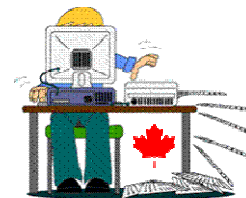


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to [U.S.](#) and 'Why nurses should lead efforts to overcome palliative care consultation barriers' (p.2), in *Forbes*.

Canada

Canada needs to find solution to serious regional health inequalities

ONTARIO | *The Globe & Mail* – 18 October 2015 – Canadians, on average, are fairly healthy. Life expectancy continues to rise, fewer of us smoke and more of us are becoming physically active. That's the problem with averages. They are misleading. In Ontario, for instance, average life expectancy is 81.5 years – a pretty decent number. It's only when you look beyond the big picture that you see the cracks. The life expectancy of a baby born in Brampton is 84. A child born the same day in Sault Ste. Marie, less than 700 kilometres away, is 79. Another telling metric is potentially avoidable deaths – how many people likely died unnecessarily because they didn't receive proper care after a heart attack, weren't vaccinated against a disease or suffered another preventable or treatable ailment. According to the Ontario average, 163 in 100,000 people die from a potentially avoidable death a year. But in reality, the numbers vary wildly across the province, from a low of 114 per 100,000 in cities such as Richmond

Hill and Vaughan, to a high of 258 in Thunder Bay, Marathon, Dryden, and the surrounding area. These numbers are from a report ... by Health Quality Ontario, a provincial agency mandated to improve the province's health care system.¹ But this isn't just an Ontario problem. Across the country, the situation is much the same: startling, persistent regional health inequalities that, quite literally, are sickening and killing countless Canadians before their time. <http://www.theglobeandmail.com/life/health-and-fitness/health/canada-needs-to-find-solution-to-serious-regional-health-inequalities/article26847899/>

Specialist Publications

'Quality of end-of-life cancer care in Canada: A retrospective four-province study using administrative health care data' (p.9), in *Current Oncology*.

1. 'Measuring Up: A Yearly Report on How Ontario's Health System is Performing,' Health Quality Ontario, October 2015. Health Quality Ontario is the operational name for the Ontario Health Quality Council, a provincial government agency. [Noted in Media Watch, 19 October 2015, #432 (p.1)] <http://www.hqontario.ca/portals/0/Documents/pr/measuring-up-2015-en.pdf>

U.S.A.

2015 State-By-State Report Card on Access to Palliative Care

Palliative care in California: Improving, but not everywhere

CALIFORNIA | *The Contra Costa Times* (Walnut Creek) – 22 October 2015 – California's system for handling serious and end-of-life care is improving, but more services are needed to meet patient demand, according to two major reports... A growing number of the state's hospitals ... are offering palliative care to comfort patients living with serious illnesses such as cancer, heart disease and dementia, protecting them from futile, often painful medical treatments, the reports say. Seventy-four percent of hospitals in the state offer some type of palliative care program, compared to a national average of 66%. In 2008, only 56% of California hospitals had such programs, according to one report...¹ But a closer look shows great geographic variability, with most care centered at large and non-profit facilities in urban parts of the state, says the second report...² Specifically, the state needs more specialists and certification programs, as well as reliable funding and better standardization of care... An estimated 14 million Californians

suffer from chronic illness; of these, seven million struggle with several chronic diseases. http://www.contracostatimes.com/breaking-news/ci_29009385/palliative-care-california-improving-but-not-everywhere

Specialist Publications

'Evolving the palliative care workforce to provide responsive, serious illness' (p.8), in *Annals of Internal Medicine*

'Long term care nurses' knowledge and perceived competency of palliative care' (p.10), in *Doctor of Nursing Practice Technical Reports No. 2*

'High intensity of end-of-life care among adolescent and young adult cancer patients in the New York State Medicaid Program' (p.15), in *Medical Care*.

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/>
2. 'Dying in California: A Status Report on End-of-Life Care,' California HealthCare Foundation and the Coalition for Compassionate Care, October 2015. <http://www.chcf.org/publications/2015/10/dying-calif-status-report>

Why nurses should lead efforts to overcome palliative care consultation barriers

FORBES | Online – 21 October 2015 – A recent report revealed palliative care (PC) patients and their families face a variety of challenges when attempting to discuss care options with consultants who can properly advise.¹ Being able to provide patients with PC enables clinicians to package psychological, spiritual, goal-setting and decision-making support into a single service-based initiative designed to supply comfort. Patients with life-threatening illnesses and their families can benefit from this kind of specialized care by taking advantage of early initiation of comfort-focused treatment goals, decreased length of stay, reduced costs of care without an increase in mortality and continuity of care. The article ... outlines nursing-specific strategies on how hospitals can better integrate PC into everyday critical care. It encourages the widespread adoption of PC services. The report noted there are two main reasons (or barriers) for health care providers not offering consultations to patients who could potentially qualify for this specific type of end-of-life planning: misunderstandings about PC, not having agreed-upon criteria for referral. <http://www.forbes.com/sites/cjarlotta/2015/10/21/why-nurses-should-lead-efforts-to-overcome-palliative-care-consultation-barriers/>

1. 'Overcoming Barriers to Palliative Care Consultation,' *Critical Care Nursing*, 2015;35(5):44-52. <http://ccn.aacnjournals.org/content/35/5/44.full>

Cont.

Noted in Media Watch, 6 October 2014, #378 (p.10):

- *BMJ OPEN* | Online – 30 September 2014 – ‘**The role and significance of nurses in managing transitions to palliative care: A qualitative study.**’ This study explored hospital-based nurses’ accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions. Four themes emerged: 1) Professional dynamics and the roles played by nurses in initiating the transition to palliative care; 2) Value of nurses’ informal interactions in timely and effective transitions; 3) Emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility; and, 4) Emotional burden experienced by nurses within this clinical context. <http://bmjopen.bmj.com/content/4/9/e006026.abstract?sid=e6e364a4-f32d-43bb-9e7e-28e212e20cf0>

Noted in Media Watch, 29 September 2014, #377 (p.14):

- *QUALITY HEALTH RESEARCH* | Online – 22 September 2014 – ‘**Negotiating futility, managing emotions: Nursing the transition to palliative care.**’ Nurses play a pivotal role in caring for patients during the transition from life-prolonging care to palliative care ... an area of nursing prone to emotional difficulty, interpersonal complexity, and interprofessional conflict ... situated within complex social dynamics, including those related to establishing and accepting futility and reconciling the desire to maintain hope. <http://qhr.sagepub.com/content/early/2014/09/22/1049732314553123.abstract>

Noted in Media Watch, 15 July 2013, #314 (p.6):

- *BRITISH JOURNAL OF COMMUNITY NURSING*, 2013;18(7):358. ‘**Empathy in palliative care: A biological inheritance.**’ Community nurses play a crucial role in the provision of palliative care throughout the U.K. Among many other important components of their role, empathy, which involves providing emotional care and support to dying patients and those important to them, is a central and sensitive aspect of their work. Empathy is a critical component of the social intelligence needed for such support and is popularly associated with the ability to identify with the emotional experiences of others. <http://www.magonlinelibrary.com/doi/10.12968/bjcn.2013.18.7.358>

Here is how much it costs to die in America

NEW YORK DAILY NEWS | Online – 21 October 2015 – A survey of 150 funeral homes in 10 cities reveals prices for the same funeral services within the same area varied by at least 100% and often by more than 200%. The huge price gaps are due to something very simple (and very American): A “lack of effective competition,” noted Stephen Brobeck, Consumer Federation of America’s Executive Director, in the report.¹ <http://www.nydailynews.com/news/national/costs-die-america-article-1.2405900>

1. ‘New National Survey Documents Funeral Home Failure to Disclose Prices That Vary Widely,’ Consumer Federation of America, October 2015. http://consumerfed.org/press_release/funeral-homes-charge-a-wide-range-of-prices-but-most-fail-to-disclose-these-prices-adequately-or-even-at-all-according-to-a-new-national-survey/

Did hospice know patients weren’t dying? Jurors will decide

GEORGIA | *The Atlanta Journal-Constitution* – 20 October 2015 – An eye-popping \$200 million is at stake when jurors ... take up the question of whether a national hospice company knowingly defrauded taxpayers by billing Medicare for patients who weren’t dying. Former employees of AseraCare hospices in Georgia, Alabama and Wisconsin blew the whistle on the company, claiming that they were pressured to admit patients who weren’t terminally ill. Already, Alabama jurors have agreed that the Medicare claims were false for 104 of 121 patients whose cases they considered. Now, the jurors must decide, essentially, if the company knew the claims were false or didn’t care to figure that out. If the jury decides against the company, it is liable for three times the damages the federal government sustained – potentially the biggest ever penalty for a hospice company. The whistle-blowers would get some of that money. Justice Department attorneys called the company’s claims “reckless and repeated (yet lucrative) business practices that resulted in the loss of millions of taxpayer dollars.” The department also has pointed out that when patients go on hospice, they give up regular medical care that might cure their illnesses. <http://investigations.blog.ajc.com/2015/10/20/did-hospice-know-patients-werent-dying-jurors-will-decide/>

As people lay dying, vivid dreams or visions bring comfort to nearly all, Buffalo research suggests

STATE OF NEW YORK | *The Buffalo News* – 20 October 2015 – As the end of life approaches, people experience dreams in which they see dead relatives waiting for them or describe preparing to take a trip. Deceased friends visit and tell them everything will be OK. It's a mysterious phenomenon reported since ancient times and given little attention by science. But a project in Buffalo indicates the experiences can be profoundly meaningful to patients and warrant more attention from doctors. Rather than dismiss dreams and visions, or try to stop them with drugs, the research strongly suggests that caregivers understand their significance. Among the key takeaways of the research: Dreams and visions are common among the dying, they're so vivid they feel real, and they appear to be part of a process of coming to terms with death. <http://www.buffalonews.com/city-region/medical/as-people-lay-dying-vivid-dreams-or-visions-bring-comfort-to-nearly-all-buffalo-research-suggests-20151020>

Representative sample of articles on deathbed experiences noted in past issues of Media Watch:

- *PSYCHOLOGY & PSYCHOTHERAPY: THEORY, RESEARCH & PRACTICE* | Online – 16 July 2015 – **'Experiences of continued presence: On the practical consequences of "hallucinations" in bereavement.'** The authors' [17 bereaved] informants heard voices of the deceased, saw their images, felt their touch, and sometimes felt their presence unspecified in any of the senses. Analysis revealed that experiences of continued presence were meaningfully connected to the immediate environments in which they happened, but also to the personal histories of the bereaved. The narratives reveal helpful and destructive potentials of these experiences. [Noted in Media Watch, 27 July 2015, #420 (p.16)] <http://onlinelibrary.wiley.com/doi/10.1111/papt.12067/abstract;jsessionid=78A3675DEA524782E45F4480ED8319A5.f03t02?userIsAuthenticated=false&deniedAccessCustomisedMessage=>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 March 2015 – **'Deathbed phenomena reported by patients in palliative care: Clinical opportunities and responses.'** The authors systematically reviewed the literature on deathbed phenomena (DBP), and provide suggestions for a clinical response to dying patients' recounts of these hard-to-explain phenomena. Reported prevalence of DBP ranged from 24-51%, with common themes described. Distinguishing between DBP and hallucinations was discussed, requiring very different clinical responses. [Noted in Media Watch, 6 April 2015, #404 (p.7)] <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.3.117>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Washington Post* – 19 October 2015 – **'Californians gained the right to die, but the terminally ill who wanted it have to wait.'** Bills passed in special session are governed by special rules: They can't take effect until 91 days after the session ends. And the session will not formally end until at least January, when lawmakers reconvene. That means the law cannot take effect until April at the earliest. Opponents of the law have until early January to collect enough signatures to force a referendum to repeal it. That would put the law in limbo until voters speak in November 2016. https://www.washingtonpost.com/national/californians-gained-the-right-to-die-but-the-terminally-ill-who-wanted-it-have-to-wait/2015/10/19/1556eab2-7360-11e5-8d93-0af317ed58c9_story.html
- STATE OF NEW YORK | *The New York Post* – 19 October 2015 – **'Terminally ill New Yorkers lose lawsuit to overturn assisted-suicide ban.'** A Manhattan judge has tossed a lawsuit by three terminally-ill New Yorkers and five doctors who wanted to overturn a law that makes assisted suicide a felony. State civil judge Joan Kenney ruled that while she was sympathetic to the patients' plight, the U.S. Supreme Court has already found that New York state laws prohibiting assisted suicide are not a violation of civil rights. The patient plaintiffs ... are appealing. <http://nypost.com/2015/10/19/terminally-ill-new-yorkers-lose-lawsuit-to-overturn-assisted-suicide-ban/>

[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.17.

International

End-of-life care in Australia

“Be there and be available” when someone is dying: Caring at end-of-life palliative care report

AUSTRALIA | *The Sydney Morning Herald* – 20 October 2015 – A new report ... has found that people are really only able to die at home if the community pulls together to help them achieve their wish.¹ The five-year research project ... found government healthcare services often contribute little and are sometimes even a hindrance. Study leader Debbie Horsfall, who interviewed over 200 carers and care providers, said Australians had access to excellent quality of end-of-life care, but it was disproportionately situated in hospitals and similar facilities when up to 80% of people wanted to die at home. “Australia does really well in terms of quality, but the quality is in the wrong place,” she said. “There are never going to be enough resources ... but I think if we re-orientate what we are doing that will help.” She said when a person was lucky enough to access care it could make all the difference. But often health services were not geared to help. Often then it came down to whether or not a family was surrounded by a community support network. <http://www.smh.com.au/national/health/be-there-and-be-available-when-someone-is-dying-caring-at-end-of-life-palliative-care-report-20151020-gkdg6i.html>

1. ‘End of Life at Home: Co-Creating an Ecology of Care,’ Research Report, Western Sydney University, May 2015. http://www.smh.com.au/cqstatic/gkdmty/EndofLife_Report_Final_14Sept.pdf

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, October 2015. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Global Commission on Drug Policy

Most of world’s population have no access to pain-relieving drugs: Report

INDIA | *The Times of India* – 19 October 2015 – Around three-fourths of the world’s population have no access to any pain-relieving drugs...¹ This means most people in late stages of cancer and/or enduring severe forms of acute or chronic pain simply do not have access to pain relief, despite these medicines being included in the WHO Model List of Essential Medicines.² 99% of the world’s supply of morphine is consumed by 17% of the global population with consumption primarily concentrated in the global north. <http://timesofindia.indiatimes.com/home/science/Most-of-worlds-population-have-no-access-to-pain-relieving-drugs-Report/articleshow/49455413.cms>

1. The Global Crisis of Avoidable Pain: The Negative Impact of Drug Control on Public Health, Global Commission on Drug Policy, October 2015. <http://www.globalcommissionondrugs.org/reports/>
2. WHO Model List of Essential Medicines, August 2015. <http://www.who.int/medicines/publications/essentialmedicines/en/>

Specialist Publications

‘Identification of challenges to the availability and accessibility of opioids in twelve European Countries: Conclusions from two Access to Opioid Medication in Europe (ATOME) six-country workshops’ (p.12), in *Journal of Palliative Medicine*.

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>

Welfare system failing thousands of its most vulnerable claimants, MPs told

U.K. | *The Guardian* – 19 October 2015 – Britain’s social security system is failing thousands of its most vulnerable claimants, with delays and errors in processing welfare benefits leaving many sick and disabled people, including some with cancer, for months without income. MPs have been told that long waits for benefit payments are the single biggest cause of food bank use and are forcing claimants into debt and “survival crime” such as shoplifting, as well as triggering stress, mental illness and homelessness. Charities and local authorities say the millions of pounds they spend providing advice and help to vulnerable individuals left in crisis by avoidable benefit delays is unsustainable, and they cannot “shore up” the system’s failings indefinitely. The claims are contained in over sixty submissions by frontline charities, food banks, councils, housing associations, private landlords, academics and individuals to a Commons select committee inquiry on benefit delivery...
<http://www.theguardian.com/politics/2015/oct/19/welfare-system-failing-thousands-vulnerable-claimants-mps-long-waits-payments>

Extract from *The Guardian* report

Care Plus, a community health social enterprise, which delivers end-of-life care in Lincolnshire, says the system often fails terminally ill claimants. “People with a cancer or a palliative care diagnosis should be fast tracked, but in reality this is not happening,” it said.

Related:

- U.K. (England) | *The Guardian* – 21 October 2015 – **‘More old people in hospital as community care “starved” – Age UK.**’ Cuts to social care services in recent years have left more than a million people over 65 in England struggling on their own to undertake at least one basic task that is vital to their wellbeing, such as washing, getting dressed, and feeding themselves. The report¹ ... shows that large numbers of older people are being admitted to hospital as medical emergencies because their illness has not been properly managed at home. <http://www.theguardian.com/society/2015/oct/21/more-old-people-in-hospital-as-community-care-starved-age-uk>

1. ‘The Health and Care of Older People 2015,’ Age UK, October 2015. http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Briefing-The_Health_and_Care_of_Older_People_in_England-2015.pdf?dtrk=true

End-of-life care in England

Is London the worst place to die?

U.K. (England) | Pan-London End of Life Alliance – 19 October 2015 – 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.¹ However, the quality of EOLC received in London currently under performs against national averages.² Just four out of thirty-three Clinical Commissioning Groups in London scored above the national average for EOLC quality indicators. There is considerable variation in the quality of care within London – with Islington the second best Clinical Commissioning Group and Newham the worst. The London Assembly Health Committee will examine end-of-life care in the capital and barriers certain groups face.³
<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
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>

End-of-life care in Singapore

End-of-life care at Accident & Emergency for the terminally ill

SINGAPORE¹ | *The Straits Times* – 18 October 2015 – A palliative care protocol was first introduced at the National University Hospital in June last year and since then four more hospitals have followed suit. Tan Tock Seng Hospital started using such a protocol in January. A palliative care team is alerted when a patient with advanced stage cancer or organ failure arrives at the emergency department. The team is also notified if a patient is suffering from extreme pain, breathlessness and other symptoms associated with dying. The aim is to shorten the wait for medicine, such as morphine which, under previous rules, was given only after the patient was warded – which could take 12 hours. The new procedures also ensure that patients' end-of-life wishes are fulfilled. <http://www.straitstimes.com/singapore/health/end-of-life-care-at-ae-for-the-terminally-ill>

1. Singapore was ranked 12th of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit (EIU), October 2015. The EIU report was commissioned by The Lien Foundation of Singapore. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | TVNZ News (Auckland) – 19 October 2015 – **'Taxpayer-funded study by euthanasia supporters "fatally flawed."**' The Government is under fire for funding a study on euthanasia that's being run by researchers who support assisted dying. The study is being led by two Auckland researchers, Dr. Phillipa Malpas and Dr. Pam Oliver, who told participants "we are independent." But they didn't reveal that they're members of the Voluntary Euthanasia Society... <https://www.tvnz.co.nz/one-news/new-zealand/exclusive-taxpayer-funded-study-by-euthanasia-supporters-fatally-flawed-q16367.html>

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

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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.

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

Evolving the palliative care workforce to provide responsive, serious illness

ANNALS OF INTERNAL MEDICINE | Online – 20 October 2015 – The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. The authors suggest one possible approach for dealing with this crisis. <http://annals.org/article.aspx?articleid=2424874>

Figure 3.2: Availability of specialised palliative care workers

5		4		3		2		1	
There are sufficient specialised palliative care professionals, including doctors, nurses, psychologists, social workers etc. Voluntary workers should have participated in a course of instruction for voluntary hospice workers. The specialist palliative care training for the core care team is accredited by national professional boards.		There is an adequate number of specialised palliative care professionals, but in some support functions (psychologists, social workers etc), there are shortages. Specialist palliative training is accredited by national professional boards, but this can be inconsistent at times.		There are specialised palliative care professionals but there are shortages of physicians, nurses and other support staff. Specialist palliative care training is generally not accredited by national professional boards.		There is a shortage of specialised palliative care professionals, and accreditation of specialist palliative care training is not the norm.		There is a severe shortage of specialised palliative care professionals and accreditation is non-existent.	
Australia UK Germany		Austria Belgium Canada Finland France Hong Kong Ireland Italy Japan	Netherlands New Zealand Norway Singapore South Korea Sweden Switzerland Taiwan US	Argentina Brazil Chile Costa Rica Cuba Czech Republic Denmark Ecuador Egypt Hungary Israel	Lithuania Mexico Mongolia Morocco Poland Portugal Spain Thailand Uganda Ukraine Uruguay Venezuela	Botswana China Colombia Dominican Republic Ethiopia Ghana Greece Guatemala India Indonesia Jordan Kazakhstan Kenya Malawi Malaysia	Myanmar Nigeria Panama Peru Puerto Rico Romania Russia Saudi Arabia Slovakia South Africa Sri Lanka Tanzania Turkey Vietnam Zambia Zimbabwe	Bangladesh Bulgaria Iran Iraq Philippines	

'2015 Quality of Death Index' (see p.32): http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Noted in Media Watch, 16 July 2012, #262 (p.10):

- *HEALTH LEADERS* | Online – 13 July 2012 – **'Palliative care challenged by physician shortage.'** There is about one cardiologist in the U.S. for every 71 people experiencing a heart attack; one oncologist for every 141 newly diagnosed cancer patients; and only one palliative care physician for every 1,200 people living with a life-threatening illness.¹ <http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage>

1. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] [http://www.jpmsjournal.com/article/S0885-3924\(10\)00602-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00602-0/abstract)

Living with and dying from advanced heart failure: Understanding the needs of older patients at the end of life

BMC GERIATRICS | Online – 15 October 2015 – Old and very old patients with advanced heart failure often do not acknowledge the seriousness and severity of the disease. Their communication with physicians predominantly focuses on curative treatment. Therefore, aspects such as self-management of the disease, dealing with emergency situations and end-of-life issues should be addressed more prominently. An advanced care planning programme for heart disease in older people could be an option to improve patient-centred care. <http://www.biomedcentral.com/1471-2318/15/125/>

N.B. Additional articles on end-of-life care in patients living with heart failure noted in past issues of Media Watch are listed in the issues of the weekly report dated 12 October 2015, #431 (p.11) and 19 January 2015, #393 (pp.11-12).

End-of-life care in Canada

Quality of end-of-life cancer care in Canada: A retrospective four-province study using administrative health care data

CURRENT ONCOLOGY, 2015;22(5):341-355. The quality of data comparing care at the end of life (EOL) in cancer patients across Canada is poor. This project used identical cohorts and definitions to evaluate quality indicators for EOL care in British Columbia, Alberta, Ontario, and Nova Scotia. Among the identified 200,285 cancer patients who died of their disease, 54% died in a hospital, with British Columbia having the lowest standardized rate of such deaths (50.2%). Emergency department use at EOL ranged from 30.7% in Nova Scotia to 47.9% in Ontario. Of all patients, 8.7% received aggressive care (similar across all provinces), and 46.3% received supportive care (range: 41.2% in Nova Scotia to 61.8% in British Columbia). Lower neighbourhood income was consistently associated with a decreased likelihood of supportive care receipt. The authors successfully used administrative health care data from four Canadian provinces to create identical cohorts with commonly defined indicators. This work is an important step toward maturing the field of EOL care in Canada. Future work in this arena would be facilitated by national-level data-sharing arrangements. <http://www.current-oncology.com/index.php/oncology/article/view/2636/1869>

Editorial:

- *CURRENT ONCOLOGY*, 2015;22(5):315-316. **'Are patients receiving the right care in the right place at the right time?'** <http://www.current-oncology.com/index.php/oncology/article/view/2912/1917>

N.B. Canada was ranked 11th of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, October 2015. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Related:

- *DIALOGUE*, 2015;11(3):35-37. **'Helping patients live as well as possible until the end.'** The [Ontario Medical Association's] 'Planning for and Providing Quality End-of-Life Care' policy ... makes it clear that physicians must communicate effectively and compassionately with patients and/or substitute decision makers, in a manner and tone that is suitable to the decisions they may be facing. This includes initiating communications as early as possible and as regularly and as often as is necessary to share information, helping patients and/or substitute decision makers understand the information shared and answering questions. <http://www.iomag.com/magazine/dialogue-volume-11-issue-3-2015/0689239001443468078/p35?short>

N.B. Canada was ranked 11th of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, October 2015. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

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

Long term care nurses' knowledge and perceived competency of palliative care

DOCTOR OF NURSING PRACTICE TECHNICAL REPORTS NO. 2 | Online – Accessed 21 October 2015 – By 2040, it is estimated 40% of the 65 years of age and older population in the U.S. will die in long term care (LTC) facilities. Because of the chronicity of the geriatric population's medical conditions, the patients may require end-of-life (EOL) care. Numerous LTC facilities are located in rural areas, which may create a disparity in the provision of quality EOL care. The study subjects responded below 50% on the Palliative Care Knowledge Test (PCKT). Registered nurses had more total knowledge of palliative care (PC) on the PCKT than the licensed practical nurses. No statistical significant difference was noted on the Self-Efficacy in Palliative Care (SEPC) Survey between the rural and urban subjects. Rural and urban nurse study subjects lacked knowledge of PC, but had a perceived confidence/competency to provide PC. <http://digitalcommons.wku.edu/cgi/viewcontent.cgi?article=1001&context=dnptechreports>

Noted in Media Watch, 30 March 2015, #403 (p.6):

- U.S. | *New York Magazine* – 24 March 2015 – ‘**Many nursing homes fall short at palliative care.**’ In a new study,¹ researchers attempted to see how well directors of nursing responded to questions about both personal knowledge of palliative care practices and about how their facilities handled these issues. Twenty-one percent of the [1,981] directors of nursing surveyed “correctly responded to only one of the knowledge items, and 43% to all items.” <http://nymag.com/scienceofus/2015/03/many-nursing-homes-fall-short-at-palliative-care.html>

1. ‘End-of-life care in nursing homes with greater versus less palliative care knowledge and practice,’ *Journal of Palliative Medicine*, 16 March 2015. This study included 58,876 residents who died in these facilities. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393?journalCode=jpm>

Noted in Media Watch, 15 December 2014, #388 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 3 December 2014 – ‘**Developing palliative care practice guidelines and standards for nursing home-based palliative care teams...**’ The palliative care guidelines and team standards identified in this study may be helpful in providing practical direction to nursing home administrators and staff looking to improve palliative care practice for their residents. [http://www.jamda.com/article/S1525-8610\(14\)00691-4/abstract](http://www.jamda.com/article/S1525-8610(14)00691-4/abstract)

N.B. Listed in this issue of Media Watch are additional articles on end-of-life care in long term care facilities and nursing homes noted in past issues of the weekly report,

End-of-life care in Japan

Availability of palliative care units and outpatient services in Japan: A nation-wide survey

GAN TO KAGAKU RYOHO (Japanese Journal of Cancer & Chemotherapy), 2015;42(9):1087-1089. The authors conducted a nation-wide survey to clarify the availability of palliative care units and outpatient palliative care services in Japan. They sent 306 questionnaires to the managing physicians of all certified palliative care units, and obtained 243 responses (79%). Eighteen percent reported that patients undergoing anti-cancer treatment are not able to apply for admission; 82% offered outpatient services. In 20% of the institutions, waiting time before admission was 11 days or longer for patients with pain and a predicted prognosis of less than 1 month. Only 10% reported that all patients who expressed a desire for admission were actually able to be admitted. Oncologists and palliative care physicians need to discuss the creation of a system so that all patients who want them can actually avail of palliative care services. <http://europepmc.org/abstract/med/26469165>

Cont.

Noted in Media Watch, 22 June 2015, #415 (p.17):

- *SUPPORTIVE CARE IN CANCER* | Online – 16 June 2015 – ‘**The effects of community-wide dissemination of information on perceptions of palliative care, knowledge about opioids, and sense of security among cancer patients, their families, and the general public.**’ The authors conducted a 3-year community intervention [in three regions of Japan] and evaluated the effects of distributing such information at the community level, and explored associations among levels of exposure, perceptions, knowledge, and the sense of security achieved. Their findings indicate that providing palliative care information via small media and lectures in the community is effective in improving perceptions of palliative care and knowledge about opioids among the community dwellers, especially for caregivers of the patients. <http://link.springer.com/article/10.1007/s00520-015-2788-4>

Noted in Media Watch, 13 April 2015, #405 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 April 2015 – ‘**Changes in perceptions of opioids before and after admission to palliative care units in Japan: Results of a nationwide bereaved family member survey.**’ Many bereaved family members had misconceptions of opioids before admission. There was improvement after bereavement, but understanding remained low. <http://ajh.sagepub.com/content/early/2015/04/09/1049909115579407.abstract>

N.B. Japanese language article. Japan was ranked 14th of the 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

End-of-life care in South Korea

Death perception, death preparation and need for death educational program of the elderly

INDIAN JOURNAL OF SCIENCE & TECHNOLOGY, 2015;8(25). The subjects of this study were 99 elderly people out of 100 who participated in the well-dying program conducted by a hospice center in Kyunggi-province: 84.7% of the subjects wanted to have natural death; 41.8% responded they wanted to be with their children most when faced [with] death; 61.7% wanted to pass away at home; 58.1% had never heard of the death educational program; and, 67% thought [there was] need [for a] death educational program. <http://www.indjst.org/index.php/indjst/article/view/80275>

N.B. Click on PDF icon for access to full text. South Korea was ranked 18th of the 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

The effect of community-based specialist palliative care teams on place of care

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 October 2015 – Prior research on community-based specialist palliative care teams used outcome measures of place of death and/or dichotomous outcome measures of acute care use in the last two weeks of life. However, existing research seldom measured the diverse places of care used and their timing prior to death. The study objective was to examine the place of care in the last 30 days of life. After matching, 3,109 patients were identified in each group, where 79% had cancer and 77% received end-of-life home care. At 30 days compared to 7 days before death, the exposed group's proportions rose from 33% to 41% receiving home care and 14% to 15% in hospital, whereas the unexposed group's proportions rose from 28% to 32% receiving home care and 16% to 22% in hospital. Linear trend analysis (proportion over time) showed that the exposed group used significantly more home care services and fewer hospital days than the unexposed group. On the last day of life (place of death), the exposed group had 18% die in an in-patient hospital bed compared to 29% in usual care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0063>

Cont.

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 October 2015 – ‘**Correlates of family satisfaction with hospice care: General inpatient hospice care versus routine home hospice care.**’ Good communication is strongly associated with greater family satisfaction across hospice care settings. Hospices must ensure that they provide patients and families with consistent information and support. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0055>

Identification of challenges to the availability and accessibility of opioids in twelve European Countries: Conclusions from two Access to Opioid Medication in Europe (ATOME) six-country workshops

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 October 2015 – Access to many controlled medicines is inadequate in a number of European countries. This leads to deficits in the treatment of moderate to severe pain as well as in opioid agonist therapy. In total, 84 representatives of the national Ministries of Health, national controlled substances authorities, experts representing regulatory and law enforcement authorities, leading health care professionals, and patient representatives ... participated in either one of the workshops. A number of challenges to opioid accessibility in the countries were identified in the domains of knowledge and educational, regulatory, legislative, as well as public awareness and training barriers that limit opioid prescription. In addition, short validity of prescriptions and bureaucratic practices resulting in overregulation impeded availability of some essential medicines. Stigmatization and criminalisation of people who use drugs remained the major impediment to increasing opioid agonist program coverage. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0051>

Figure 5.2: Availability of opioid painkillers

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Freely available and accessible		Available, but access is somewhat restricted by bureaucratic red tape		Not easily available and/or access is restricted through laws and bureaucratic red tape or prejudices		Only available in limited circumstances		Illegal
Argentina	Malaysia	Chile	Turkey	Brazil	Indonesia	Bangladesh	Nigeria	
Australia	Netherlands	Jordan	Uruguay	Bulgaria	Iran	Botswana	Philippines	
Austria	New Zealand	South Africa		China	Mexico	Egypt	Russia	
Belgium	Norway			Colombia	Mongolia	India	Saudi Arabia	
Canada	Poland			Cuba	Morocco	Iraq	Sri Lanka	
Costa Rica	Portugal			Dominican Republic	Panama	Kazakhstan	Tanzania	
Czech Republic	Puerto Rico			Ecuador	Peru	Kenya	Zambia	
Denmark	Singapore			Ethiopia	Romania	Malawi	Zimbabwe	
Finland	Slovakia			Ghana	Thailand	Myanmar		
France	South Korea			Greece	Uganda			
Germany	Spain			Guatemala	Ukraine			
Hong Kong	Sweden			Hungary	Venezuela			
Ireland	Switzerland				Vietnam			
Israel	Taiwan							
Italy	UK							
Japan	US							
Lithuania								

‘2015 Quality of Death Index’ (see p.42): http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Gender differences in caregiving at end of life: Implications for hospice teams

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 October 2015 – Researchers have identified important gender differences in the experience of caring for a family member or friend living with advanced disease; however, trends suggest that these differences may be diminishing over time in response to changing gender roles. In addition, while many studies have found caregiving experiences and outcomes to be poorer among female caregivers, noteworthy exceptions exist. The primary aim of this study was to determine how, if at all, current day caregiving at end of life varies by gender. As it related to caregiving, females had significantly lower self-esteem and more negative impact on their schedule, health, and family support than males. No gender differences were detected with regard to the impact of caregiving on individuals' finances. Despite changing social expectations, pronounced gender differences persist in caregiving at the end of life. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0214>

Related:

- *PSYCHO-ONCOLOGY* | Online – 18 October 2015 – ‘**Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients.**’ Psychological support interventions for family caregivers should take gender-specific risk factors into account. Interventions focusing on keeping up hope while caring for a terminally ill family member may be a valuable addition to palliative services to improve support for family carers. Women may benefit from interventions that address adaptive coping and strategies to deal with the dual demands of employment and caring. <http://onlinelibrary.wiley.com/doi/10.1002/pon.4005/abstract>
- *QUALITATIVE HEALTH RESEARCH* | Online – 21 October 2015 – ‘**Gendered processes in hospice palliative home care for seniors with cancer and their family caregivers.**’ There has been limited investigation into the processes that shape gender (in)equities in hospice palliative home care. The authors examined how and why gender relations occur in this context. Findings suggest that to promote equity, health care providers and policy makers must attend to gender as a prevalent social determinant of health and health care. Implications for policy, practice, education, and research are discussed. <http://qhr.sagepub.com/content/early/2015/10/20/1049732315609571.abstract>

Noted in Media Watch, 8 July 2013, #313 (pp.2-3):

- U.S. | *Forbes* – 2 July 2013 – ‘**The rapid rise of the male caregiver.**’ In 2009 men accounted for 34% of the nearly 65 million family caregivers in the U.S.¹ More recent surveys show the number of men in this traditionally female role has risen rapidly, driven by a combination of factors. A 2012 analysis finds men may represent as many as 45% of all family caregivers.² One study reports between 1996 and 2011, the percentage of men among adults caring for a family member with Alzheimer’s disease or dementia almost doubled, to 40% from 19%.³ <http://www.forbes.com/sites/nextavenue/2013/07/02/the-rapid-rise-of-the-male-caregiver/>
 1. ‘Caregiving in the U.S.’, National Alliance for Caregiving & American Association for Retired Persons, 2009. <http://www.caregiving.org/pdf/research/CaregivingUSAllAgesExecSum.pdf>
 2. ‘Family Caregivers Online,’ The Pew Research Center’s Internet & American Life Project, 2012. http://www.pewinternet.org/~media/Files/Reports/2012/PIP_Family_Caregivers_Online.pdf
 3. ‘2013 Alzheimer’s Disease Facts & Figures,’ *Alzheimer’s & Dementia* (The Journal of the American Alzheimer’s Association), 2013;9(2):208-245. [Noted in Media Watch, 6 May 2013, #304; (p.7)] [http://www.alzheimersanddementia.com/article/S1552-5260\(13\)00076-9/fulltext#abstract](http://www.alzheimersanddementia.com/article/S1552-5260(13)00076-9/fulltext#abstract)

[Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com/community/pg/file/owner/MediaWatch)

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>

Perinatal palliative care

Primary palliative care in the delivery room: Patients' and medical personnel's perspectives

JOURNAL OF PERINATOLOGY | Online – 22 October 2015 – Most of delivery room (DR) staff [i.e., study participants] did not report relevant signs of distress in dying neonates, and providing palliative care was not named as a relevant care-related source of distress by medical personnel. However, half of the participants reported on high degrees of caregiver's emotional distress in primary palliative care (PPC) situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. Caregiver's emotional distress primarily originates from providing support to parents, not from providing medical care to the dying newborn. Implications for future practice include the need for structured education to improve DR staff's communication and counselling skills... <https://www.google.com/url?rct=j&sa=t&url=http://www.nature.com/journal/vaop/ncurrent/full/jp2015127a.html&ct=ga&cd=CAEYAioTNzM0MTA2NTgxNzAwNzkyMTc0NTIZMDI5ZTA5MmI3YjIY2Q2MzpjYTpIbjpDQQ&usq=AFQjCNGKTAEjsw6klwrT-ErBBzsvtn2nyA>

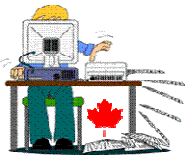
Noted in Media Watch, 10 August 2015, #422 (p.8):

- *ADVANCES IN NEONATAL CARE*, 2015;15(4):239-240. '**Palliative and end-of-life care for newborns and infants.**' This revised statement reflects how we now view palliative care.¹ Clinical recommendations span identification of eligible infants before and after birth, delineate components of a palliative care program, and discuss emotional support for parents, families and health care providers. http://journals.lww.com/advancesinneonatalcare/Citation/2015/08000/Palliative_and_End_of_Life_Care_for_Newborns_and.5.aspx

1. 'Palliative and End-of-Life Care for Newborns and Infants,' National Association of Neonatal Nurses, February 2015. http://www.nann.org/uploads/files/PalliativeCare6_FINAL.pdf

Noted in Media Watch, 29 December 2014, #390 (pp.9-10):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(3):143-148. '**Perinatal palliative care: A developing specialty.**' Little data is available on perinatal palliative care and its impact on babies and families... This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies. <http://www.magonlineibrary.com/doi/abs/10.12968/ijpn.2014.20.3.143>
- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. '**Clinician perspectives of barriers in perinatal palliative care.**' Study participants expressed more obstacles at the health-care systems level, reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians were more confident in their ability to counsel patients than nurses. Both expressed similar feelings of distress and helplessness caring for families expecting a fetal or neonatal demise. Participants reported a lack of societal support/understanding about perinatal palliative care. http://journals.lww.com/mcnjournal/Abstract/2015/01000/Clinician_Perspectives_of_Barriers_in_Perinatal.8.aspx



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>

High intensity of end-of-life care among adolescent and young adult cancer patients in the New York State Medicaid Program

MEDICAL CARE | Online – 21 October 2015 – Little is known about the care adolescent and young adult (AYA) cancer patients receive at the end of life (EOL). Using linked patient-level data ... the authors identified 705 Medicaid patients who were diagnosed with cancer between the ages of 15 and 29 in the years 2004-2011, who subsequently died, and who were continuously enrolled in Medicaid in the last 60 days of life: 75% of AYA Medicaid decedents used at least 1 aspect of intensive EOL care; 38% received chemotherapy in the last 2 weeks of life; 21% received intensive care unit care, 44% had emergency room visit, and 64% were hospitalized in the last month of life. Only 23% used hospice. 65% of patients died in acute care settings, including the inpatient hospital or emergency room. Given the high rates of intensive measures and low utilization of hospice at the EOL among AYA Medicaid enrollees, opportunities to maximize the quality of EOL care in this high-risk group should be prioritized. http://journals.lww.com/ww-medicalcare/Abstract/publishahead/High_Intensity_of_End_of_Life_Care_Among.99001.aspx

Seven heavens? The character and importance of afterlife belief among contemporary Australians

MORTALITY | Online – 20 October 2015 – This article draws on in-depth qualitative interviews with 52 people to examine the meaning and character of afterlife belief... It explores the varieties of afterlife belief and considers the impact such beliefs have, particularly in relation to death and dying. The analysis reveals afterlife belief is varied, individualistic and mainly arrived at with little to no reference to orthodox religious teaching. People variously believe in heaven, reincarnation, life on another plane or something more abstract. Those who follow faithfully a religious tradition are largely ignorant of detailed theological doctrines about life after death and like other kinds of believers, exercise their own authority and judgment over matters of belief. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2015.1099521>

Noted in Media Watch, 3 November 2014, #382 (p.14):

- *ATLANTA MEDICINE*, 2014;85(1):9-12. 'The history of afterlife.' Each of us comes to her or his own conclusions about afterlife; thoughts on this subject are natural for humans everywhere. Our ethnic culture, our specific faith tradition and our exposure to educational influences all affect our ultimate persuasion. No single opinion can be called "right" or "wrong." It is helpful, however, to appreciate the perceptions of others because the range of beliefs is broad. No matter what one's final conclusion, both past and present provide examples showing that others – somewhere, sometime – have come to similar convictions. No one is alone. <http://www.mdatl.com/wp-content/uploads/2014/07/AM-February-March-2014.pdf#page=11>

Prolonging support after brain death: When families ask for more

NEUROCRITICAL CARE | Online – 21 October 2015 – The manner in which brain death protocols in the U.S. address family objection to death by neurologic criteria has not been explored. Institutional brain death protocols from hospitals in the U.S. were reviewed to identify if and how the institution addressed situations in which families object to determination of brain death or discontinuation of organ support after brain death. Protocols from 331 institutions in 25 different states and the District of Columbia were reviewed. There was no mention of how to handle a family's objections in 77.9 % (258) of the protocols. Of those that allowed for accommodation, reasons to defer brain death declaration or prolong organ support after brain death declaration included: 1) Religion; 2) Moral objection; 3) Non-specific social reasons; or 4) Awaiting arrival of family. Recommendations to handle these situations included: 1) Seek counsel;(2) maintain organ support until cardiac cessation; (3) extubate against the family's wishes; (4) obtain a second opinion; or (5) Transfer care of the patient to another practitioner or facility. Protocols differed on indications and length of time to continue organ support, code status while support was continued, and time of death. The majority of protocols reviewed did not mention how to handle circumstances in which families object to determination of brain death or discontinuation of organ support after brain death. The creation of guidelines on management of these complex situations may be helpful to prevent distress to families and hospital staff. <http://link.springer.com/article/10.1007/s12028-015-0209-7>

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Related:

- *ADVANCED CRITICAL CARE*, 2015;26(4):356-363. '**Considerations in patients with cardiac implantable electronic devices at end of life.**' The purpose of this article is to educate clinicians about the legal and ethical principles that underlie withdrawal of life-sustaining therapies such as device deactivation and the importance of proactive communication with patients and families in these situations. http://journals.lww.com/aacnadvancedcriticalcare/Abstract/2015/10000/Considerations_in_Patients_With_Cardiac.11.aspx
- *JOURNAL OF MEDICAL ETHICS* | Online – 20 October 2015 – '**Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: Family experiences.**' Withdrawal of artificially delivered nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS) requires judicial approval in England & Wales, even when families and healthcare professionals agree withdrawal is in the patient's best interests. Part of the rationale underpinning the original recommendation for such court approval was the reassurance of patients' families, but there has been no research as to whether or not family members are reassured by the requirement for court proceedings or how they experience the process. The authors' analysis of family experience supports arguments grounded in economic and legal analysis that court approval should no longer be required. <http://jme.bmj.com/content/early/2015/09/30/medethics-2015-102777.full.pdf+html>

Bringing the economic cost of informal caregiving into focus

PALLIATIVE MEDICINE | Online – 22 October 2015 – Do specialised palliative care services improve outcomes for patients with advanced progressive illness at the end of life and their families at lower or acceptable cost compared with traditional health and social care services? Economic evaluations systematically compare the relative costs and benefits of competing options and thus provide information about how best to improve patient and family outcomes within funding constraints. Costs and outcomes are jointly considered to evaluate how best to achieve value for money from scarce resources. However, there is sparse evidence on the efficiency and equity of palliative and end-of-life care, in part due to the difficulties associated with conducting research in this context, particularly measuring costs and outcomes. Informal caregivers, not healthcare systems, provide the majority of care for people at the end of life, yet health service evaluations often ignore both the outcomes and costs borne by this group. <http://pmj.sagepub.com/content/early/2015/10/14/0269216315612653.full.pdf+html>

Bereaved parents' strategies and reactions when supporting their surviving children

WESTERN JOURNAL OF COMMUNICATION | Online – 14 October 2015 – Bereaved parent-child communication and support can significantly affect surviving children's well-being and family functioning, yet offering support may be difficult for bereaved parents amidst their own distress. The results from 11 in-depth interviews outline bereaved parents' support strategies (e.g., direct conversation, concealment, sharing space and time, enabling outside communication, commemoration) and positive and negative reactions. This study focused on support from the provider perspective, so implications for parental support and grief processes are discussed. Practical considerations for supporting surviving children are explored. <http://www.tandfonline.com/doi/abs/10.1080/10570314.2015.1079332>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *HEALTH POLICY* | Online – 14 October 2015 – '**Ethical considerations in the regulation of euthanasia and physician-assisted death in Canada.**' On 6 February 2015 the Supreme Court of Canada (SCC) released their decision on *Carter v Canada* (Attorney General) to uphold a judgment from a lower court which determined that the current prohibition in Canada on physician-assisted dying violated the s. 7 [Charter of Rights & Freedoms] rights of competent adults whose medical condition causes intolerable suffering. The purpose of this article is to briefly examine current regulations from Oregon (U.S.), Belgium, and The Netherlands, in which physician-assisted death and/or euthanasia is

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currently permitted, as well as from the province of Quebec which recently passed Bill-52, “An Act Respecting End-of-Life Care.” The authors present ethical considerations that would be pertinent in the development of policies and regulations across Canada in light of this SCC decision: patient and provider autonomy, determining a relevant decision-making standard for practice, and explicating challenges with the SCC criteria for assisted-death eligibility with special consideration to the provision of assisted-death, and review of assisted-death cases. [http://www.healthpolicyjrnl.com/article/S0168-8510\(15\)00253-5/abstract](http://www.healthpolicyjrnl.com/article/S0168-8510(15)00253-5/abstract)

- *THE MEDICAL POST* (Canada) | Online – 13 October 2015 – ‘**Making headway with assisted dying.**’ As physicians take the lead in creating a practical framework for assisted dying, words must be chosen carefully and terms defined precisely for members of the profession to be comfortable, results from a *Medical Post* poll suggest. The Canadian Physician Trends 2015 Survey ... found a relatively high degree of willingness to provide this service compared with other polls. In response to ... “When physician-assisted suicide is legal under strictly defined circumstances, I would be inclined to assist people in need,” 48% agreed (14% strongly, 34% moderately); 53% disagreed (27% strongly, 26% moderately) ... a nearly even split, the percentage of physicians willing to assist patients was higher than in a similar poll the Canadian Medical Association (CMA)... The CMA poll, involving 1,403 doctors, asked: “Following the Supreme Court of Canada decision regarding medical aid in dying, would you consider providing medical aid in dying if it was requested by a patient?” The response: 63% said “no,” 29% “yes” and 8% “don’t know.” http://www.canadianhealthcarenetwork.ca/physicians/news/special-reports/making-headway-with-assisted-dying-41584?utm_source=EmailMarketing&utm_medium=email&utm_campaign=Physician_TOC_Newsletter

N.B. Access to this article requires a subscription.

[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>

Worth Repeating

How well do the general public understand palliative care? A mixed methods study

BMJ SUPPORTIVE & PALLIATIVE CARE, 2014;4(Supplement). International research suggests that the general public appear to be confused about what palliative care is and who provides it. An understanding of public views is needed in order to target education and policy campaigns, and to manage future needs, expectations and resourcing of care. Responses [to a community-based, cross-sectional survey] indicated limited knowledge about palliative care. Respondents who worked in healthcare themselves or who had a close relative or friend who had used a palliative care service were more aware of palliative care and the availability of different palliative care services. The main barriers to raising awareness were fear, lack of interaction with health services and perception of lack of resources. [Noted in Media Watch, 24 March 2014, #350 (p.8)] http://spcare.bmj.com/content/4/Suppl_1/A2.1.abstract

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

The Economist Intelligence Unit

Figure 6.2: Public awareness of palliative care

5		4		3		2		1	
Public has a strong understanding and awareness of palliative care services. Information on palliative care is readily available from government portals and community mechanisms.		Public has a somewhat good understanding and awareness of palliative care services. Some information on palliative care is available from government portals and community mechanisms.		Public has a mediocre understanding and awareness of palliative care services. Limited information on palliative care is available from government portals and community mechanisms.		Public has a limited understanding and awareness of palliative care services. Little to no information on palliative care is available from government portals and community mechanisms.		Public has no understanding or awareness of palliative care services. There is no information on palliative care available from government portals and community mechanisms.	
Belgium France	New Zealand UK	Australia Canada Germany Ireland Japan	Netherlands Norway Taiwan US	Austria Brazil Chile Costa Rica Denmark Finland Hungary Israel Italy Mongolia	Poland Portugal Singapore Slovakia South Korea Sweden Switzerland Uganda Ukraine Zimbabwe	Argentina Bangladesh Bulgaria China Colombia Cuba Czech Republic Ecuador Egypt Ethiopia Ghana Greece Guatemala Hong Kong India Indonesia Iraq Jordan Kazakhstan Kenya Lithuania	Malawi Malaysia Mexico Morocco Nigeria Panama Peru Philippines Puerto Rico Romania Russia Saudi Arabia South Africa Spain Sri Lanka Tanzania Thailand Turkey Uruguay Venezuela Vietnam Zambia	Botswana Dominican Republic	Iran Myanmar

'2015 Quality of Death Index' (see p.47): http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

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