [the state of] Kerala [in South India] is praised for bucking the trend providing good end-of-life care... The Economic Intelligence Unit (EIU) report found ... developing countries like India [at 67th] at the bottom of the index of 80 countries [surveyed]. However, it praised Kerala's provision of palliative care for patients with serious illnesses [see p.45 of EIU report]. "With only 3% of India's population, the tiny state provides two-thirds of India's palliative care services," said the ... report. "The state has a formal palliative care policy in place (it is the only Indian state with such a policy) and its government provides funding for community-based care programmes," it said. Kerala's unique system revolves around the Neighbourhood Network in Palliative Care project, co-founded by Suresh Kumar with the aim of improving both accessibility and quality of end-of-life care. <http://www.outlookindia.com/news/article/india-one-of-worst-places-to-die-uk-report/915824>

Noted in Media Watch, 4 May 2015, #408 (p.9):

- *BMC RESEARCH NOTES* | Online – 30 April 2015 – '**Palliative care in South Asia: A systematic review of the evidence for care models, interventions, and outcomes.**' The search identified only 16 articles, reporting a small range of services. The 16 articles identified India as having greatest number of papers within South Asia, largely focused in the state of Kerala. Nepal and Pakistan reported a single study each, with nothing from Bhutan, Afghanistan, Maldives or Bangladesh. Despite the large population of South Asia, the authors found only 4 studies reporting intervention outcomes, with the remaining reporting service descriptions. The dearth of evidence in terms of palliative care outcomes, and the lack of data from beyond India, highlight the urgent need for greater research investment and activity to guide the development of feasible, acceptable, appropriate and effective palliative care services. <http://www.biomedcentral.com/content/pdf/s13104-015-1102-3.pdf>

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

End-of-life care in Sweden

Great variation between ICU physicians in the approach to making end-of-life decisions

ACTA ANAESTHESIOLOGICA SCANDINAVICA | Online – 8 October 2015 – End-of-life (EOL) decision-making in the intensive care unit (ICU) is difficult, but rarely practiced in simulated settings. The authors explored different strategies ICU physicians use when making EOL decisions, and whether attitudes towards EOL decisions differ between a small-group simulation setting and a large-group plenary setting. The study took place during a Scandinavian anaesthesiology and intensive care conference. The simulated ICU patient had a cancer disease with a grave prognosis, had undergone surgery, suffered from severe co-morbidities, and had a son present demanding all possible treatment. The participants were asked to make a decision regarding further ICU care. The authors presented the same case scenario in a plenary session with voting opportunities. There was great variation between ICU physicians in the approach to making EOL decisions, and large variations in their life expectancy estimates. Participants in the simulation group were more willing to admit and readmit the patient to the ICU, despite being more pessimistic towards life expectancies. Simulation can be used ... in EOL decision-making training. <http://onlinelibrary.wiley.com/doi/10.1111/aas.12640/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage>

N.B. Sweden was ranked 16th of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Cont.

Noted in Media Watch, 28 September 2015, #429 (p.10):

- *AUSTRALIAN CRITICAL CARE* | Online – 18 September 2015 – ‘**End-of-life decisions in the Intensive Care Unit (ICU): Exploring the experiences of ICU nurses and doctors – A critical literature review.**’ There were differences reported in the decision making process and collaboration between both doctors and nurses (which depended on physician preference or seniority of nurses), with overall accountability assigned to the physician. Role ambiguity, communication issues, indecision on futility of treatment, and the initiation of end-of-life discussions were some of the greatest challenges. [http://www.australiancriticalcare.com/article/S1036-7314\(15\)00079-X/abstract](http://www.australiancriticalcare.com/article/S1036-7314(15)00079-X/abstract)

2015 Quality of Death Index: The U.K.

The best place in the world to die: But could still be better

BRITISH MEDICAL JOURNAL | Online – 15 October 2015 – The ‘2015 Quality Of Death Index’ from the Economist Intelligence Unit once again ranks the U.K. as providing the best “quality of death” and “quality of palliative care” in a comparison of 80 countries.¹ The exemplary features of the highest scoring health economies include a national policy framework for palliative care, relatively high levels of healthcare expenditure, good training in specialist and generalist palliative care, financial subsidies (from the charitable sector in the case of the U.K.), availability of opioids, and public awareness of palliative care. However, even within the U.K., there are notable failings. The report highlights examples of poor symptom control at the end of life, poor communications with patients and families, and inadequate generalist and specialist out of hours services. <http://www.bmj.com/content/351/bmj.h5440>

1. ‘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

End-of-life care in Poland

The role of a pharmacist in a hospice: A nationwide survey among hospice directors, pharmacists and physicians

EUROPEAN JOURNAL OF HOSPITAL PHARMACY | Online – 13 October 2015 – Nineteen (61%) hospices collaborate with at least one pharmacist, who performs pharmaceutical services on the premises. Twelve (75%) pharmacists provide advice concerning medicines and 11 (69%) are involved in various roles related to procurement, dispensing and storage of drugs, as well as creating procedures for these activities. Despite pharmacists’ great level of involvement in drug policy, most of them are not members of the therapeutic team and they do not participate in ward rounds. Furthermore, the provision of clinical pharmaceutical services forms a minority of Polish hospital pharmacy practice. Although the role of a hospice-based pharmacist is focused on the provision of drugs, it should become more clinical, that is, more patient oriented. <http://ejhp.bmj.com/content/early/2015/10/13/ejhpharm-2015-000730.abstract>

Noted in Media Watch, 15 September 2014, #375 (p.12):

- *JOURNAL OF PHARMACY PRACTICE & RESEARCH* | Online – 5 September 2014 – ‘**Forging an advanced practice role for pharmacists in palliative care.**’ This paper describes the incorporation of an advanced practice pharmacist into a large metropolitan palliative care service. The focus of this appointment has been to develop strategic engagement with primary care providers to better support medicines management for people registered within a metropolitan palliative care service. <http://onlinelibrary.wiley.com/doi/10.1002/jppr.1008/abstract;jsessionid=8D6829FD12DB8A8CE5B1064C4EB93AA7.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

[Media Watch: Back Issues](#)

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

Breaking significant news: The experience of clinical nurse specialists in cancer and palliative care

EUROPEAN JOURNAL OF NURSING ONCOLOGY | Online – 11 October 2015 – Four themes emerged from the data: 1) Importance of relationships; 2) Perspective taking; 3) Ways to break significant news; and, 4) Feeling prepared and putting yourself forward. The findings revealed that highly experienced clinical nurse specialists (CNSs) felt confident in their skills in delivering significant news and they report using patient centred communication to build a trusting relationship so significant news was easier to share with patients. CNSs were aware of guidelines and protocols for breaking significant and bad news but reported that they used guidelines flexibly and it was their years of clinical experience that enabled them to be effective in disclosing significant news. Some areas of disclosure were found to be challenging in particular news of a terminal prognosis to patients who were of a younger age. [http://www.ejoncologynursing.com/article/S1462-3889\(15\)30029-6/abstract](http://www.ejoncologynursing.com/article/S1462-3889(15)30029-6/abstract)

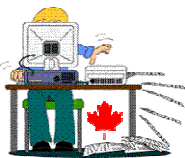
Related:

- *PATIENT EDUCATION & COUNSELING* | Online – 15 October 2015 – ‘**Relationships between personal attitudes about death and communication with terminally ill patients: How oncology clinicians grapple with mortality.**’ Clinicians [i.e., study participants] described three communication styles used with patients about death and dying: 1) Direct; 2) Indirect; or 3) Selectively direct. Most reported an acceptance of their mortality that was “conditional,” meaning that they could not fully know how they would respond if actually terminally ill. For many clinicians, caring for dying patients affected their outlook on life and death, and their own perspectives on life and death affected their approach to caring for dying patients. [http://www.pec-journal.com/article/S0738-3991\(15\)30091-4/abstract](http://www.pec-journal.com/article/S0738-3991(15)30091-4/abstract)

Report of the European Respiratory Society/European Cystic Fibrosis Society task force on the care of adults with cystic fibrosis

EUROPEAN RESPIRATORY JOURNAL | Online – 9 October 2015 – The improved survival in people with cystic fibrosis has led to an increasing number of patients reaching adulthood. This trend is likely to be maintained over the next decades, suggesting a need to increase the number of centres with expertise in the management of adult patients with cystic fibrosis. These centres should be capable of delivering multidisciplinary care addressing the complexity of the disease, in addition to addressing the psychological burden on patients and their families. Further issues that require attention are organ transplantation and end-of-life management. <http://erj.ersjournals.com/content/early/2015/10/08/13993003.00592-2015.abstract>

Cont. next page



[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>

Noted in Media Watch, 14 September 2015, #427 (p.10):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 8 September 2015 – ‘**Cystic fibrosis healthcare workers feel unprepared in providing suitable end-of-life care and desire more education: Results of a nationwide survey.**’ The majority of non-physician CF care providers [i.e., survey respondents] reported that they felt “somewhat” or “very” involved in palliative or end-of-life care in their current role. Yet, when asked whether they felt adequately prepared to deliver palliative and end-of-life care, only 18% reported that they were “fully prepared” and 45% felt that they were only “minimally” or “not” prepared. [http://www.cysticfibrosisjournal.com/article/S1569-1993\(15\)00201-5/abstract](http://www.cysticfibrosisjournal.com/article/S1569-1993(15)00201-5/abstract)

N.B. Selected articles, reports, etc., on end-of-life care for people living with cystic fibrosis noted in past issues of Media Watch are listed in this issue of the weekly report.

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

Palliative care: Continued progress, but gaps remain

HEALTH AFFAIRS | Online – 9 October 2015 – The Center to Advance Palliative Care and the National Palliative Care Research Center have been tracking growth in the prevalence of hospital palliative care (PC) services in the U.S. since 1998, and released its latest report of 2014 data on 1 October 2015.¹ The findings suggest continued growth in the prevalence of hospital PC programs, especially in the largest hospitals that serve the majority of U.S. patients. Gaps in access persist, however, associated with geography, hospital ownership, hospital size, and other hospital characteristics. Steady growth in the number of hospital PC programs has resulted in near universal access to PC in hospitals with more than 300 beds (90%) as well as in U.S. teaching (87%) and medical school-associated hospitals (96 %). Hospitals in these categories train the next generation of clinicians and, in combination, serve over 50% of all Medicare beneficiaries. At the end of 2014, 67% of U.S. hospitals with more than 50 beds provide PC services, up from 15% in 1998 and 53% in 2006. Disparities in access to PC have persisted since these data were first tracked in 1998. As in other aspects of health care, where one lives matters. Hospitals (referred to in this report as those with more than 50 beds) in the East South Central (42%) and West South Central (43%) parts of the U.S. are markedly less likely to have a PC program as compared to New England (88%), Pacific (77%) and Mid-Atlantic (77%) states. Hospital ownership is also a strong predictor of

access to PC. Not-for-profit (77%) and public (59%) hospitals are significantly more likely than for-profit (23%) hospitals to have PC programs. Given the evidence PC care improves value for the highest-risk highest-cost patients, efforts to improve and standardize access to it should be prioritized. Despite growth in the prevalence of hospital PC services over the last 20 years, it is important to note that the presence of a PC program in a hospital is not equivalent to actual receipt of PC by patients who can benefit. <http://healthaffairs.org/blog/2015/10/09/palliative-care-continued-progress-but-gaps-remain/>

The myth regarding the high cost of end-of-life care

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 15 October 2015 – the authors conducted an analysis for the Institute of Medicine Committee on Approaching Death using existing national data sets, peer-reviewed literature, and published reports. They estimated that in 2011, among those with the highest costs, only 11% were in their last year of life, and approximately 13% of the \$1.6 trillion spent on personal health care costs in the U.S. was devoted to care of individuals in their last year of life. Public health interventions to reduce health care costs should target those with long-term chronic conditions and functional limitations.

<http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2015.302889>

1. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. [Noted in Media Watch, 5 October 2015, #430 (p.14)] <https://reportcard.capc.org/>

N.B. The U.S. was ranked 9th of the 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Knowledge and uncertainty, circulation of experiences: Interdisciplinarity in paediatric palliative care

MÉDECINE PALLIATIVE | Online – 9 October 2015 – The author questions the position of the professionals involved in palliative care in order to discuss interdisciplinarity in paediatric palliative care, by focusing on: 1) The plurality of expertise facing a symptom of the end of life; 2) The contribution and place of a paediatric palliative care team in the reflection with other teams of care providers; and, from there, 3) Verbal exchanges would be possible and would always provide a space full of presence and meaning. If “interdisciplinarity is the consideration of different knowledge, by trying to articulate them towards a common goal” [Depaulis, 2013]... the following are required: 1) Sufficient knowledge and certainty to be considered expert in palliative care; and, 2) Sufficient uncertainty and lack of knowledge to be open to the views of others, because we need them to work with different specialties in complex and often long path. <http://www.sciencedirect.com/science/article/pii/S163665221500121X>

N.B. French language article.

France was ranked 10th of the 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Noted in Media Watch, 4 November 2013, #330 (p.13):

- *PEDIATRICS*, 2013;132(5):966-972. ‘**Pediatric palliative care and hospice care commitments, guidelines and recommendations.**’ Guidelines and recommendations [in the American Academy of Pediatrics Policy Statement] include ensuring all large health care organizations serving children with life-threatening conditions have dedicated interdisciplinary pediatric palliative care and pediatric hospice care teams, which should develop collaborative relationships between hospital- and community-based teams that – 1) PPC-PHC be provided as integrated multimodal care and practiced as a cornerstone of patient safety and quality for patients with life-threatening conditions; 2) PPC-PHC teams should facilitate clear, compassionate and forthright discussions about medical issues and the goals of care and support families, siblings, and health care staff; 3) PPC-PHC be part of all pediatric education and training curricula, be an active area of research and quality improvement, and exemplify the highest ethical standards; and, 4) PPC-PHC services be supported by financial and regulatory arrangements to ensure access to high-quality end-of-life care by all patients with life-threatening and life-shortening diseases. <http://pediatrics.aappublications.org/content/132/5/966.full.pdf+html>

Related:

- *CRITICAL CARE NURSE*, 2015;35(6). ‘**Caring for pediatric patients’ families at the child’s end of life.**’ The practical strategies outlined in this article may enable nurses to confidently communicate with the child’s family during the dying process and after the child’s death, while providing a profound and meaningful experience for the family. A bereavement program that supports the hospital staff’s connection with the family after the child’s death attends to the family’s grief journey and acknowledges the value of their child’s life and unique legacy. <http://www.aacn.org/wd/Cetests/media/C156p.pdf>

N.B. ‘Children’s Palliative Care & Human Rights,’ Open Society Foundations (New York, NY), 8 October 2015. This fact sheet examines the global need for children’s palliative care, the recognition of children’s palliative care under international human rights laws, and what steps governments should take to promote, protect, and ensure access to care. <https://www.opensocietyfoundations.org/sites/default/files/childrens-palliative-care-human-rights-20151008.pdf>

Palliative care in the U.S. Military Health System

MILITARY MEDICINE, 2015;180(10):1024-102. Currently, the Military Health System (MHS) has only two palliative care teams across all of its 56 facilities: one at Walter Reed National Military Medical Center and the other at Madigan Army Medical Center. Although the MHS is a leader in trauma and point of injury care, we are lagging far behind the Veterans Health Administration (VHA) and the civilian sector in provid-

Cont.

ing essential palliative care services to our patients. In May 2014, the Secretary of Defense ordered a comprehensive review of the MHS, which was published in August 2014. In brief, the MHS includes over 50 inpatient medical treatment facilities and provides care for 9.6 million beneficiaries, spending more than \$50 billion per year. Approximately 22% of the MHS beneficiaries are over the age of 65, which parallels the civilian sector. The review focused on issues including quality of care and patient satisfaction in hopes of providing direction on how to improve the MHS. Although not mentioned in the report, providing inpatient and outpatient palliative care services is one important way to improve the MHS. <http://publications.amsus.org/doi/full/10.7205/MILMED-D-15-00047>

Toward evidence-based end-of-life care

NEW ENGLAND JOURNAL OF MEDICINE | Online – 14 October 2015 –The disquieting patterns of end-of-life care in the U.S. have been well documented. In the last month of life, one in two Medicare beneficiaries visits an emergency department, one in three is admitted to an intensive care unit, and one in five has inpatient surgery. But one of the most sobering facts is that no current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence that the Food & Drug Administration would require to approve even a relatively innocuous drug. For example, more than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System's Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. <http://www.nejm.org/doi/full/10.1056/NEJMp1509664>

Noted in Media Watch, 5 October 2015, #430 (p.10):

- *CANCER BIOLOGY & MEDICINE*, 2015;12(3):1930200. '**Reality of evidence-based practice in palliative care.**' The complex multi-morbidity of end-of-life care involves considerations of the patient's physical, psychological, social and spiritual needs. In addition, the field of palliative care covers a heterogeneous group of chronic and incurable diseases no longer limited to cancer. Adequate sample sizes can be difficult to achieve, reducing the power of studies and high attrition rates can result in inadequate follow up periods. This review uses examples of the management of cancer-related fatigue and death rattle to demonstrate the current state of evidence-based medicine (EBM) in palliative care. The future of EBM in palliative care needs to be as diverse as the patients who ultimately derive benefit. <http://www.cancerbiomed.org/index.php/cocr/article/view/871>

Noted in Media Watch, 7 September 2015, #426 (p.12):

- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):133-140. '**Evidence-based palliative care 13 years on: Has anything changed?**' There is a paucity of data on whether interventions in individual palliative care units are evidence based. Results show the evidence base for interventions in palliative care continues to evolve, but that there are still areas for which further high-quality studies are needed. <http://search.proquest.com/openview/4d455887ccea4b6127fde6e347f82e/1?pq-origsite=gscholar>

Expressions of loss and separation

Teenagers' reasoning about a parent's recent death in cancer

PALLIATIVE & SUPPORTIVE CARE | Online – 14 October 2015 – Importantly, all teenagers appreciated participating in the interviews. Some had not previously talked in such depth about this with anyone, while others had more open communications within their families and with others. Their parent's death was the worst thing that could happen, but they still expressed the feeling it had been a relief for both the ill parent and themselves. The death had relieved the parent from suffering and a life with severe illness. Many of the teenagers empathized with the surviving parent's grief and worried about him or her as well as the

Cont.

entire home situation. As a consequence, the teenagers did not show their grief, as they did not want to burden the grieving parent. Seeing the parent grieving could lead to feelings of loneliness and hopelessness and the support they needed was not there for them. Nevertheless, some teenagers could grieve together with the surviving parent in common understanding and with openness. A tentative conclusion is the teenagers who were more likely to talk and grieve together with their surviving parent coped better with their situation than teenagers who did not. Parentally bereaved teenagers tend to take on a responsibility to support the grieving parent, when it is they themselves who need and should receive support. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10004625&fulltextType=RA&fileId=S1478951515001054>

Related:

- *BMC PALLIATIVE CARE* | Online – 14 October 2015 – ‘**Exploring barriers to assessment of bereavement risk in palliative care: Perspectives of key stakeholders.**’ Assessment following the patient’s death presented substantial barriers, directing assessment to the pre-death period. Four themes were identified relating to issues in need of consideration to develop a risk assessment model: 1) Systems of care encompassing logistics of contact with caregivers; 2) Gate keeping; 3) Conflation between caregiver stress, burden and grief; and, 4) A way forward. These group discussions provide a data-driven explanation of the issues affecting bereavement risk assessment in palliative care settings. <http://www.biomedcentral.com/content/pdf/s12904-015-0046-7.pdf>
- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 12 October 2015 – ‘**Hospice services for complicated grief and depression: Results from a national survey [in the U.S.]**’ Fifty-five percent of hospices provided screening for complicated grief (CG) and depression and access to bereavement therapy, 13% provided screening but not access to bereavement therapy, 24% provided access to bereavement therapy, but not screening, and 8% neither screened nor provided access to bereavement therapy. Hospices with 100 patients per day or more were significantly more likely to provide screening and access to bereavement therapy. Hospices appear to have high capacity to provide screening for CG and depression and to deliver group and individual therapy, but data are needed on whether screeners are evidence based and whether therapy addresses CG or depression specifically. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13656/abstract>

The positioning of palliative care in acute care

PALLIATIVE & SUPPORTIVE CARE | Online – 12 October 2015 – The positioning and meaning of palliative care within the healthcare system lacks clarity which adds a level of complexity to the process of transition to palliative care. The key findings [of this study] depict a scope of palliative care that was uncertain for users of the system and for those working within the system. Becoming “palliative” is not a defined event; nor is there unanimity around referral to a palliative care service. As such, ambiguity and tension contribute to the difficulties involved in negotiating the transition to palliative care. Findings point to uncertainty around the scopes of practice in the transition to palliative care. The challenge in the transition process lies in achieving greater coherency of care within an increasingly specialized healthcare system. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10000575&fulltextType=RA&fileId=S1478951515000917>

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>

Cont.

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

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – ‘**Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review.**’ Papers highlighted the many and varied potential threats to dignity for people with palliative care needs ... including symptom control and existential distress, approaches and models in care provision, and healthcare settings and design. <http://pmj.sagepub.com/content/early/2015/03/20/0269216315575681.abstract>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 October 2015 – ‘**Unexpected death on an acute palliative care unit.**’ While most deaths in patients with advanced cancer are expected, no data are available on unexpected death. This event can be really stressful for physicians who are unable to anticipate, prevent or discuss unexpected death, and for relatives who are not ready for such an acute emotional burden, despite previous good communication about the short-term prognosis. There is the need for more information, particularly in the setting of an acute palliative care unit where most patients are discharged to follow different therapeutic pathways, including continuing oncologic treatment, home care, or hospice. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00530-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00530-8/abstract)

End-of-life care in Italy

Advance directives in Italy: A goal not yet reached but already passed?

RECENTI PROGRESSI IN MEDICINA, 2015; 106(10):479-85. Advance directives (ADs) have been adopted in many countries to defend patient autonomy. In Italy, in the past, this topic gave rise to a heated debate involving philosophers, theologians, and politicians. In 2009, the government presented a bill of law on ADs firmly criticized from a scientific, moral and juridical point of view because the bill's content is against the principles of [the] Italian Constitution, Italian Code of Medical Ethics, Oviedo Convention, and official statements of many scientific societies. Although the bill has passed the Low Chamber it lies, even since, in the Senate, lacking in regard any agreement among the political parties. The purpose of this article is to highlight that, in our country, patients, relatives and doctors deserve a law not only related to the specific topic of ADs, but – as in other European countries (Germany, Spain, France, U.K.) – aimed to deal with the complex issue of end-of-life care as a whole. This law should take into account the sound evidence existing in regard to the four fundamental principles supporting the best scientific and ethical approaches to the end-of-life issues: 1) Shared decision making process between doctors and patients/relatives; 2) Rejection of dying process marked by the suffering; 3) Withholding/withdrawing futile treatments together with palliative sedation as two crucial

contributions to suppress the patient suffering and pain; and, 4) Clear-cut difference between these clinical/ethical options and euthanasia. http://www.recentiproggressi.it/articoli.php?archivio=yes&vol_id=2032&id=22078

Early palliative care in advanced oncologic and non-oncologic chronic diseases: A systematic review of literature

REVIEWS ON RECENT CLINICAL TRIALS | Online – Accessed 15 October 2015 – Twelve papers reporting the data of 9 trials were considered eligible and included into the analysis. Two non-randomized trials were also included into the selection because of the methods used by the authors. The early, simultaneous approach was reported to improve quality of life in two out of 7 papers, symptoms control in 1 out of 5 papers, overall survival in 2 out of 3 papers, quality of care in 5 out of 8 papers, patients' or caregivers' satisfaction in 3 out of 4 papers; and to reduce the costs of assistance in 2 out of 3 papers. Early palliative care improves the main outcomes of the assistance in patients with advanced oncologic and non-oncologic chronic diseases. The available data are probably enough to consider early palliative care a novel standard of care in these groups of patients. <http://benthamscience.com/journals/reviews-on-recent-clinical-trials/article/135802/>

N.B. Italian language article.

Cont.

Italy was ranked 21st of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

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

- *INTENSIVE CARE MEDICINE* | Online – 2 August 2012 – '**Regulation of advance directives in Italy: A bad law in the making.**' In Italy, the role of ADs has recently been the subject of heated debate involving political parties and the Roman Catholic Church. In February 2009, the conservative government coalition presented a bill of law on this issue. It has been passed by the Low Chamber and is now being discussed in the Senate. This article highlights any possible bill's contradiction with Italian Constitution, Italian Code of Medical Ethics and Oviedo Convention contents, relevant for intensivists. http://icmjournal.esicm.org/journals/abstract.html?v=0&j=134&i=0&a=2656_10.1007_s00134-012-2656-3&doi

Their memorials live after them: Learning from a village graveyard

RURAL THEOLOGY, 2015;13(2):113-123. This study offers a close examination of the memorial stones and memorial inscriptions in Amberley graveyard [Gloucestershire, England] from the eighteenth, nineteenth and twentieth centuries in order to address two research questions. The first question explores the significance of the inscriptions themselves. The second question explores the further insights that can be gained into the individuals there commemorated and into the history and life of the community itself. <http://www.maneyonline.com/doi/abs/10.1179/1470499415Z.00000000049>

Noted in Media Watch, 7 February 2011, #187 (p.6):

Of related interest:

- U.K. | *Daily Mail* – 5 February 2011 – '**Modern face of mourning: The colourful "poundland" shrines across Britain that councils are trying to wipe out.**' All my life I've loved to walk in graveyards, reading tombstones commemorating long-dead grandfathers, mothers, sons, grief expressed in the timeless symbolism of carved angels, broken urns, cherub heads, flowers and hourglasses. I believe it useful to meditate on the quiet dignity of the inscriptions – the love expressed in a simple, well-tended grave is a fitting memorial to life and loss. What a contrast to look at grief in modern Britain. <http://www.dailymail.co.uk/news/article-1353815/Colourful-poundland-graveyard-shrines-British-councils-trying-wipe-out.html>

Attributes and weights in health care priority setting: A systematic review of what counts and to what extent

SOCIAL SCIENCE & MEDICINE | Online – 9 October 2015 – In most societies resources are insufficient to provide everyone with all the health care they want. In practice, this means that some people are given priority over others. On what basis should priority be given? In this paper the authors are interested in the general public's views on this question. They set out to synthesis what the literature has found as a whole regarding which attributes or factors the general public think should count in priority setting and what weight they should receive. A systematic review was undertaken ... to address these questions based on empirical studies that elicited stated preferences from the general public. While there is heterogeneity, results suggest the young are favoured over the old, the more severely ill are favoured over the less severely ill, and people with self-induced illness or high

socioeconomic status tend to receive lower priority. In those studies that considered health gain, larger gain is universally preferred, but at a diminishing rate. The review highlights considerable heterogeneity in both methods and results. <http://www.sciencedirect.com/science/article/pii/S0277953615301477>

Extract from *Social Science & Medicine* article

Evidence from the small number of studies that explored preferences over different components of health gain suggests life extension is favoured over quality of life enhancement; however, this may be reversed at the end of life. The majority of studies that investigated end-of-life care found weak/no support for providing a premium for such care.

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 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>

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net