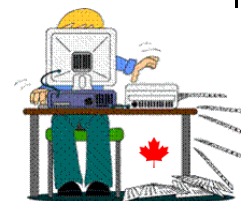


## **Media Watch...**

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

**Compiled & Annotated by Barry R. Ashpole**

**Clinical ethics in end-of-life care: Scroll down to U.S.A. and 'Tough issues when faith conflicts with medical advice' (p.4), broadcast on California's Valley Public Radio.**

## **Canada**

### **In 2014, death came out of the closet**

*THE GLOBE & MAIL* | Online – 23 December 2014 – The end-of-life conversation, which for so long was conducted in apprehensive, hushed tones, finally worked its way into the mainstream media, various legislatures and all the way up to the Supreme Court of Canada. The vast majority of people now die of chronic illnesses, in a fairly predictable manner. Patients with terminal illnesses know they're going to die, at least in the abstract. What they want is a more honest conversation about how their pain and suffering ... can be minimized. One of the greatest benefits to come from ... [the] ... high-profile stories and legal cases is that they have drawn attention to the lamentable state of palliative care in Canada. <http://www.theglobeandmail.com/globe-debate/the-year-we-put-death-above-indignity/article22179037/>

### **U.S.A.**

**'2014: The year we finally learned how to talk seriously about dying'** (p.4), in *The Washington Post*.

**N.B.** See also 'Palliative care in 2014,' *The ASCO Post* (American Society of Clinical Oncology). [Noted in Media Watch, 22 December 2014, #389 (p.11)] <http://www.ascopost.com/issues/december-15-2014/palliative-care-in-2014.aspx>

### **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.11.

### **Too few people dying in Ontario get proper palliative care: Editorial**

ONTARIO | *The Toronto Star* – 21 December 2014 – Thousands of dying Ontarians are not receiving the end-of-life care they want due to an appalling lack of high quality palliative care. Often it means their final days are spent in the intensive care unit of a hospital instead of comfortably at home, making the existing system unnecessarily costly as well as cruel. And it's all poised to get worse as the province's growing number of seniors inevitably die. Change is obviously needed.

Cont.

And some welcome steps forward are outlined in a new report calling for dramatic improvements to end-of-life care in Ontario.<sup>1</sup> There's a need for more professionals trained in delivering palliative care ... Patients should be encouraged to make their end-of-life desires known to family members and to health care providers. And those wishes should be respected. "Death is an intensely personal experience which must be guided through discussions in advance with medical professionals and loved ones," says Dr. Joshua Tepper, a family doctor and head of Health Quality Ontario. But this doesn't happen often enough. It's estimated that fewer than one in three people with chronic illness currently receive high-quality, team-based palliative care. [http://www.thestar.com/opinion/editorials/2014/12/21/too\\_few\\_people\\_dying\\_in\\_ontario\\_get\\_prop\\_or\\_palliative\\_care\\_editorial.html](http://www.thestar.com/opinion/editorials/2014/12/21/too_few_people_dying_in_ontario_get_prop_or_palliative_care_editorial.html)

1. 'Health Care for People Approaching the End of Life: An Evidentiary Framework,' Health Quality Ontario (Ontario Health Technology Advisory Committee). Published in *Ontario Health Technology Assessment Series*, 2014;14(14):1-45. [Noted in Media Watch, 22 December 2014, #389 (p.3)] <http://www.hqontario.ca/Portals/0/Documents/eds/synthesis-report-eol-1412-en.pdf>

**N.B.** There is a need for 755 to 1,080 hospice palliative care beds in Ontario. There are 289 beds in the province ... [and] ... about 20 hospices at various stages of planning, development and construction, which would add a further 200 beds throughout Ontario; many are waiting on provincial funding. [Source: *The Trent Hills Independent* (Belleville), 22 December 2014] <http://www.insidebelleville.com/news-story/5227896-bridge-hospice-chair-responds-to-auditor-general-s-report/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 21 December 2014 – '**Canadian doctors preparing for "all eventualities" in case top court strikes down ban on assisted suicide.**' The nation's largest doctors' group is quietly preparing for possible changes in federal laws governing physician-assisted death, as support among its own members for medical aid in dying grows. The Canadian Medical Association has consulted medical associations in jurisdictions around the world where euthanasia or assisted suicide is legal to devise possible protocols for Canada if the federal law is changed. The powerful doctors' lobby says it would be naïve not to prepare for "all eventualities" as the country awaits a Supreme Court of Canada ruling over whether the federal prohibition outlawing assisted suicide is unconstitutional. The Supreme Court could strike down Canada's ban on assisted suicide and give Parliament one year to craft new legislation, as it did with prostitution. <http://news.nationalpost.com/2014/12/21/canadian-doctors-preparing-for-all-eventualities-in-case-top-court-strikes-down-ban-on-assisted-suicide/>

Noted in Media Watch, 25 August 2014, #372 (p.2):

- CTV NEWS | Online – 19 August 2014 – '**Doctors debate end-of-life care at CMA meeting.**' Doctors tackled the delicate question of medically assisted death at a session devoted to end-of-life care at the annual conference of the Canadian Medical Association... The session ended with an overwhelming vote – 90% – in favour of an advisory resolution that supports "the right of all physicians, within the bonds of existing legislation, to follow their conscience when deciding whether to provide so-called medical aid in dying." <http://www.ctvnews.ca/health/doctors-debate-end-of-life-care-at-cma-meeting-1.1966254>



### 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>

## U.S.A.

### Dying and profits: The evolution of hospice

*THE WASHINGTON POST* | Online – 26 December 2014 – The influx of for-profit companies into the hospice field has benefited patients, advocates say, because the commercial companies made big investments in technology, focused on efficiency and made care more accessible. But a Washington Post analysis of hundreds of thousands of U.S. hospice records indicates that, as those companies transformed a movement once dominated by community and religious organizations into a \$17 billion industry, patient care suffered along the way. On several key measures, for-profit hospices as a group fall short of those run by non-profit organizations. The typical for-profit hospice: spends less on nursing per patient; is less likely to have sent a nurse to a patient's home in the last days of life; is less likely to provide more intense levels of care for patients undergoing a crisis in their symptoms; and, has a higher percentage of patients who drop out of hospice care before dying. High rates of dropout are often viewed as a sign that patients were pushed out of hospice when their care grew ex-

pensive, left dissatisfied or were enrolled for hospice even though they were not close to death. The quality of individual hospices varies widely. In some cases, for-profit hospices provide service at levels comparable to nonprofits, according to the review. But the data analysis, based on hundreds of thousands of Medicare patient and hospice records from 2013, shows the gap between the for-profits as a whole and non-profits is striking and consistent, regardless of hospice size. [http://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e\\_story.html](http://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e_story.html)

#### 'Business of Dying'

Each installment in *The Washington Post* series has been noted in Media Watch. See 15 December 2014, #388 (p.4) issue of the weekly report for a complete listing.

Noted in Media Watch, 8 September 2014, #374 (p.5):

- *AMERICAN JOURNAL OF NURSING*, 2014;114(9):21-22. **'The effects of the profit motive on the hospice movement.'** The 1983 enactment of the Medicare hospice benefit meant that Medicare would cover end-of-life care, at a *per-diem* rate, for beneficiaries expected to live six months or less if the illness "runs its normal course." With about 45% of deaths involving hospice care, most of it covered by Medicare, it's becoming an increasingly for-profit enterprise. [http://journals.lww.com/ajnonline/Fulltext/2014/09000/The\\_Effects\\_of\\_the\\_Profit\\_Motive\\_on\\_the\\_Hospice.20.aspx](http://journals.lww.com/ajnonline/Fulltext/2014/09000/The_Effects_of_the_Profit_Motive_on_the_Hospice.20.aspx)

Noted in Media Watch, 3 March 2014, #347 (p.9):

- *JAMA INTERNAL MEDICINE* | Online – 24 February 2014 – **'National hospice survey results: For-profit status, community engagement, and service.'** A total of 591 hospices completed the authors' survey... For-profit hospices were less likely than non-profit hospices to provide community benefits, including serving as training sites, conducting research and providing charity care. <https://archinte.jamanetwork.com/article.aspx?articleid=1832198>

**N.B.** Articles on non-profit and for-profit hospice are noted in the issues of Media Watch of 25 August 2014, #372 (p.2), 23 June 2014, #363 (p.2), 3 March 2014, #347 (p.4, pp.9-10) and, 13 January 2014, #340 (pp.3-4).

### Why and when denial is good for caregivers

PBS NEWSHOUR | Online – 24 December 2014 – When caring for an older parent, ailing spouse or sibling struggling with a devastating diagnosis, denial is often a place caregivers dwell. They may be driven there because they feel overwhelmed or angry, or because they don't understand "medical speak" and want to tune out. And while an initial state of denial is neither uncommon nor unhealthy, according to Dr. Ira Byock, a leading palliative care physician ... it's not a place to stay for the long haul. A persistent state of denial paralyzes caregivers and can ultimately impede the advocacy and support your loved one needs. Byock contends that providing quality care requires conversation. <http://www.pbs.org/newshour/rundown/denial-good-caregivers/>

## Tough issues when faith conflicts with medical advice

CALIFORNIA | Valley Public Radio (Fresno) – 23 December 2014 – Among the hardest cases in clinical ethics consulting are those in which patients' or families' religious beliefs motivate medical choices contrary to best professional advice. A common example is when a family requests that medically ineffective life-sustaining treatments not be withdrawn while they hope for divine intervention. These cases usually can be ethically managed with education and counseling. This allows decision makers to come to grips with the medical reality, including that continued aggressive treatment will most likely only increase the patient's suffering. Some cases, however, are much harder: family choices can cause patients to suffer through otherwise manageable pain, to languish for years in a permanent vegetative state, or even to die prematurely – all because their religious convictions preclude the medically appropriate response. These choices cause real harm. Families and patients make harmful medical choices for a range of reasons, but those that are relig-

iously motivated share a striking feature: Far more often than not, once faith is invoked, health care professionals accept that decision, even if doing so runs contrary to their best professional judgment. By contrast, when the reasons are secular – like medical ignorance, financial gain, or family dysfunction – the treating team will often aggressively engage the decision makers and strive to get them to change their position. The reason for this difference is understandable and seemingly wise: Who are health care professionals to question someone's faith?<http://kvpr.org/post/commentary-tough-issues-when-faith-conflicts-medical-advice>

### Specialist Publications

'Honoring Choices Minnesota: Preliminary data from a community-wide advance care planning model' (p.8), in *Journal of the American Geriatrics Society*.

Noted in Media Watch, 23 June 2014, #363 (p.3):

- *THE ATLANTIC* | Online – 18 June 2014 – '**When patients are counting on miracles.**' An estimated 60% of people think divine intervention can save patients who are in a vegetative state. A new study looks at what happens when doctors and divinity seem to be competing...<sup>1</sup>  
<http://www.theatlantic.com/health/archive/2014/06/living-on-a-prayer-and-a-ventilator/372972/>

1. 'AMEN in challenging conversations: Bridging the gaps between faith, hope, and medicine,' *Journal of Oncology Practice*, 6 May 2014. All health care practitioners face patients and families in desperate situations who say, "We are hoping for a miracle." Few providers have any formal training in responding to this common, difficult, and challenging situation.  
<http://jop.ascopubs.org/content/early/2014/05/06/JOP.2014.001375.abstract>

## 2014: The year we finally learned how to talk seriously about dying

*THE WASHINGTON POST* | Online – 20 December 2014 – A new rule just approved in Massachusetts will reportedly make the state the first to require doctors to discuss with terminally ill patients how they wanted to be cared for at the end of their lives. Though doctors already have been voluntarily holding these types of conversations with patients for years, most patients don't have an end-of-life care plan – and that could make the last few days or weeks of life needlessly painful, confusing and expensive for the patient and the patient's family. If 2014 should be remembered for anything in health policy, it's the year that marked a turning point in how we talk about dying. <http://www.washingtonpost.com/blogs/wonkblog/wp/2014/12/20/2014-the-year-we-finally-learned-how-to-talk-seriously-about-dying/>

## International

### Home care in England

U.K. (England) | *The Telegraph* – 23 December 2014 – The details of the councils which are offering the pensioners just 15 minutes of daily care can be revealed by *The Telegraph*. The list – obtained under the Freedom of Information Act – discloses the number of local authorities booking carers for the shortest possible time slot has risen to 74% from 69% in the same survey last year. Unison, the public sector union, surveyed 149 metropolitan, county and unitary authorities that commission home care and found that 110 councils were commissioning 15-minute visits, up from 100 out of 144 last year. They include Suffolk, Cambridgeshire, Herefordshire, central Bedfordshire, Nottingham, Derbyshire and Sunderland. Jeremy Hunt, the Health Secretary, described the figures as "unacceptable," saying there were "too many examples of councils buying rushed care visits." <http://www.telegraph.co.uk/news/uknews/11310247/Revealed-where-pensioners-are-getting-just-15-minutes-of-daily-home-care.html>

Noted in Media Watch, 4 August 2014, #369 (p.7):

- U.K. (England) | *The Guardian* – 28 July 2014 – '**Are 15-minute homecare visits always bad?**' Local authorities often face criticism for the regimented way they purchase care and particularly for the hourly rates they offer. Interested observers will talk about the need to purchase care around outcomes, rather than the seemingly outdated method of paying by the hour, half hour or 15 minutes. In reality this is a bit of a holy grail as very few local authorities have mastered the art of outcome-based commissioning. <http://www.theguardian.com/social-care-network/2014/jul/28/are-15-minute-homecare-always-bad>

Noted in Media Watch, 13 May 2013, #305 (p.6):

- U.K. (England) | *The Oxford Times* – 8 May 2013 – '**MP calls for answers on "rushed" home care visits.**' One in five visits by care staff to the elderly and frail is for 15 minutes or less in Oxfordshire – about double the national average. In a five-week period leading up to the end of March, 21.7% of home visits to help the elderly or frail was of the shortest time slot of 0-15 minutes. The national average last year in comparison was 10% and 63% respectively. [http://www.oxfordtimes.co.uk/news/10404419.MP\\_calls\\_for\\_answers\\_on\\_rushed\\_home\\_care\\_visits/](http://www.oxfordtimes.co.uk/news/10404419.MP_calls_for_answers_on_rushed_home_care_visits/)

### **Cartoons kill: Kids' movies show more death than adult ones, study finds**

RUSSIA | RT.com – 21 December 2014 – The number of onscreen deaths of main characters in children's films is two-and-a-half times greater than in movies for adult audiences, a survey that examined 45 of the highest-grossing animated flicks in history revealed.<sup>1</sup> "Rather than being the innocuous form of entertainment they are assumed to be, children's animated films are rife with on-screen death and murder." According to the researchers from University College London and the University of Ottawa, the death of an important character occurred in two thirds of children's animated films, with the figure for adult flicks standing at around a half. The deaths in movies for kids are often violent,

which "might be more traumatic for children," the survey entitled 'Cartoons kill' said. <http://rt.com/news/215759-cartoons-death-children-adults/>

#### **Extract from RT.com report**

*Films [however] could provide a valuable resource for initiating discussions about death between children and adults. Indeed, cinema therapy is sometimes used to facilitate counseling with grieving adolescents, a therapeutic practice that might be extended to younger children.*

1. 'Cartoons kill: Casualties in animated recreational theater in an objective observational new study of kids' introduction to loss of life,' *British Medical Journal*, 16 December 2014. <http://www.bmj.com/content/349/bmj.g7184>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *The Hindu* (New Delhi) – 25 December 2014 – **'Government endorses Supreme Court guidelines on passive euthanasia.'** Three years after a Supreme Court judgment legalised passive euthanasia under "exceptional circumstances," the government has fully endorsed the court's guidelines giving High Courts the power to decide on applications seeking permission to withdraw life support in the best interest of the patient. On 7 March 2011, a Bench of Justices Markandeya Katju and Gyan Sudha Misra set out a series of guidelines for High Courts to process applications seeking passive euthanasia by "near relatives or next friend or the doctors/hospital staff." The Bench then observed that these guidelines would hold good until Parliament decides or passes a law on passive euthanasia. The court was deciding the case of Aruna Shaunbag, who was paralysed and slipped into a coma after a brutal attack on 27 November 1973 at Mumbai's King Edward Memorial Hospital by a staffer. In his written reply ... Health Minister J.P. Nadda said the guidelines of the Supreme Court should be treated as law and made binding. Mr. Nadda said the matter of mercy killing was examined with the Law Ministry. There was no proposal to enact a legislation in this regard at present, he said. <http://www.thehindu.com/news/national/govt-endorses-sc-guidelines-on-passive-euthanasia/article6723278.ece>

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

### **Care planning needs of palliative home care clients: Development of the interRAI palliative care assessment clinical assessment protocols**

*BMC PALLIATIVE CARE* | Online – 15 December 2014 – The interRAI palliative care (interRAI PC) assessment instrument provides a standardized, comprehensive means to identify person-specific need and supports clinicians to address important factors such as aspects of function, health, and social support. The interRAI clinical assessment protocols (CAPs) inform clinicians of priority issues requiring further investigation where specific intervention may be warranted and equip clinicians with evidence to better inform development of a person-specific plan of care. This is the first study to describe the interRAI PC CAPs development process and provide an overview of distributional properties of the eight interRAI PC CAPs among community dwelling adults receiving palliative home care services. <http://www.biomedcentral.com/content/pdf/1472-684X-13-58.pdf>

Noted in Media Watch, 2 April 2012, #247 (p.12):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 22 March 2012 – **'Predictors of caregiver distress among palliative home care clients in Ontario: Evidence based on the interRAI palliative care.'** The present results point to the need for a care planning protocol that may be used on a targeted basis for clients experiencing or at elevated risk of caregiver distress. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8518883&fulltextType=RA&fileId=S1478951511000824>

Of related interest:

- *AMERICAN JOURNAL OF MANAGED CARE*, 2014;20(12):988-992. **'Quality of end-of-life care for cancer patients: Does home hospice care matter?'** The findings demonstrate the valuable contributions of HH [home hospice] and palliative care. Clinicians should consider referring cancer patients to palliative care services and establishing working relationships with HH and palliative care providers. <http://www.ajmc.com/publications/issue/2014/2014-vol20-12/Quality-of-End-of-Life-Care-for-Cancer-Patients-Does-Home-Hospice-Care-Matter>



## Dying to be heard: Hearing healthcare at the end of life

*HEARING JOURNAL*, 2015;68(1):18-22. Good hearing healthcare is essential for people facing the end of life, and yet it often goes overlooked by care providers and families focused on the many other medical, financial, social, legal, and additional concerns that come up when someone is dying. "Advance planning, management of emotional distress, counseling the patient and caregivers, attention to psychological and social needs, personalized revision of care plans – all of this involves hearing," said Barbara E. Weinstein ... of Health Sciences Doctoral Programs at the City University of New York Graduate Center. "Hearing and communication are so critical at the end of life because at this stage, what people are left with is the need to communicate with family, physicians, and other caregivers. Doctors are so concerned with patient-centered care, but they often have not been educated to appreciate the role that better hearing can play in that care." [http://journals.lww.com/thehearingjournal/Fulltext/2015/01000/Dying\\_to\\_Be\\_Heard\\_\\_Hearing\\_Healthcare\\_at\\_the\\_End.1.aspx](http://journals.lww.com/thehearingjournal/Fulltext/2015/01000/Dying_to_Be_Heard__Hearing_Healthcare_at_the_End.1.aspx)

Noted in Media Watch, 20 August 2012, #267 (p.12, under 'Worth Repeating'):

- *HEC FORUM*, 2002;14(3):197-208. **'American Sign Language and end-of-life care: Research in the deaf community.'** The authors describe a community-based participatory research process used to develop a means of discussing end-of-life care needs of deaf seniors. This process identified a variety of communication issues ... in working with this special population. They overview the unique linguistic and cultural characteristics of this community and their implications for working with deaf individuals to provide information for making informed decisions about end-of-life care, including completion of health care directives. [https://dada.cs.washington.edu/research/projects/compression2/jjtran/Papers/ASSETS%202010/References/fulltext\\_5.pdf](https://dada.cs.washington.edu/research/projects/compression2/jjtran/Papers/ASSETS%202010/References/fulltext_5.pdf)

Noted in Media Watch, 13 August 2012, #266 (p.6):

- *JOURNAL OF PALLIATIVE CARE*, 2012;28(2):105-112. **'Palliative and end-of-life care in Newfoundland's deaf community.'** Qualitative research was used to explore the experiences of family caregivers who provided end-of-life care for a deaf person. Key findings indicate that the deaf community has limited understanding of their options for palliative and end-of-life care. Communication and health literacy are key barriers to accessing appropriate end-of-life care. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by deaf people when caring for loved ones at the end of life. <http://www.ncbi.nlm.nih.gov/pubmed/22860383>

## Grief experiences of nurses in Ireland who have cared for children with an intellectual disability who have died

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 19 December 2014 – Of the eight main themes identified [in this study], the four most prevalent are discussed in detail: 1) grief; 2) relationship with the child; 3) end of life; and, 4) support. The findings demonstrate that nurses have a good understanding of grief, but the way they experience and manage it varies. The study suggests that nurses who have cared for children with an intellectual disability who have died may experience disenfranchised grief. Nurses seek support from a variety of sources. Organisational support is important for nurses following the death of a child for whom they have provided care. <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2014.20.12.584>

### [Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

## Honoring Choices Minnesota: Preliminary data from a community-wide advance care planning model

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2014;62(12):2420-2425. The objective of this report is to describe the process, which began in 2008, of implementing Honoring Choices Minnesota in a large, diverse metropolitan area. All eight large healthcare systems in the metropolitan area agreed to participate in the project, and as of 30 April 2013, the proportion of hospitalized individuals 65 and older with advance care directives in the electronic medical record was 12.1% to 65.6%. The proportion of outpatients aged 65 and older was 11.6% to 31.7%. Organizations that had sponsored recruitment initiatives had the highest proportions of records containing healthcare directives. It was concluded that it is possible to reduce redundancy by recruiting all healthcare systems in a metropolitan area to endorse the same advance care planning model, although significantly increasing the proportion of individuals with a healthcare directive in their medical record requires a campaign with recruitment of organizations and individuals. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13136/full>

**N.B.** Honoring Choices Minnesota website: <http://www.honoringchoices.org/>

Of related interest:

- *AMERICAN JOURNAL OF MEDICINE*, 2014;127(12):1142-1143. 'Increasing rates of advance care planning through interdisciplinary collaboration.' In 2014, 24% of the U.S. population is aged 50 years and over, and 17 million are between 75 and 85 years. By 2044, the 17 million U.S. older adults just between 75 and 85 years is estimated to grow to 30 million. These unprecedented numbers of aging adults in the U.S. present major challenges for the health care system as well as the economy. For example, 18% of the U.S. gross national product is spent on health care. Of that total, Medicare accounts for 21%, or \$554 billion. Most alarmingly, of the \$554 billion spent on Medicare, 28%, or about \$170 billion, is spent on health care during the last 6 months of life. [http://www.amjmed.com/article/S0002-9343\(14\)00676-7/abstract](http://www.amjmed.com/article/S0002-9343(14)00676-7/abstract)
- *JOURNAL OF ADVANCED NURSING* | Online – 23 December 2014 – '**Study protocol for 'we DECide': Implementation of advance care planning for nursing home residents with dementia.**' 'We DECide' focuses on three crucial moments for discussing advance care planning: the time of admission, crisis situations and everyday conversations. The 'ACP-audit' assesses participants' views on the organization of advance care planning, the 'OPTION scale' evaluates the degree of shared decision-making in individual conversations and the 'IFC-SDM Questionnaire' assesses participants' views on Importance, Frequency and Competence of realizing shared decision-making. The study hypothesis is that 'we DECide' results in a higher realization of shared decision-making in individual conversations on advance care planning. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12601/abstract>

## Measuring experience with end-of-life care: A systematic literature review

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 December 2014 – The authors identified 88 articles containing 51 unique surveys with available content. They characterized 14 content areas variably present across the 51 surveys. Information and care planning, provider care, symptom management, and overall experience were the most frequent areas addressed. There was also considerable variation across the surveys in the identification of proxy respondents, the timing of survey administration, and in the health care settings and services being evaluated. This review identified several comprehensive surveys aimed at measuring the experiences of end-of-life care, covering a variety of content areas and practical issues for survey administration. Future work should focus on standardizing surveys and administration methods so experiences of care can be reliably measured and compared across care settings. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00940-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00940-3/abstract)



## Discovering the truth beyond the truth

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 December 2014 – Truth within the field of medicine has gained relevance because of its fundamental relationship to the principle of patient autonomy. In order to fully participate in their medical care, patients must be told the truth – even in the most difficult of situations. Palliative care emphasizes patient autonomy and a patient-centered approach, and it is precisely among patients with chronic, life-threatening, or terminal illnesses that truth plays a particularly crucial role. For these patients, finding out the truth about their disease forces them to confront existential fears. As physicians, we must understand that truth, similar to the complexity of pain, is multidimensional. In this article, the authors discuss the truth from three linguistic perspectives: the Latin *veritas*, the Greek *aletheia*, and the Hebrew *emeth*. *Veritas* conveys an understanding of truth focused on facts and reality. *Aletheia* reveals truth as a process, and *emeth* shows that truth is experienced in truthful encounters with others. In everyday clinical practice, truth is typically equated with the facts. However, this limited understanding of the truth does not account for the uniqueness of each patient. Although two patients may receive the same diagnosis (or facts) each will be affected by this truth in a very individual way. To help patients apprehend the truth, physicians are called to engage in a delicate back-and-forth of multiple difficult conversations in which each patient is accepted as a unique individual. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00919-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00919-1/abstract)

Representative sample of articles on truth and truth-telling noted in recent issues of Media Watch:

- *BMJ OPEN* | Online – 8 October 2014 – "**Conditional candour**" and "**knowing me**": **An interpretive description study on patient preferences for physician behaviours during end-of-life communication.**' Two major concepts regarding helpful physician behaviour during end-of-life conversations emerged [during this study]: 1) "knowing me," which reflects the importance of acknowledging the influence of family roles and life history on values and priorities expressed during end-of-life communication; and, 2) "conditional candour," which describes a process of information exchange that includes an assessment of patients' readiness, being invited to the conversation, and sensitive delivery of information. [Noted in Media Watch, 13 October 2014, #379 (p.10)] <http://bmjopen.bmj.com/content/4/10/e005653.full>
- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2014;6(2):128. '**Disclosing the truth: A dilemma between instilling hope and respecting patient autonomy in everyday clinical practice.**' While medical ethics place a high value on providing truthful information to patients, disclosure practices are far from being the norm in many countries. [Noted in Media Watch, 6 January 2014, #339 (p.7)] <http://www.ccsenet.org/journal/index.php/gjhs/article/view/31080>

## Clinician perspectives of barriers in perinatal palliative care

*MCN, AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. Perinatal palliative care (PPC) is a developing model of care aimed at providing supportive services to families anticipating fetal or neonatal demise. This study measured barriers physicians and advance practice nurses report in providing and referring patients to PPC. [They] ... differed significantly in the barriers they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Both express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about PPC. [http://journals.lww.com/mcnjournal/Abstract/2015/01000/Clinician\\_Perspectives\\_of\\_Barriers\\_in\\_Perinatal.8.aspx](http://journals.lww.com/mcnjournal/Abstract/2015/01000/Clinician_Perspectives_of_Barriers_in_Perinatal.8.aspx)

Cont.

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(3):143-148. **'Perinatal palliative care: A developing specialty.'** Neonates and babies have the highest death rate in the paediatric population. Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. End-of-life decision-making for babies with an adverse prognosis also remains ethically challenging. 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.magonlinelibrary.com/doi/abs/10.12968/ijpn.2014.20.3.143>

### **Understanding the challenges of palliative care in everyday clinical practice: An example from a COPD action research project**

*NURSING INQUIRY* | Online – 16 December 2014 – Although palliative care [PC] policies increasingly require all healthcare professionals to have at least basic or non-specialist skills in PC, international evidence suggests there are difficulties in realising such policies. This study reports on a ... project aimed at developing respiratory nursing practice to address the PC needs of patients with advanced chronic obstructive pulmonary disease. Findings suggest inter-level dynamics at individual, team, interdepartmental and organisational levels are an important factor in the capacity of respiratory nurses to embed non-specialist PC in their practice. At best, current efforts to embed PC in everyday practice may improve end-of-life care in the final hours/days/weeks of life. Embedding PC in everyday practice requires a fundamental shift in the organisation of care. <http://onlinelibrary.wiley.com/doi/10.1111/nin.12089/abstract;jsessionid=0B54FBEDE9C1D468C11E043534474105.f02t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

#### **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 and research 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.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC PALLIATIVE CARE* | Online – 23 December 2014 – '**Unbearable suffering and requests for euthanasia prospectively studied in end-of-life cancer patients in primary care.**' In a population of end-of-life cancer patients cared for in primary care [i.e., study participants] no differences in unbearable suffering were found between patients with and without explicit requests for EAS [euthanasia and (or) physician assisted suicide]. The study raises the question whether unbearable suffering is the dominant motive to request for EAS. Most patients suffered from unbearable symptoms, indicating that the compulsory criterion of unbearable suffering may be met a priori in most end-of-life cancer patients dying at home, whether they request EAS or not. <http://www.biomedcentral.com/content/pdf/1472-684X-13-62.pdf>

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### Media Watch Online

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/12/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](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

#### Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

#### 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>

- *JOURNAL OF MEDICAL ETHICS*, 2015;41(1):40-43. **'The debate about physician assistance in dying: 40 years of unrivalled progress in medical ethics?'** Some issues in medical ethics have been present throughout the history of medicine, and thus provide us with an opportunity to ascertain: 1) whether there is progress in medical ethics; and 2) what it means to do good medical ethics. One such perennial issue is physician assistance in dying (PAD). This paper provides an account of the PAD debate in this journal over the last 40 years. It concludes that there is some (but limited) progress in the debate. The distinctions, analogies and hypothetical examples have proliferated, as have empirical studies, but very little has changed in terms of the basic arguments. The paper further argues that many of the contributions to the debate fail to engage fully with the concerns people have about the legal introduction of PAD in the healthcare system, perhaps because many of the contributions sit on the borderline between academic analysis and social activism. <http://jme.bmj.com/content/41/1/40.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 December 2014 – **'New Zealanders' attitudes toward physician-assisted dying.'** The results [of this study] have highlighted the high value respondents place on patient autonomy with regards to end-of-life choices; however the choice to hasten death is not a "right" that should be available to all. Results have clearly shown that New Zealanders believe regulation will play a key role in maintaining compliance with any assisted dying legislation, and in restricting access, so that only patients who are suffering intolerably and hopelessly are able to legally gain medical assistance to end their life. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0299>

Noted in Media Watch, 8 December 2014, #387 (p.15):

  - *INTERNATIONAL NURSING REVIEW* | Online – 1 December 2014 – **'Nurses and the euthanasia debate: Reflections from New Zealand.'** In New Zealand, euthanasia remains illegal, but in 2012, the End of Life Choice Bill was put in the ballot for potential selection for consideration by Parliament, later to be withdrawn. However, it is increasingly likely that New Zealand will follow international trends to offer people a choice about how their lives should end, and that such a Bill will be resubmitted in the near future. <http://onlinelibrary.wiley.com/doi/10.1111/inr.12145/abstract>

Noted in Media Watch, 7 July 2014, #365 (p.13):

    - *JOURNAL OF THE NEW ZEALAND MEDICAL ASSOCIATION*, 2014;127(1397). **'A critical analysis of the End of Life Choice Bill 2013.'** If passed into legislation, the End of Life Choice Bill will create the most momentous changes to clinical practice and the regulation of certain professional activities of medical practitioners that this country has ever seen. Whether they choose to be or not, sooner or later every medical practitioner will be affected by the legislation. It therefore behoves every medical practitioner to examine and understand this Bill and its implications. <http://journal.nzma.org.nz/journal/abstract.php?id=6198>
- *PSYCHOLOGY, HEALTH & MEDICINE* | Online – 20 December 2014 – **'Trends of psychology-related research on euthanasia: A qualitative software-based thematic analysis of journal abstracts.'** This study highlighted four different thematic areas which characterized the scientific discourse on euthanasia: 1) moral values, in terms of religious, philosophical, and social implications concerning the individual's decision to die; 2) professional ethics, in terms of health and social workers' legal responsibility in death assistance; 3) end-of-life care, with regard to medical options provided to support individuals nearing death; and, 4) patient's right to healthcare, in terms of access to palliative care and better quality of dying. Euthanasia discourse over the last decades seems to be overall characterized by two main dimensions: 1) the increasing trend of social legitimacy and acceptability of euthanasia over time, which moved from ethical to healthcare issues; and, 2) the curvilinear temporal trend about the request/provision process in euthanasia, which moved from patient's decision for ending life (mainly characterizing the most past and recent research) to the role of health professionals (with a peak in the 1990s). The results suggest palliative care as a potential future research area which can provide healthcare providers with skills to "connect" with patients, understand patients' hidden agendas, and grant a good quality of life and dying process. <http://www.tandfonline.com/doi/abs/10.1080/13548506.2014.993405>

## Worth Repeating

### **Being me and being us in a family living close to death at home**

*QUALITATIVE HEALTH RESEARCH*, 2011;21(5):683-695. The authors used interpretive description to describe how everyday life close to death was experienced and dealt with in families with one member who had a life-threatening illness. They performed 28 individual, couple, and group interviews with five families. The authors found two patterns, namely, "being me in a family living close to death" and "being us in a family living close to death." "Being me" meant that every individual in the family had to deal with the impending death, regardless of whether or not he or she was the person with the life-threatening illness. This was linked to ways of promoting the individual's self-image, or "me-ness." This pattern was present at the same time as the pattern of "being us," or in other words, being a family, and dealing with impending death and a new "we-ness" as a group. "Striving for the optimal way of living close to death" was the core theme. <http://qhr.sagepub.com/content/21/5/683.short>

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