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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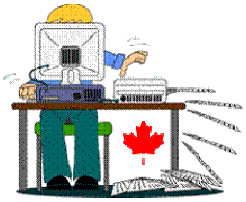

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Developing a palliative care competence framework for health and social care professionals: The experience in the Republic of Ireland' (p.8), in *BMJ Supportive & Palliative Care*.

Canada

Compassionate care leave to expand up to 26 weeks...

CBC NEWS | Online – 22 December 2015 – The Trudeau government is following through on a Conservative plan to extend compassionate care leave for the care of terminally ill loved ones from six to 26 weeks, starting 3 January 2016. But the government says it plans to rework the program later in the year to expand the number of people who can take advantage of the enriched employment insurance plan. The regulations coming into effect on 3 January apply specifically to people caring for a terminally ill loved one. In the 2013-2014 fiscal year, 6,003 people claimed compassionate care benefits... That was a decrease of 1.6% from the previous year. http://www.cbc.ca/news/politics/compassionate-care-benefit-expansion-1.3376763

Selected articles on job protection and income security for family caregivers in Canada

- *THE GLOBE & MAIL* | Online – 20 January 2015 – **'Employers want to help caregivers balance responsibilities...'** Canadian employers do not realize how many of their workers balance their jobs with the responsibilities of caring for a loved one.[1] [Noted in Media Watch, 26 January 2015, #394 (p.2)] http://www.theglobeandmail.com/news/national/employers-want-to-help-caregivers-balance-responsibilities/article22530359/

  1. 'Report from the Employer Panel for Caregivers – When work and caregiving collide: How employers can support their employees who are caregivers,' Government of Canada, January 2015. http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml

- *THE FINANCIAL POST* | Online – 1 December 2014 – **'Don't make employees choose between their job and providing end-of-life care to a loved one.'** Fifty-nine percent of 692 organizations polled had formal compassionate care leave policies that recognize and accommodate employees' family and dependent care responsibilities...[1] [Noted in Media Watch, 8 December 2014, #387 (p.1)] http://business.financialpost.com/2014/12/01/dont-make-employees-choose-between-their-job-and-providing-end-of-life-care-to-a-loved-one/

  1. 'Compassionate Care Policy,' Human Resources Professionals Association (Ontario, Canada), October 2014. http://www.hrpa.ca/Documents/360/Compassionate_Care_Policy.pdf

Cont.

- CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – **'Balancing work and care-giving obligations: New guide walks you through it.'** The Commission has released its 'Guide to Balancing Work & Caregiving Obligations: Collaborative approaches for a supportive and well-performing workplace.' [Noted in Media Watch, 16 June 2014, #362 (p.1)] http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

Compassionate Care Benefit: An historical perspective

Noted in past issues of Media Watch:

'Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit,' *International Journal for Equity in Health*, 1 November 2012. http://www.equityhealthj.com/content/pdf/1475-9276-11-65.pdf

'The workplace perspective on supporting family caregivers at end of life: Evaluating a new Canadian social program,' *Community, Work & Family*, 26 March 2012. http://www.tandfonline.com/doi/abs/10.1080/13668803.2012.664891

'Family caregivers' ideal expectations of Canada's Compassionate Care Benefit,' *Health & Social Care in the Community*, 15 September 2011. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01028.x/abstract

'Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?' *BMC PUBLIC HEALTH*, 18 May 2011. http://www.biomedcentral.com/content/pdf/1471-2458-11-335.pdf

'The uncompassionate elements of the Compassionate Care Benefits program: A critical analysis,' *Global Health Promotion*, 2010;17(1):50-59. http://ped.sagepub.com/content/17/1/50.short

'Evaluating Canada's Compassionate Care Benefit: The perspective of family caregivers,' McMaster University (Canada), 2010. http://www.coag.uvic.ca/eolcare/documents/CCB%20evaluation%20final%20report%20-%20English.pdf

advocacy
to change "what is"
into "what should be"

N.B. The Compassionate Care Benefit has its roots in a 1999 initiative of the Communications Committee of the then Ontario Palliative Care Association to advocate for job protection and income security for family caregivers. Additional background information on the initiative is available on request.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CTV News – 22 December 2015 – **'Quebec court overturns injunction against assisted-dying law.'** Quebec's Court of Appeal has overturned a lower-court decision that prevented the province's doctor-assisted-dying law from going into effect. The Dying with Dignity law, which outlines how terminally ill patients can end their lives with medical help, was adopted by members of the National Assembly in June 2014, and became law 10 December. But last month, a Superior Court justice in the province sided with a group of doctors who asked that the law be postponed until February, at least. That judgment concluded that certain provisions in the law run afoul of the Criminal Code, which prohibits assisted suicide. The Court of Appeal justices noted that the Supreme Court of Canada has deemed those sections of the Code dealing with assisted death unconstitutional. That meant it could no longer be argued that the Criminal Code provisions were paramount to provincial legislation. It said the Quebec law, called an Act Respecting End-of-Life Care, "does not conflict with either the effect or the objectives of the order suspending" the Criminal Code provisions. "On the contrary, the suspension order is directed precisely at allowing Parliament and the provincial legislatures who wish to do so, to legislate with respect to physician-assisted death promptly and within their respective legislative spheres," the court said in its ruling. http://www.ctvnews.ca/health/quebec-court-overturns-injunction-against-assisted-dying-law-1.2709818

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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.14.

Assisted-death ruling: Federal law isn't always paramount

QUEBEC | *The Globe & Mail* – 23 December 2015 – When a provincial law conflicts with a federal law, it triggers a legal principle known as the "paramountcy doctrine," under which the provincial law is deemed inoperative. Agreeing that paramountcy applies, the Quebec Superior Court initially granted the injunction. But the Quebec Court of Appeal took a very different approach. In order for paramountcy to apply, it said, the competing laws must be "valid." In this case, the federal law had already been found unconstitutional; it remained in effect only by the grace of the Supreme Court of Canada. Therefore, the Court of Appeal reasoned, the relevant conflict was not between the Quebec law and the Criminal Code, but between the Quebec law and the Supreme Court's ruling. And, based on the Supreme Court's reasons for granting the delay in the first place – to enable governments to devise protective, rights-respecting schemes – the Court of Appeal found that no such conflict exists. http://www.theglobeandmail.com/globe-debate/assisted-death-ruling-federal-law-isnt-always-paramount/article27910462/

- *THE NATIONAL POST* | Online – 21 December 2015 – **'Use the notwithstanding clause, if you must.'** When the Supreme Court struck down the Criminal Code provision banning assisted suicide in February last year, it delayed the effect of its decision for one year to give the federal and provincial governments time to put a new legal framework in place. That year is nearly up, and the federal government has not yet passed a law on assisted suicide nor is it in a position to move forward with such a law in the next two months. Earlier this month, the federal government asked the Supreme Court to further delay the effect of its decision, arguing that it needed more time to research the matter and consult the public before enacting a new law. There's a simple, if controversial, way for the Liberals to buy time to craft a proper assisted suicide law This request is unnecessary. The federal government already has a tool at its disposal should it need more time: section 33 of the Charter, also known as "the notwithstanding clause." A controversial compromise which secured patriation of the constitution in 1982, section 33 permits governments to override certain Charter rights for a five-year period. Section 33 is often portrayed as an "anti-rights" provision that cannot be reconciled with the respect and value we have for rights in Canada. However, this is not the case. Section 33 is not inherently bad. While we should fear the abuse of section 33, we should tolerate its occasional use. http://news.nationalpost.com/full-comment/sarah-burningham-use-the-notwithstanding-clause-if-you-must

U.S.A.

End-of-life talk often comes too late for blood cancer patients

U.S. NEWS & WORLD REPORT | Online – 21 December 2015 – Many doctors wait too long to have end-of-life discussions with blood cancer patients, a new study finds.[1] Researchers analyzed surveys completed by 349 blood cancer specialists and found 56% said end-of-life discussions with patients happen too late. Nearly 43% said they had their first end-of-life discussions with patients at less-than-ideal times... About 23% of the doctors said they waited until death was imminent before discussing hospice care. And nearly 40% waited until death was imminent before they asked patients where they wanted to die. Several factors may contribute to the delay in end-of-life discussions with blood cancer patients, according to Dr. Oreofe Odejide, from the Dana-Farber Cancer Institute in Boston, and colleagues. While solid tumors are incurable after they reach an advanced stage, many advanced blood cancers remain potentially curable. The lack of a clearly defined point when there is no remaining hope for blood cancer patients may contribute to delays in end-of-life discussions, the researchers said. The findings show that blood cancer specialists are aware of gaps in end-of-life care for their patients, but are uncertain how to tackle the issue, Dr. Thomas LeBlanc, from the Duke University School of Medicine in Durham, North Carolina' explained...[2] http://health.usnews.com/health-news/articles/2015-12-21/end-of-life-talk-often-comes-too-late-for-blood-cancer-patients

Specialist Publications

'Evaluating a new era in Medicare hospice and end-of-life policy' (p.7), in *Health Affairs*.

Cont.

1. 'Timeliness of end-of-life discussions for blood cancers: A national survey of hematologic oncologists,' *JAMA Internal Medicine*, 21 December 2015. http://archinte.jamanetwork.com/article.aspx?articleid=2475022

2. 'Addressing end-of-life quality gaps in hematologic cancers: The importance of early concurrent palliative care,' *JAMA Internal Medicine*, 21 December 2015. http://archinte.jamanetwork.com/article.aspx?articleid=2475019

International

India ranks low in palliative care: Report

INDIA | *The Indian Express* (Noida, Uttar Pradesh) – 22 December 2015 – The 2015 Quality of Death Index compiled by The Economist Intelligence Unit ... has put India at one of the lowest rankings in palliative care (PC) across the world.[1] India ranks a dismal 67th on the list while the U.K. has the best quality of death... This is due to comprehensive national policies, the extensive integration of PC into its National Health Service, and a strong hospice movement. Priyadarshani Kulkarni, Secretary, Indian Association of Palliative Care, said that there was a time when most terminally ill patients were cared for at home and allowed to die peacefully. Today, they are rushed to hospitals. Our unrealistic hope is that once we take the patient to the hospital, he or she will get cured. Doctors are trained to try every heroic remedy possible and technology can keep vital organs functioning for long periods of time. This way, the duration of life is increased, the statement said. Last year, the Indian Association of Palliative Care and Indian Society of Critical Care Medicine jointly formulated guidelines for end-of-life care. But to implement these, a comprehensive national policy on PC is needed, which may include subsidies, and training for both doctors and nurses. http://indianexpress.com/article/cities/pune/india-ranks-low-in-palliative-care-report/

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Selected articles on end-of-life care in India

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2015;29(4):412-415. **'Pain, palliative care, and compassion in India.'** An estimated one million new cases of cancer occur each year in India, with over 80% presenting at the point at which the disease is incurable. This narrative includes five case studies exploring differing aspects of palliative care: 1) Pain management; 2) Difficulties faced in accessing morphine; 3) Importance of compassion in end-of-life care; and, 4) Psychological effects on families. [Noted in Media Watch, 21 December 2015, #441 (p.12)] file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/9T1OFYF5/15360288.2015.1101642.pdf

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2015;21(3):258-261. **'Constitutional and legal protection for life support limitation in India.'** The physician approach is hampered by misperceptions of the legal liability linked to treatment limitation, in part due to the unclear signals from the legal community. Faced with the risks of lawsuits and societal unawareness of legitimate treatment foregoing options, the Indian physician is often compelled ... to continue expensive, burdensome and heroic efforts till the very end or resort to an ethically problematic "left against medical treatment" decision. [Noted in Media Watch, 14 September 2015, #427 (p.8)] http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2015;volume=21;issue=3;spage=258;epage=261;aulast=Mani

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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

- *CANCER CONTROL*, 2015;3:57-62. **'The current status of palliative care in India.'** Less than 1% of India's 1.2 billion population has access to palliative care (PC). In recent years, a few of the major barriers have begun to be overcome. The South Indian state of Kerala, which has 3% of India's population, stands out in terms of achieving coverage of PC. On the national level, recent years saw several improvements, including the creation of a National Program for Palliative Care by the government of India in 2012. The year 2014 saw the landmark action by the Indian Parliament, which amended India's infamous Narcotic Drugs & Psychotropic Substances Act, thus overcoming many of the legal barriers to opioid access. Education of professionals and public awareness are now seen to be the greatest needs for improving access to PC in India. [Noted in Media Watch, 7 September 2015, #426 (p.7)] http://www.cancercontrol.info/wp-content/uploads/2015/07/57-62-MR-Rajagopal-.pdf

End-of-life care in Scotland

A good death takes more than a framework

U.K. (Scotland) | *Third Force News* (Edinburgh) – 22 December 2015 – You might not know that it is thought that over 10,000 people die in Scotland every year who would have benefited from palliative care (PC), but didn't receive it. You might not know that, basically, there is no data on PC services: we simply don't know whether the care people receive across Scotland is good, bad or indifferent. But what we do know is that good, holistic PC makes a huge difference to people who are dying, and to their families. Not only does good PC control pain and other distressing symptoms, it can provide much needed practical, social, emotional and spiritual support for patients and their carers. Anyone who has had this support will testify to this, just as people who have watched their loved ones die with poor or no PC can tell you that things could have been much, much better. So the Scottish Government's new framework for PC is good news,[1] or at least a welcome first step towards its vision of a Scotland where everyone who would benefit from PC receives it. The framework sets out ten strong and much-needed commitments on things such as finding ways to identify people who can benefit from PC through to supporting better public and personal discussion of bereavement, death and dying. These commitments are positive – but will they make any difference? http://thirdforcenews.org.uk/blogs/a-good-death-will-take-more-than-a-framework

Specialist Publications

'Developing a palliative care competence framework for health and social care professionals: The experience in the Republic of Ireland' (p.8), in *BMJ Supportive & Palliative Care*.

'Comfort care for patients dying in the hospital' (p.8), in *New England Journal of Medicine.*

'Rhetoric and reality – matching palliative care services to meet the needs of patients of all ages, with any diagnosis' (p.11) in *Palliative Medicine.*

1. 'Strategic Framework for Action on Palliative and End-of-Life Care,' Scottish Government, December 2015. [Noted in Media Watch, 21 December 2015, #441 (p.8)] file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/BXO49UAX/00491388.pdf

End-of-life care in New Zealand

Improved palliative care guidance

NEW ZEALAND | *Scoop Independent News* – 21 December 2015 – Health Minister Jonathan Coleman welcomes new guidance on providing the best possible care for people during the last days of their lives. The new guidance for the health sector[1] ... places a much greater focus on developing individual care plans. It also highlights the importance of clear and respectful communication, and providing patient-centred services. http://www.scoop.co.nz/stories/PA1512/S00422/improved-palliative-care-guidance.htm

1. 'Te Ara Whakapiri: Principles and Guidance for the Last Days of Life,' Ministry of Health, December 2015. http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life

Cont.

Selected articles on end-of-life care in New Zealand

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 December 2015 – **'New Zealand doctors on the care of the dying patient.'** Hospice and specialist palliative care (PC) have transformed the quality of care for the dying and their families in New Zealand. While survey respondents seemed realistic about what PC can and cannot achieve, patients and their families may have unrealistic expectations of both hospice and palliative medicine. [Noted in Media Watch, 7 December 2015, #439 (p.8)] http://ajh.sagepub.com/content/early/2015/11/25/1049909115619906.abstract

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 October 2015 – **'General practice and specialist palliative care teams: An exploration of their working relationship from the perspective of clinical staff working in New Zealand.'** With a focus on end-of-life care provision in the community, the role of the general practice team and their relationship with specialist palliative care (PC) providers is key to responding effectively to the projected increase in PC need. [Noted in Media Watch, 2 November 2015, #434 (p.12)] http://onlinelibrary.wiley.com/doi/10.1111/hsc.12296/abstract

- *HEALTH PROMOTION INTERNATIONAL* | Online – 9 July 2015 – **'A cultural analysis of New Zealand palliative care brochures.'** The authors examined ninety-nine brochures from palliative care services in New Zealand and held two focus groups with twelve Māori elders (kaumātua) and extended family (whanau) members. The findings raise questions about the capacity of agencies to convey culturally resonant messages to kaumātua and their whānau. [Noted in Media Watch, 20 July 2015, #419 (p.13)] http://heapro.oxfordjournals.org/content/early/2015/07/09/heapro.dav067.abstract

  N.B. Additional articles on Māori beliefs and practices in the context of end-of-life care are noted in issues of Media Watch dated 15 June 2015, #414 (p.5), 16 June 2014, #362 (p.8), and 17 March 2014, #349 (p.9).

N.B. New Zealand was ranked 3rd of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

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

Advance care planning: The attitudes and views of a group of Catholic nuns in Singapore

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 December 2015 – The themes that emerged ... were autonomy and freedom, spirituality and quality of life, and the meaning of advance care planning (ACP). [Slightly more than half of the twenty-three nuns participating in this study had heard of ACP prior to the focus group discussions.] The findings suggested spirituality and faith define the way the participants lived their lives, including their views and preferences on end-of-life care. Integrating spirituality into an essential domain of care will help the spiritual community honor a crucial part of end-of-life discussions and afford a greater discernment of the deep meaning that ACP holds. http://ajh.sagepub.com/content/early/2015/12/23/1049909115615563.abstract

Related:

- *CLINICAL ORTHOPAEDICS & RELATED RESEARCH* | Online – 21 December 2015 – **'End-of-life care planning and fragility fractures of the hip: Are we missing a valuable opportunity?'** The authors' findings suggest that physicians may be missing a valuable opportunity to help patients and their families be better prepared for potential future health issues. End-of-life care planning respects patient autonomy and enhances the quality of care. Accordingly, they recommend that discussion of goals, expectations, and preferences should be initiated routinely when patients present with a fragility fracture of the hip. http://link.springer.com/article/10.1007/s11999-015-4675-1

Top 10 Articles from *Evidence-Based Oncology* for the Year 2015

AMERICAN JOURNAL OF MANAGED CARE | Online – 22 December 2015 – **'The role of palliative care in accountable care organizations.'** [file:///C:/Users/admin/Downloads/EBO%20April.pdf] was the most read. Accountable care organizations were developed as a tool that can ensure quality healthcare while reducing unnecessary or avoidable costs to the healthcare system. In this article, published in a special issue on palliative care (PC), the authors describe how PC has consistently demonstrated its ability to maximize healthcare value, especially for seriously ill patients with the greatest need and highest risk. http://www.ajmc.com/newsroom/top-10-articles-from-ievidence-based-oncologyi-for-the-year-2015

Related:

- *HEALTH AFFAIRS* | Online – 22 December 2015 – **'Evaluating a new era in Medicare hospice and end-of-life policy.'** New Year's Day 2016 will herald three policy changes, each of which individually would be the most consequential modification of Medicare program benefits for patients facing the end of life since the introduction of the hospice benefit in 1983. These changes will need to be evaluated to understand their impact on patients and the Medicare program's fiscal health. This article describes the changes to end-of-life policy that the coming year will bring and suggests key questions and metrics that should be used to evaluate the impact of the reforms. It also suggests ways to hone and improve methods of non-experimental inference and expand data systems to support this evaluation. http://healthaffairs.org/blog/2015/12/22/evaluating-a-new-era-in-medicare-hospice-and-end-of-life-policy/

Impact of a hospice rapid response service on preferred place of death, and costs

BMC PALLIATIVE CARE | Online – 23 December 2015 – Many people with a terminal illness would prefer to die at home. A new palliative rapid response service (RRS) provided by a large hospice provider in South East England was evaluated (2010) to provide evidence of impact on achieving preferred place of death and costs. The RRS was delivered by a team of trained health care assistants and available 24/7. The purpose of this study was to 1) Compare the characteristics of RRS users and non-users; 2) Explore differences in the proportions of users and non-users dying in the place of their choice; and, 3) Monitor the whole system service utilisation of users and non-users, and compare costs. Of 688 patients referred to the hospice when the RRS was operational, 247 (35.9 %) used it. Higher proportions of RRS users than non-users lived in their own homes with a co-resident carer (40.3 % vs. 23.7 %); more non-users lived alone or in residential care (58.8 % vs. 76.3 %). Chances of dying in the preferred place were enhanced 2.1 times by being a RRS user, compared to a non-user, and 1.5 times by having a co-resident carer, compared to living at home alone or in a care home. Total service costs did not differ between users and non-users, except when referred to hospice very close to death (users had higher costs). http://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-015-0065-4

Noted in Media Watch, 9 February 2015, #396 (p.12):

- *CHEST*, 2015;147(2):560-569. **'Integration of palliative care in the context of rapid response: A report from the Improving Palliative Care in the ICU Advisory Board.'** The Improving Palliative Care in the ICU (IPAL-ICU) Project brings together interdisciplinary expertise and existing data to address: 1) Special challenges for providing palliative care (PC) in the rapid response setting; 2) Knowledge and skills needed by rapid response teams (RRTs) for delivery of high-quality PC; and, 3) Strategies for improving the integration of PC with rapid response critical care. The authors discuss key components of communication with patients, families, and primary clinicians to develop a goal-directed treatment approach during a rapid response event. They highlight the need for RRT expertise to initiate symptom relief. Strategies including specific clinician training and system initiatives are recommended... The authors conclude by suggesting as evaluation of their impact on other outcomes continues, performance by RRTs in meeting PC needs of patients and families should also be measured and improved. http://journal.publications.chestnet.org/article.aspx?articleID=2107414

Cont.

- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – '**Hospital rapid response team and patients with life-limiting illness: A multicentre retrospective cohort study.**' Patients [i.e., study participants] with a life-limiting illness had worse outcomes post-rapid response team consultation. The authors' findings suggest a routine clarification of goals of care for this cohort, within 3 days of hospital admission, may be advantageous. These discussions may provide clarity of purpose to treating teams, reduce the burden of unnecessary interventions, and promote patient-centred care agreed upon in advance of any deterioration. http://pmj.sagepub.com/content/early/2015/01/23/0269216314560802.abstract

Developing a palliative care competence framework for health and social care professionals: The experience in the Republic of Ireland

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 23 December 2015 – A Palliative Care Competence Framework Steering Group, comprising a range of health and social care professionals, was established to oversee and drive the development of the framework, through identification of core competences and related indicators and supporting the work of 10 working groups to develop discipline specific competences. The framework describes universal core competences in palliative care (PC) while also detailing individual competences for each health and social care discipline. It is envisioned that the framework will inform academic curricula and professional development programmes, and so will enhance the care of people with life-limiting illness, fostering greater interprofessional and interorganisational collaboration in PC provision. http://spcare.bmj.com/content/early/2015/12/22/bmjspcare-2015-000872.abstract

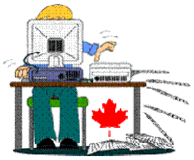
Related:

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2015;373 (26):2549-2561. '**Comfort care for patients dying in the hospital.**' Nearly a half century after the founding in London of St. Christopher's, the first modern hospice, in 1967, palliative care (PC) has been recognized throughout the world as an important medical specialty. Considerable advances have been made during that time in our knowledge of the management of symptoms in terminal illnesses – advances that deserve widespread incorporation into the clinical practice of both generalists and specialists. The information presented here should provide clinicians in fields other than PC with a framework for delivering basic comfort care to hospitalized patients who are near death. http://www.nejm.org/doi/full/10.1056/NEJMra1411746

- *REVISTA BIOÉTICA*, 2015;23(3). '**Palliative care and primary health care: Scoping review.**' The ageing population has increased the incidence of chronic health conditions, requiring the inclusion of different levels of palliative care (PC) in different parts of the health care system, including primary health care (PHC). Ethical problems found were: 1) Lack of resources; 2) Lack of knowledge about PC; 3) Lack of communication skills; difficulty in establishing limits in clinical relationship; work overload; lack of support from referral services. These problems, in general are similar to those experienced in the PHC, but with differences in specific situations.

  Original Spanish language version: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300593&lng=en&nrm=iso&tlng=es

  English language version: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300593&lng=en&nrm=iso&tlng=en



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

End-of-life experiences of mothers with advanced cancer: Perspectives of widowed fathers

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 18 December 2015 – Despite the importance of parenting-related responsibilities for adult patients with terminal illnesses who have dependent children, little is known about the psychological concerns of dying parents and their families at the end of life (EOL). According to fathers [i.e., the respondents to a web-based survey], 38% of mothers had not said goodbye to their children before death and 26% were not at all "at peace with dying." Ninety per cent of widowed fathers reported that their spouse was worried about the strain on their children at the EOL. Fathers who reported clearer prognostic communication between wife and physician had lower Center for Epidemiologic Studies Depression Scale and Texas Revised Inventory of Grief scores. To improve EOL care for seriously ill patients and their families, we must understand the concerns of parents with dependent children. http://spcare.bmj.com/content/early/2015/12/18/bmjspcare-2015-000976.abstract

Extract from University of North Carolina study

38% of mothers had not said goodbye to their children before death and 26% were not at all "at peace with dying."

Related:

- *JOURNAL OF PEDIATRIC ONCOLOGY NURSING* | Online – 14 December 2015 – **'Bereaved siblings' advice to health care professionals working with children with cancer and their families.'** The most common advice, suggested by 56% of siblings [surveyed], related to their own support. One third suggested giving better medical information to siblings. Some wanted to be practically involved in their brother's or sister's care and suggested health care professionals (HCPs) should give parents guidance on how to involve siblings. Other advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted. http://jpo.sagepub.com/content/early/2015/12/14/1043454215616605.abstract

Discussing death matters

DYNAMICS OF HUMAN HEALTH, 2015;2(4). Those of us who work in health, especially the pointy end of it in aged care or palliative care (PC), and acute areas working with trauma and/or in intensive care, are regularly present to death. Undertaking death work risks a raft of ills from compassion fatigue to counter transference. Elizabeth Menzies (1960) in her classic work on health professionals encounters with death and trauma highlighted the defences that they employed in order to manage their experiences.[1] Often, within these contexts, death is thoroughly medicalised; a specific discourse of death and dying that may offer a defence of sorts in its objectification and thus distancing, but may not be useful in a wider cultural sense. Although discourses such as spirituality are also utilised by health professionals, especially PC, the primary vehicle for health care professionals to make sense of death is as the failure of the physical body. http://journalofhealth.co.nz/?page_id=986

1. 'A case-study in the functioning of social systems as a defence against anxiety: A report on a study of the nursing service of a general hospital,' *Human Relations*, 1960;13(2):95-121. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/CO7JBP8D/Human%20Relations-1960-Menzies-95-121.pdf

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

"Something normal in a very, very abnormal environment"

Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia

INTENSIVE & CRITICAL CARE NURSING | Online – 10 December 2015 – The majority of deaths of children and infants occur in paediatric and neonatal intensive care settings. For nurses, managing an infant/child's deterioration and death can be very challenging. Nurses play a vital role in how the death occurs, how families are supported leading up to and after the infant/child's death. This paper describes the nurses' endeavours to create normality amidst the sadness and grief of the death of a child in paediatric and neonatal ICU. Four themes emerged [in this study] from thematic analysis: 1) Respecting the child as a person; 2) Creating opportunities for family involvement/connection; 3) Collecting mementos; and, 4) Planning for death. http://www.intensivecriticalcarenursing.com/article/S0964-3397(15)00083-X/abstract

Palliative care case conferences in long term care: Views of family members

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 17 December 2015 – Main concerns raised by family members [i.e., study participants] prior to a Palliative Care Case Conference (PCCC) were physical and medical needs, pain, end-of-life care (EOLC) planning, nutrition and hydration. Families rated a high level of concern, 7.5 on a 10-point scale, prior to the PCCC. A formalised PCCC process ensured issues relating to EOLC planning, pastoral care, pain and comfort, and physical and medical needs were well documented by staff. Issues relating to care processes and the family role in care were less well documented. All families, interviewed post intervention, recommended PCCC; 90% of families felt their issues were addressed to their satisfaction. Families reported an increased understanding of the resident's current and future care. Increased communication between staff and family, in the form of a PCCC, may reduce stress, anxiety and unwanted hospitalisations during the palliative phase. http://onlinelibrary.wiley.com/doi/10.1111/opn.12105/abstract;jsessionid=CFB59944818F2B9029FA9C4929D8BF6C.f01t04?userIsAuthenticated=false&deniedAccessCustomisedMessage=

Selected articles on family conferences in the end-of-life care setting

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 July 2015 – **'A systematic review of family meeting tools in palliative and intensive care settings.'** The authors sought to identify tools available to aid the conduct of family meetings in palliative, hospice, and intensive care unit settings. The authors identified 16 articles containing 23 tools in 7 categories: 1) Meeting guide; 2) Meeting planner; 3) Documentation template; 4) Meeting strategies; 5) Decision aid/screener; 6) Family checklist; and, 7) Training module. They found considerable variation across tools in usage and content and a lack of tools supporting family engagement. [Noted in Media Watch, 3 August 2015, #421 (p.7)] http://ajh.sagepub.com/content/early/2015/07/23/1049909115594353.abstract

- *CRITICAL CARE MEDICINE* | Online – 6 January 2015 – **'How clinicians discuss critically ill patients' preferences and values with surrogates: An empirical analysis.'** In a third of [the 71] ICU family conferences [recorded] for patients at high risk of death, neither clinicians nor surrogates discussed patients' preferences or values about end-of-life decision making. In less than 12% of family conferences did participants address the values of high importance to most patients, such as cognitive and physical function. Interventions are needed to ensure patients' values and preferences are elicited and integrated into end-of-life decisions in ICUs. [Noted in Media Watch, 19 January 2015, #393 (p.9)] http://journals.lww.com/ccmjournal/Abstract/publishahead/How_Clinicians_Discuss_Critically_Ill_Patients_.97364.aspx

- *CRITICAL CARE MEDICINE*, 2004;32(7):1484-1488. **'Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction.'** The authors identified family conferences in intensive care units of four Seattle [State of Washington] hospitals during which discussions about withdrawing life support were likely to occur. On average, family members spoke 29% and clinicians spoke 71% of the time. This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. [Noted in Media Watch, 24 March 2014, #350 ('Worth Repeating,' p.16)] http://journals.lww.com/ccmjournal/Abstract/2004/07000/Family_satisfaction_with_family_conferences_about.5.aspx

An inter-hospital, interdisciplinary needs assessment of palliative care in a community critical care

JOURNAL OF PALLIATIVE CARE, 2015;31(4):234-242. The study was set in a 10-bed, open intensive care unit and emergency department at a community hospital. Gaps were identified in palliative care (PC), goals of care and end-of-life discussions, and resources. Community hospital health care professionals did not fully appreciate their essential contribution to the provision of PC in the intensive care unit. In addition, there was a lack of expertise, and a lack of interest in gaining expertise, in palliative/end-of-life care. Interrelated needs in a complex interprofessional, inter-hospital context were captured. Further studies are required to obtain data on palliative practice in the care of critically ill patients in various community hospital contexts. http://www.ingentaconnect.com/content/iug/jpc/2015/00000031/00000004/art00005

Multi-hospital observational study

Using nurse ratings of physician communication in the ICU to identify potential targets for interventions to improve end-of-life care

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 December 2015 – Communication among doctors, nurses, and families contributes to high-quality end-of-life care (EOLC), but is difficult to improve. Several topics of physician-nurse communication, as rated by nurses [i.e., survey respondents] were associated with higher nurse-rated quality of dying, whereas one topic, nurses' concerns for patient or family, was associated with poorer ratings. Higher nurse ratings of physician-family communication were uniformly associated with higher quality of dying, highlighting the importance of this communication. Physician support of family decision making was particularly important, suggesting a potential target for interventions to improve EOLC. http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0155

Extract from University of Washington study

Discussions between nurses and physicians about nurses' concerns for patients or families were negatively associated.

Rhetoric and reality – matching palliative care services to meet the needs of patients of all ages, with any diagnosis

PALLIATIVE MEDICINE, 2016;30(1):3-5. In the 21st century the major expenditure for health services worldwide is on chronic, non-communicable disease and the disabling *sequelae* of acute illness, with its attendant multi-morbidity and incapacity. Persistent illness and disability also present the greatest challenges to effective service design. Successful care requires services to couple responsiveness to unavoidable acute on chronic deterioration with long-term, continuous efforts to prevent avoidable further complications and maximise quality of life. These approaches require different skills. The evidence is clear that in chronic, symptomatic illness a psychologically-informed approach is necessary to inform and motivate people to change established beliefs and habits, giving themselves the greatest chance of the best possible physical and psychological health in the longer term. This impact is going to be greatest in those overcoming the greatest disease burden, at the youngest age, to contain accumulating morbidity on morbidity. There are frequent policy restatements regretting that hospitals are still only designed to meet the needs of those with acute conditions where life-saving treatment or single interventions are required, but not suited to managing chronicity: little changes. The significant advances in the effective acute medical management of myocardial infarction, stroke, and chronic respiratory illness, the care of trauma patients, and the transition of cancer to a chronic illness for many, are impressive achievements. Sadly the quality of survival of people with chronic, progressive disease does not yet reliably match the standard of their acute care, with increasing evidence in the literature of hidden distress and blighted lives for both patient and family. http://pmj.sagepub.com/content/30/1/3.extract

Psychosocial oncology care resources in Europe: A study under the European Partnership for Action Against Cancer

PSYCHO-ONCOLOGY | Online – 21 December 2015 – Cancer is a complex health problem requiring multidisciplinary care. There are clinical guidelines available in order to improve the process and outcomes of cancer care within Europe. However, strategic action is still needed in many European Union (EU) Member States to develop or improve national cancer control plans (NCCPs), which play a key role in cancer control and care. Twenty-seven (90%) countries returned questionnaires of which 21 (78%) include psychosocial oncology care (PSOC) in their NCCP: only 10 (37%) reported having specific budgets for PSOC, 8 (30%) having nationally recommended PSOC clinical guidelines, and 6 countries (22%) reported having an official certification for PSOC education. Findings indicate the need to develop national policies concerning PSOC with clear targets for deliverables in an appropriate timetable in order that psychosocial services and existing clinical guidelines are implemented and fully integrated into EU NCCPs. http://onlinelibrary.wiley.com/doi/10.1002/pon.4044/abstract

Responding to suffering

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2015;314(24):2623-2624. Patients suffer. Yet clinical care has moved away from addressing suffering. Suffering – "severe distress that threatens the integrity of the person" – spans physical, emotional, social, spiritual, existential, and financial domains, and as a whole-person problem it doesn't fit neatly within current biomedical paradigms. Suffering occurs in many clinical contexts, not only at the end of life, and calls on us as physicians to address our patients as whole persons, particularly challenging in our age of specialization and atomization in medicine. http://jama.jamanetwork.com/article.aspx?articleid=2478207

Selected articles on psychosocial aspects of end-of-life care

- *PALLIATIVE MEDICINE & HOSPICE CARE OPEN*, 2014;1(1):1-3. **'Importance of psychological research in palliative care: Barriers in its development.'** Barriers to research identified in this study related to: 1) Psychological issues are subjective, variables or constructs are complex and difficult to operationalize; 2) Psychological variables are difficult to measure; 3) The patients are fragile, their condition (physical and psychological) is mediated by the progress of the disease and the presence of impending death; 4) Health professionals have limited time to conduct assessments or research; and, 5) There is a lack of validated clinical tools. [Noted in Media Watch, 12 May 2014, #357 (p.13)] http://openventio.org/PalliativeMedicineandHospiceCareOpenJournal/ImportanceofPsychologicalResearchinPalliativeCareBarriersinitsDevelopment-PMHCOJ-1-101.pdf
- *HEALTH & SOCIAL WORK* | Online – 28 May 2015 – **'Social work assessment notes: A comprehensive outcomes-based hospice documentation system.'** The system was developed to guide assessment of patients' and caregivers' needs related to end-of-life psychosocial issues, facilitate collaborative care plan development... [Noted in Media Watch, 8 June 2015, #413 (p.12)] http://hsw.oxfordjournals.org/content/early/2015/05/28/hsw.hlv033.abstract
- *PALLIATIVE MEDICINE* | Online – 28 April 2015 – **'Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.'** Integration of patient, parent and clinician perspectives on end-of-life needs reveal mutual themes across stakeholders: 1) Holding to hope; 2) Communicating honestly; 3) Striving for relief from symptom burden; and, 4) Caring for one another. Shared priorities included: 1) Care access; 2) Cost analysis; 3) Social support to include primary caregiver support; 4) Sibling care; 5) Bereavement outreach; 6) Symptom assessment and interventions to include physical and psychological symptoms; 7) Communication approaches to include decision-making; and, 8) Overall care quality. [Noted in Media Watch, 4 May 2015, #408 (p.14)] http://pmj.sagepub.com/content/early/2015/04/22/0269216315583446.abstract

Worth Repeating

Truth may hurt but deceit hurts more: Communication in palliative care

PALLIATIVE MEDICINE, 2002;16(4):297-303. Healthcare professionals often censor their information giving to patients in an attempt to protect them from potentially hurtful, sad or bad news. There is a commonly expressed belief that what people do not know does not harm them. Analysis of doctor and nurse-patient interactions reveals that this well-intentioned but misguided assumption about human behaviour is present at all stages of cancer care. Less than honest disclosure is seen from the moment that a patient reports symptoms, to the confirmation of diagnosis, during discussions about the therapeutic benefits of treatment, at relapse and terminal illness. This desire to shield patients from the reality of their situation usually creates even greater difficulties for patients, their relatives and friends and other members of the healthcare team. Although the motivation behind economy with the truth is often well meant, a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion not one of calm and equanimity. Ambiguous or deliberately misleading information may afford short-term benefits while things continue to go well, but denies individuals and their families opportunities to reorganize and adapt their lives towards the attainment of more achievable goals, realistic hopes and aspirations. Examples and consequences of accidental, deliberate, if well-meaning, attempts to disguise the truth from patients, taken verbatim from interviews, are given, together with cases of unintentional deception or misunderstandings created by the use of ambiguous language. The authors provide evidence from research studies showing that although truth hurts, deceit may well hurt more. http://pmj.sagepub.com/content/16/4/297.short

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.

Media Watch: Links to Articles, Reports, etc.

Some recipients of Media Watch have, in recent weeks, reported some difficulties accessing certain articles, reports, etc. particularly when a link is to a pdf file ...but, it appears that not everyone has experienced this same problem. At this time, there seems no simple remedy (see above, 'Links to Sources'). Sincere apologies for any inconvenience, which is, hopefully, only temporary.

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/publications/newsletter/2015/12/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

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