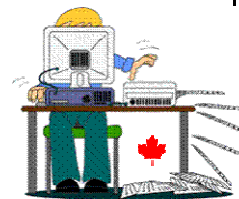


## Media Watch...

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.

24 November 2014 Edition | Issue #385



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

Compiled & Annotated by Barry R. Ashpole

**Palliative care and rehabilitation: Scroll down to [Specialist Publications](#) and 'Goal setting in palliative care: A structured review' (p.13), in *Progress in Palliative Care*.**

## Canada

### Could new approach to seniors save Canada's health-care system? Top doctor says yes

ONTARIO | *The Ottawa Citizen* – 18 November 2014 – The future of Canada's health system depends on rethinking the way seniors are cared for, the president of the Canadian Medical Association [CMA] said... The CMA is calling for a national seniors strategy that would get elderly patients with chronic ailments out of hospitals and into institutions and programs better suited to their needs. Restructuring the health system through a seniors strategy could save it, said association president Dr. Chris Simpson. "Can our universal health-care system remain sustainable? It won't unless we start rethinking seniors care and how it affects the overall system." Canada's 5.2 million seniors make up about 15% of the population, but

account for almost half of all health costs. If nothing changes ... seniors will account for 59% of health costs in 2031. Simpson, chief of cardiology at Kingston General Hospital, called hospitals a toxic environment for patients who have chronic, but not acute, diseases. <http://ottawacitizen.com/news/national/could-new-approach-to-seniors-save-canadas-health-care-system-top-doctor-says-yes>

#### Quote from *The Ottawa Citizen* article

"No longer should just 16% of Canadians have access to palliative care."

Noted in Media Watch, 17 November 2014, #384 (p.2):

- CANADIAN PRESS | Online – 12 November 2014 – '**Family MDs group pushes Ottawa for home-care strategy...**' Canada's family doctors are calling on the federal government to develop a national home-care strategy for seniors... <http://winnipeg.ctvnews.ca/family-mds-group-pushes-ottawa-for-home-care-strategy-plan-to-end-child-poverty-1.2098797>

**N.B.** Footnoted in this issue of Media Watch are several articles on meeting the present and future needs for health and social services of Canada's ageing population noted in past issues of the weekly report.

Cont.

Of related interest:

- ONTARIO | *The Windsor Star* – 20 November 2014 – '**Salaries of top positions at CCAC [Community Care Access Centre] rise despite home care service cuts.**' Over the past five years, the number of salaries higher than \$100,000 at Erie St. Clair CCAC has more than doubled. In 2008, there were 9. In 2013, there were 21. Funded by the Ministry of Health & Long Term Care, Erie St. Clair CCAC is meant to provide and co-ordinate home care for vulnerable sectors of the population – mainly seniors and those who require special medical support. <http://blogs.windsorstar.com/news/salaries-of-top-positions-at-ccac-rise-despite-service-cuts>
- ONTARIO | *The Toronto Star* – 19 November 2014 – '**Home-care system in free fall after more cuts.**' While Ontario Health Minister Eric Hoskins says home and community care are "the cornerstones" of a major health-system transformation, nurses are furious with a fresh wave of cuts in home- and community-care services. Show me the examples of where patient care is suffering, Hoskins said in an interview after his speech [at the Ontario Nurses' Association annual convention]. Well, one person who could show Hoskins some examples is the woman who – ironically – formally introduced the minister ... [at the conference] ... "Appalled. Disgusted. Horrified." Those strong words are used by Linda Haslam-Stroud, president of the nurses' association, to describe how Windsor-area health-care professionals feel about a [re-cent] controversial decision to slash daily nursing home-care services by 33%. [http://www.thestar.com/opinion/commentary/2014/11/19/homecare\\_system\\_in\\_free\\_fall\\_after\\_more\\_cuts\\_hepburn.html](http://www.thestar.com/opinion/commentary/2014/11/19/homecare_system_in_free_fall_after_more_cuts_hepburn.html)

### **Palliative care experts say it's time for Canadians to talk about end-of-life care**

CBC | *The Current* – 17 November 2014 – American oncologist Atul Gawande believes doctors spend so much time helping people live longer, they've neglected how to improve the quality of living towards the end of life. Gawande talks about what he thinks can be done to make the last weeks or months of life more fulfilling. A Canadian perspective is offered by Susan MacDonald, president of the Canadian Society of Palliative Care Physicians and an Associate Professor of Medicine & Family Medicine at Memorial University of Newfoundland, Mark Handelman, a health law lawyer specializing in the legal aspects of end-of-life decisions, and Karen Henderson, of the Long Term Care Planning Network. <http://www.cbc.ca/thecurrent/episode/2014/11/17/being-mortal-and-what-matters-in-the-end/>

Noted in Media Watch, 10 November 2014, #383 (pp.1-2):

- *THE GLOBE & MAIL* | Online – 6 November 2014 – '**End-of-life patients aren't being heard.**' A gap between doctors' goals and patients' wishes may mean seriously ill patients are receiving aggressive forms of treatment that they don't actually want at the end of their lives.<sup>1</sup> <http://www.theglobeandmail.com/life/end-of-life-patients-arent-being-heard/article21479080/>

1. 'What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families,' *Canadian Medical Association Journal*, 3 November 2014. <http://www.cmaj.ca/site/press/cmaj140673.pdf>

Noted in Media Watch, 22 July 2013, #315 (p.2):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 15 July 2013 – '**Just ask: Discussing goals of care with patients in hospital with serious illness.**' Engagement in regular audits of end-of-life communication and decision-making may help drive local quality improvement in the hospital setting. <http://www.cmaj.ca/content/early/2013/07/15/cmaj.121274>

### **[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.

## **Taking Edmonton baby off life support is "kindest" option, judge rules after mother fights to keep her alive**

ALBERTA | *The National Post* – 16 November 2014 – A baby born in Edmonton earlier this year touched off the latest in a string of emotional end-of-life court battles, dying after a judge said removing her from life support was the "kindest" option available, a just-released written ruling reveals. Ava Chalifoux-Campiou was so severely disabled by a deadly genetic defect, she often looked in pain and even had a "silent cry," medical staff said. They insisted she be allowed to succumb to her condition peacefully. Her mother, though, said the girl was a "fighter" and opposed disconnecting her from a ventilator. Still grieving over the deaths of two other children, Roseanne Chalifoux took the hospital to court. The issue of who has the final say on life-and-death medical treatment remains legally hazy in most provinces, despite numerous court clashes. <http://news.nationalpost.com/2014/11/16/taking-edmonton-baby-off-life-support-is-kindest-option-judge-rules-after-mother-fights-to-keep-her-alive/>

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

### **An easier death, and less costly, too**

*THE NEW YORK TIMES* | Online – 20 November 2014 – Saving money isn't really the point of hospice care. Helping dying patients have the best possible remaining life, followed by a good death, is really the purpose. But whether hospice care saves money has prompted debate for years. Most hospice patients die at home, which is what the great majority of Americans say they prefer, or in nursing homes. Wouldn't that save money compared with the cycle of 911 calls and hospitalizations that characterize so many American deaths? Studies of this question have been small and have reported contradictory results. "There hasn't been a lot of consensus," said Dr. Ziad Obermeyer, an emergency physician and health policy specialist at Harvard Medical School. "There are people in the policy establishment who are still skeptical about whether the costs are lower." He hopes the large study he and his colleagues at Brigham and Women's Hospital in Boston published recently<sup>1</sup> ... will finally put that concern to rest. It matched two groups, each containing more than 18,000 older Americans with metastatic cancer, comparing patients who enrolled in hospice with those who had the same poor prognosis but didn't use hospice. The re-

searchers tracked participants in both groups until their deaths. The hospice patients had far fewer hospitalizations and less than half as many intensive care unit stays, their Medicare records showed. They endured half as many invasive procedures. <http://newoldage.blogs.nytimes.com/2014/11/20/an-easier-death-and-less-costly-too/?ref=health&r=0>

### **Specialist Publications**

**'Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: A systematic review'** (p.9), in *Critical Care*.

**'Laws that conflict with the ethics of medicine: What should doctors do?'** (p.9), in *The Hastings Report*.

**'Nearly half of palliative care clinicians plan to exit the field within a decade'** (p.11), in *Oncology Times*.

**'Developing competencies for pediatric hospice and palliative medicine'** (p.12), in *Pediatrics*.

1. 'Association between the Medicare Hospice Benefit and health care utilization and costs for patients with poor-prognosis cancer,' *Journal of the American Medical Association*, 2014; 312(18):1888-1996. [Noted in Media Watch, 17 November 2014, #384 (p.4)] <http://jama.jamanetwork.com/article.aspx?articleid=1930818>

## Health for American seniors better in some areas, worse in others

*U.S. NEWS & WORLD REPORT* | Online – 19 November 2014 – U.S. seniors are sicker than aging populations in other countries and are more likely to struggle with getting access to health care and paying their medical bills, according to a survey...<sup>1</sup> The good news: American seniors are among the most likely to discuss health-promoting behavior with doctors, to have a chronic care plan tailored to their daily life, and to engage in end-of-life care planning. The report appeared to show that all 11 countries surveyed would likely need to reformat portions of their health care systems to support an aging population. Life expectancy is increasing in industrialized countries, but just because citizens are living long doesn't mean they are living well. According to the report, many have chronic conditions and trouble managing their daily lives. They often get care from several providers, take prescription drugs and manage complicated regimens. The survey ... took responses from 15,617 adults age 65 and older. It compared Australia, Canada, France, Germany, The Netherlands, New Zealand, Norway, Swe-

den, Switzerland, the U.K., and the U.S. <http://www.usnews.com/news/blogs/datamine/2014/11/19/health-for-american-seniors-better-in-some-areas-worse-in-others>

### Extract from *Health Affairs* article

There was wide variation in reports across countries of the occurrence of various advance care planning practices. The U.S. stood out for the frequency with which respondents reported having had a conversation (78%) about advance care planning and having a written plan naming a health care proxy (67%), and U.S. respondents were among the most likely to report having a written plan regarding the end-of-life treatment they wanted (55%). Germany and Canada also had large proportions of respondents reporting end-of-life discussions and plans. In contrast, France, Norway and Sweden ranked much lower in reported advance care planning. In France, doctors have traditionally made many end-of-life decisions on behalf of patients, even against the wishes of patients and family members, although that practice is currently under challenge.

1. 'International survey of older adults finds shortcomings in access, coordination, and patient-centered care,' The Commonwealth Fund, published in *Health Affairs*, 19 November 2014. <http://content.healthaffairs.org/content/early/2014/11/13/hlthaff.2014.0947.full.pdf+html>

## Right-to-try laws

### More states adopt laws to ease access to experimental treatments

ARIZONA | National Public Radio – 18 November 2014 – Arizona voters approved a referendum that allows terminally ill patients to receive treatment with drugs and devices that haven't been approved by the Food & Drug Administration. Arizona became the fifth state to approve a so-called right-to-try law this year. Supporters say the laws give patients faster access to experimental, potentially life-saving therapies than the FDA's existing approach, often referred to as "expanded access" or "compassionate use." But critics of the state laws charge that they're feel-good measures that don't address some of the real reasons patients don't receive experimental treatments in the first place. Nevertheless, legislatures in Colorado, Louisiana, Michigan and Missouri also passed right-to-try laws this year as part of a nationwide effort spearheaded by the conservative Goldwater Institute, which hopes to get right-to-try laws on the books in all 50 states. <http://www.npr.org/blogs/health/2014/11/18/364935413/more-states-adopt-laws-to-ease-access-to-experimental-treatments>

## Oversight to hospice programs

### **Fox 4 investigation finds Missouri lags behind in surveying hospice facilities**

MISSOURI | Fox 4 News (Kansas City) – 17 November 2014 – Last year alone more than 1.5 million people in the U.S. needed hospice care, but when it comes to choosing which facility someone you love spends their final moments in, how do you know you're choosing the right one? A FOX 4 investigation found out you can't count on the state of Missouri to ensure your loved ones are safe in their most vulnerable moments. A 1992 statute requires the state to survey hospice facilities once a year, but FOX 4 found one third of hospice care centers in our area haven't been surveyed in at least six years. In the past year, the state has only surveyed three of out 27 in our metro area. Hospice facility directors say they've been told there's not enough money for regular surveys. The Missouri Department of Health & Senior Services says "inspections are done at hospices when possible." The state of Missouri has only 10 inspectors who also handle surveys of outpatient physical therapy and home health facilities, among other programs. <http://fox4kc.com/2014/11/17/fox-4-investigation-finds-missouri-lags-behind-in-surveying-hospice-facilities/>

Noted in Media Watch, 3 November 2014, #382 (p.5):

- *THE WASHINGTON POST* | Online – 26 October 2014 – **'Quality of U.S. hospices varies, patients left in dark.'** Though the federal government publishes consumer data about the quality of other health-care companies ... it provides no such information about hospices. After years of public pressure, Congress in 2010 required that the government publish information about hospice quality, but the Medicare agency said in May that such consumer information would not be forthcoming until 2017 – at the earliest. Similarly, state records of hospice inspections are often unpublished, sparse, and, when ... available, difficult to find and understand. [http://www.washingtonpost.com/business/economy/quality-of-us-hospices-varies-patients-left-in-dark/2014/10/26/aa07b844-085e-11e4-8a6a-19355c7e870a\\_story.html](http://www.washingtonpost.com/business/economy/quality-of-us-hospices-varies-patients-left-in-dark/2014/10/26/aa07b844-085e-11e4-8a6a-19355c7e870a_story.html)

Noted in Media Watch, 13 October 2014, #379 (p.4):

- *THE NEW YORK TIMES* | Online – 6 October 2014 – **'Extra scrutiny for hospices.'** Bipartisan legislation will bring greater federal oversight to hospice programs across the country. [http://newoldage.blogs.nytimes.com/2014/10/06/extra-scrutiny-for-hospices/?\\_php=true&\\_type=blogs&ref=health&\\_r=0](http://newoldage.blogs.nytimes.com/2014/10/06/extra-scrutiny-for-hospices/?_php=true&_type=blogs&ref=health&_r=0)

## **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- NATIONAL PUBLIC RADIO | Online – 20 November 2014 – **'Debate: Should physician-assisted suicide be legal?'** Advocates of assisted-suicide laws believe that mentally competent people who are suffering and have no chance of long-term survival, should have the right to die if and when they choose. If people are have the right to refuse life-saving treatments, they argue, they should also have the freedom to choose to end their own lives. Opponents say that such laws devalue human life. Medical prognoses are often inaccurate, they note – meaning people who have been told they will soon die sometimes live for many months or even years longer. They argue seriously ill people often suffer from undiagnosed depression or other mental illnesses that can impair their ability to make an informed decision. <http://www.npr.org/2014/11/20/365509889/debate-should-physician-assisted-suicide-be-legal>
- PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 18 November 2014 – **'Death with dignity legislation sparks support, opposition in Pennsylvania.'** It's not suicide. That's the stance of two Pennsylvania legislators who recently entered bills into the state House and Senate ... proposing a law similar to Oregon's Death with Dignity Act, which permits terminally ill adult Oregonians to obtain from their doctor and self-administer a lethal dose of medication. <http://www.post-gazette.com/news/health/2014/11/18/Two-state-bills-would-allow-terminally-ill-patients-in-Pennsylvania-to-end-their-own-lives/stories/201411100009>

## International

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

#### **Hardly anyone wants to die in hospital. Let's do something about it**

U.K. (England) | *The Spectator* – 22 November 2014 – Of the 500,000 people who die in England each year, about half die in hospital. Many of these people have no clinical need to be there and very few of them want to die in hospital. In fact, 80% of those asked would choose home or a hospice as the place where they'd prefer to spend their last days. It is hardly surprising that most people would opt to die peacefully at home or in the calm environment of a hospice rather than in a busy, often noisy, hospital ward. Indeed there is mounting evidence that the care which a significant number of people receive in hospitals is inadequate. This was highlighted both in Baroness Neuberger's report on the use of the Liverpool Care Pathway and, more recently, in the National Care of the Dying Audit for Hospitals published earlier this year.<sup>1,2</sup> These shortcomings in care can be traced to a number of causes, including a lack of rele-

vant palliative care skills among hospital doctors. The truth is hospitals have a different culture. Their primary objectives are to mend and cure, so it is not surprising palliative care is not high on their list of priorities. <http://www.spectator.co.uk/health/features-health/9370122/hardly-anyone-wants-to-die-in-hospital-lets-do-something-about-it/>

#### **Specialist Publications**

**'The perceived impact of public involvement in palliative care in a provincial palliative care network in The Netherlands: A qualitative study'** (p.12), in *Health Expectations*.

**'Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care'** (p.11), in *Palliative Medicine*.

1. 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>
2. 'National Care of the Dying Audit of Hospitals,' the Royal College of Physicians in collaboration with the Marie Curie Palliative care Institute Liverpool, 14 May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)] <http://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

#### **Number of elderly dying in Hong Kong while awaiting care home places soars**

CHINA (Hong Kong) | *The South China Morning Post* – 20 November 2014 – The number of elderly people who die while waiting for places in care homes has shot up in the past four years, the Audit Commission has revealed in a damning report. It recommended a review of the assessment system and urged the government to provide more subsidised places to meet rising demand. The commission found that 5,700 people died last year while waiting to enter care homes, up from the average of 4,000 to 4,500 annual deaths recorded before 2010. In addition to the increasing mortality rate, the report showed that the Social Welfare Department had been watering down its statistics to downplay the severity of the space shortage. <http://www.scmp.com/news/hong-kong/article/1644463/5700-hong-kong-elderly-died-awaiting-place-care-home-last-year-1200>

Noted in Media Watch, 13 February 2012, #240 (p.8):

- *ASIAN JOURNAL OF GERONTOLOGY & GERIATRICS*, 2011;6(2):103-106. **'End-of-life care in Hong Kong.'** The Hong Kong government does not have a clear policy on developing end-of-life care services as a critical part of health care, nor on promoting dying in place, either at home or in a residential care home for the elderly ... [where] ... staff are not trained to handle dying patients [http://hkag.org/Publications/AJGG/V6N2/RA1\\_JKH%20Luk.pdf](http://hkag.org/Publications/AJGG/V6N2/RA1_JKH%20Luk.pdf)

## Scottish Palliative Care Guidelines

U.K. (Scotland) | National Health Service Scotland – Accessed 18 November 2014 – The guidelines reflect a consensus of opinion about good practice in the management of adult patients with life limiting illness. They are designed for healthcare professionals from any care setting who are involved in supporting people with a palliative life-limiting condition. The guidelines have been developed by a multidisciplinary group of professionals working in the community, hospital and specialist palliative care services throughout Scotland. <http://www.testing29.scot.nhs.uk/>

**N.B.** The guidelines complement 'Scottish Government Interim Guidance: Caring for people in the last days and hours of life,' National Health Service Scotland, December 2013. [Noted in Media Watch, 23 December 2013, #337 (p.8)] <http://www.scotland.gov.uk/Resource/0044/00441053.pdf>

Noted in Media Watch, 19 May 2014, #358 (p.3):

- U.K. (Scotland) | Scottish Partnership for Palliative Care – 16 May 2014 – '**Call for a new Scottish Government strategy to improve end-of-life care in Scotland.**' Marie Curie Cancer Care and the Scottish Partnership for Palliative Care calls on the Scottish Government to act on recent promises to replace *Living & Dying Well: A national action plan for palliative and end-of-life care in Scotland*. <http://www.palliativecarescotland.org.uk/content/publications/Are-We-Living-and-Dying-Well-Yet-FINAL-REPORT.pdf>

## Public health facilities [in Uganda] lack resuscitation devices, newborn deaths high

UGANDA | *New Vision* (Kampala) – 15 November 2014 – Majority of public health facilities are lacking basic equipment to resuscitate newly born babies leading to a high number of newborn deaths, a new report reveals. The report also indicates that in the few health centers where there is equipment, medical workers do not know how to use it. The study follows a survey that was conducted ... in three pilot districts of Lira, Mityana and Kabale... The district health officer [of] Mityana, Dr. Fred Lwasampijja ... estimated in a month about ten newborn babies die due to failure of midwives to resuscitate them when they are born distressed, tired and cannot breathe. <http://www.newvision.co.ug/news/661863-public-health-facilities-lack-resuscitation-devices-newborn-deaths-high-study.html>

### Access to opioids for the terminally ill

## Keep Russian doctors out of courtroom

RUSSIA | Human Rights Watch – 14 November 2014 – It's rare that a high-level Russian official takes a public stand for justice *vis-a-vis* the law enforcement establishment. But Russia's health minister did just that. The minister, Veronika Skvorstova, publicly endorsed the acquittal of a doctor charged in Krasnoyarsk for prescribing an opioid pain reliever to a man with terminal cancer when his regular physician refused to issue him a prescription. The patient, Viktor Sechin, died in 2011 – the same year Dr. Alevtina Khorniyak, and a pharmacist, Lidia Tabarintseva, faced drug trafficking charges for helping him get pain relief. On 31 October, after a three-year legal battle, Khorniyak and Tabarintseva won their case. Skvortsova praised Khorniyak, saying that she "did the right thing and it's the right thing that she has been acquitted." And, the minister continued, "Those who allowed shortages of [the medication] are the ones who should stand trial ... they were not only witnesses; they were complicit" in causing a dying man to suffer. Skvortsova finally voiced what has been obvious from the very start: instead of prosecuting the two women for fulfilling a dying man's right to be free from pain, authorities should have made sure that no patients suffer in [the] absence of pain treatment. <http://www.hrw.org/news/2014/11/14/dispatches-keep-russian-doctors-out-courtroom>

Cont.

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | *World Report 2014* (Extract, p.478) – 23 January 2014 – '**Palliative care: International perspective.**' Restrictive government policies [in Russia] and limited availability of pain treatment persists and severely hinders the delivery of palliative care. Each year, tens of thousands of dying cancer patients are denied their right to adequate pain relief. [http://www.hrw.org/sites/default/files/wr2014\\_web\\_0.pdf](http://www.hrw.org/sites/default/files/wr2014_web_0.pdf)

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- SWITZERLAND | Swissinfo.com – 19 November 2014 – '**Most doctors back assisted suicide – but few would do it.**' Three-quarters of Swiss doctors think assisted suicide is acceptable in principle, but fewer than half are personally prepared to carry it out, according to a study by the Swiss Academy of Medical Sciences (SAMS). "The results show the ambivalence of doctors concerning this issue," said Michelle Salathé, SAMS deputy general-secretary. For the majority of the 1,318 respondents, support for assisted suicide depended on the specific situation: the more clearly a purely physical and terminal disease is present, the greater the acceptance of physician-assisted suicide. Thus, three-quarters were opposed to assisted suicide in the case of people who are old but otherwise healthy, while over half rejected assisted suicide for patients with mental illness. The study ... also investigated physicians' personal experiences in this area: somewhat less than half of the respondents had, on at least one occasion, received a serious request for assisted suicide. <http://www.swissinfo.ch/eng/most-doctors-back-assisted-suicide---but-few-would-do-it/41124062>
- AUSTRALIA (Queensland) | *The Brisbane Times* – 16 November 2014 – '**The euthanasia lobby has hijacked the phrase "dying with dignity."**' The hijacking of the term "dying with dignity" by supporters of euthanasia and assisted suicide is an insult to the dedicated doctors, nurses and pastoral carers who daily provide compassionate care, pain alleviation and spiritual comfort to the sick, the dying and their families. Debates about euthanasia and assisted suicide are emotionally harrowing. All the more so when they occur during election campaigns. The timing and manner of the current debate exacerbates the fear of dying held by many in the community and diverts attention from the conversation about providing the dying with the innovative medical and healthcare they need, in homes, hospitals and aged-care facilities. <http://www.brisbanetimes.com.au/comment/the-euthanasia-lobby-has-hijacked-the-phrase-dying-with-dignity-20141114-11mpcg.html>

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

#### **Grief and Major Depression – Controversy over changes in *DSM-5* diagnostic criteria**

*AMERICAN FAMILY PHYSICIAN*, 2014;90(10):690-694. In May 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic & Statistical Manual of Mental Disorders* (DSM-5). One of the more controversial revisions in the *DSM-5* is the elimination of the bereavement exclusion criterion for major depressive disorder (MDD), suggesting to some that grief is not a normal process. Within the *DSM-5* text revision, persons who experienced the death of a loved one and who had a depressed mood would not be diagnosed with MDD unless symptoms persisted beyond two months or were characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation. <http://www.aafp.org/afp/2014/1115/p690.html>

**N.B.** Articles on *DSM-5* noted in past issues of Media Watch: 2 December 2013, #334 (p.10); 30 September 2013, #325 (p.12); and, 13 May 2013, #305 (pp.4-5).

Cont.



Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2014;70(2):169-194. **'The possible effects on bereavement of assisted after-death communication during readings with psychic mediums: A continuing bonds perspective.'** Effects of traditional grief counseling, with its focus on the client's acceptance of separation and integration of loss, are unclear. Within the model of continuing bonds, however, grief resolution includes an ongoing relationship between the living and deceased. Spontaneous and induced experiences of after-death communication have been shown to be beneficial in the resolution of grief by demonstrating these continued bonds. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,4:journal,1,276;linkingpublicationresults,1:300329,1>

### **Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: A systematic review**

*CRITICAL CARE* | Online – 18 November 2014 – The aim of this ... review was to describe physician-related barriers to adequate communication within the team and with patients and families, and to patient and family-centred decision making, towards the end of life in ICU, according to the quality indicators ... developed by the Robert Wood Johnson Foundation's critical care end-of-life peer workgroup. The authors determined 90 barriers, of which 46 related to physician attitudes, 24 to physician knowledge and 20 to physician practice. Stronger evidence was found for physicians' lack of communication training and skills, their attitudes towards death in the ICU and their focus on clinical parameters and lack of confidence in their own judgment of the patient's true condition. <http://ccforum.com/content/pdf/s13054-014-0604-z.pdf>

### **Laws that conflict with the ethics of medicine: What should doctors do?**

*THE HASTINGS REPORT*, 2014;44(6):11-14. This past July, five professional societies, whose members together provide the majority of clinical care in the U.S., published a statement objecting to "inappropriate legislative interference" with the physician-patient relationship and reiterated the importance of "putting patients' best interests first." What should a physician do when confronted with a law that attempts to intervene in the doctor-patient relationship in a way that the physician believes undercuts good medical care? [http://www.thehastingscenter.org/Publications/HC\\_R/Detail.aspx?id=7180](http://www.thehastingscenter.org/Publications/HC_R/Detail.aspx?id=7180)

### **Caregivers of people at the end of life: Emerging evidence**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE*, 2014;8(4):391-393. It appears that although the volume and quality of studies reporting outcomes for this population is increasing, there is still a paucity of evidence that has reliable quality and can inform policy and practice. One trial has been reported, which found that a one-to-one psycho-educational intervention found no change in distress at 1 week after intervention, but found improvements in preparedness and competence. Follow-up data at 8 weeks found that distress worsened significantly less for those with one home visit, but surprisingly not for those who received two visits ... compared with controls. Although the evidence of outcome studies is small, the research agenda is broadening to include non-traditional families and caregivers in low-and middle-income countries. [http://journals.lww.com/co-supportiveandpalliative-care/Fulltext/2014/12000/Caregivers\\_of\\_people\\_at\\_the\\_end\\_of\\_life\\_emerging.14.aspx](http://journals.lww.com/co-supportiveandpalliative-care/Fulltext/2014/12000/Caregivers_of_people_at_the_end_of_life_emerging.14.aspx)

Cont.

Of related interest:

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE*, 2014;8(4):394-398. **'Trust and autonomy in end of life: Considering the interrelation between patients and their relatives.'** Our study results and recent literature suggest that existing relational patterns determine experiences, family dynamics, and decision-making processes at the end of life. Relatives as a resource can promote patients' autonomy. In doubt of the patients' judgment or prioritizing their own needs, relatives can undermine patient's autonomy in a paternalistic way. Trust in others should be seen as a reciprocal process. [http://journals.lww.com/care/Fulltext/2014/12000/Trust\\_and\\_autonomy\\_in\\_end\\_of\\_life\\_considering\\_the.15.aspx](http://journals.lww.com/care/Fulltext/2014/12000/Trust_and_autonomy_in_end_of_life_considering_the.15.aspx)

### **Mr. Roberts wanted treatment: He wanted to treat his death**

*THE HASTINGS REPORT*, 2014;44(6):5-6. At face value, his question seemed sensible. We target cancer with chemotherapy and bone pain with narcotics. Why not also treat the "pathology" of dying? There exists precedent, after all, for the medicalization of less common human traits or conditions: shyness has become social anxiety disorder, and nocturnal leg jerking has become periodic limb movement disorder. We have developed therapies for these. It could follow that Mr. Roberts's dying might become a "life sustenance disorder" for which we could also prescribe therapy. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=7185>

### **Student nurses learning about death, dying, and loss: Too little, too Late?**

*ILLNESS, CRISIS, & LOSS*, 2014;22(4):293-310. Concerns about the care provided to people dying from life-threatening illness have prompted a number of international reforms to improve the quality of palliative and end-of-life (EOL) care. The majority of this care is provided by nurses. They spend more time with dying patients than any other health professionals and therefore, need specific clinical skills and knowledge. Palliative and EOL care education is increasingly being positioned as a specialism, available only to a small number of registered nurses as part of continuing professional development. However, increasing numbers of patients with life-threatening illness are being treated in non-specialist settings by nurses with a generalist education. Furthermore, undergraduate nurse education has traditionally had a limited focus on palliative and EOL care, hence claims that undergraduate nursing curricula are inadequate. This review explores the evidence about the adequacy of undergraduate curricula in this area. It considers the extent to which palliative and EOL curriculum is included in undergraduate nurse education and draws upon evidence from students and registered nurses, who as consumers of education, report feeling unprepared to care for and communicate with, dying patients. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,9;journal,1,80;linkingpublicationresults,1:103734,1>

Noted in Media Watch, 14 January 2013, #288 (p.3):

- U.S. (Massachusetts) | *The New York Times* – 10 January 2013 – **'As nurse lay dying, offering herself as instruction in caring.'** It was early November when Martha Keochareon called the nursing school at Holyoke Community College, her *alma mater*. She had a proposal... "I have cancer," she said after introducing herself, "and I'm wondering if you'll need somebody to do a case study on, a hospice patient." <http://www.nytimes.com/2013/01/11/us/fatally-ill-and-making-herself-the-lesson.html?pagewanted=all>

Noted in Media Watch, 5 November 2012, #278 (p.7):

- *NURSE EDUCATION IN PRACTICE* | Online – 29 October 2012 – **'Seeing is believing – Reducing misconceptions about children's hospice care through effective teaching with undergraduate nursing students.'** Education can go part way to changing attitudes and knowledge about the key contribution of hospices, thus improving future care. Alternative and innovative strategies to stimulate meaningful learning are pivotal to children's nurse education and this paper examines one such innovation adopted with 2nd year children's nursing students. [http://www.nurseeducationinpractice.com/article/S1471-5953\(12\)00173-4/abstract](http://www.nurseeducationinpractice.com/article/S1471-5953(12)00173-4/abstract)

## Medical humanities in Nepal: Present scenario

*JOURNAL OF NEPAL MEDICAL ASSOCIATION*, 2014;52(193):746-749. Humanities have an essential role in medical education. The current gap between the humanities and medicine has to be bridged and there should be continuous and vigorous debate about the theory and practice of medical humanities. Medical humanities is a relatively new concept even in developed countries, and is at infancy stage in developing countries. In Nepal, modules on medical humanities have been initiated in certain medical schools by enthusiastic faculties and it requires further debates for inclusion in the curriculum. <http://jnma.com.np/jnma/index.php/jnma/article/viewFile/1187/1707>

### U.S. national survey

#### Nearly half of palliative care clinicians plan to exit the field within a decade

*ONCOLOGY TIMES* | Online – 14 November 2014 – Forty-five percent of palliative care clinicians [surveyed] ... are seriously thinking of leaving the field within the next 10 years. And one in four say there is a good chance they will leave by 2018. "If you round on wards, this is the type of statement you hear quite often: 'I just don't know how much longer I can do this,'" said Arif H. Kamal, Director of Quality & Outcomes at Duke Cancer Institute, speaking at the [recent] Palliative Care in Oncology Symposium. Kamal, a medical oncologist and palliative care physician, presented findings from a survey of members of the American Academy of Hospice & Palliative Medicine. While retirement is the most common reason palliative care specialists are planning to leave, many survey respondents cited burnout as one reason they are considering their exit. <http://journals.lww.com/oncology-times/blog/asco11spotlightnews/pages/post.aspx?PostID=167>

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

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

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

#### Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care

*PALLIATIVE MEDICINE* | Online – 13 November 2014 – A multidisciplinary European Association of Palliative Care Taskforce was established to scope the extent of and learn what facilitates and hinders the development of palliative care in the community across Europe. Being unable to identify appropriate patients for palliative care in the community was a major barrier internationally. The systematic review identified tools that might be used to help address this. Various facilitators such as national strategies were identified. A primary palliative care toolkit has been produced and refined, together with associated guidance. Many barriers and facilitators were identified. <http://pmj.sagepub.com/content/early/2014/11/12/0269216314545006.abstract>

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#### [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>

Of related interest:

- **HEALTH EXPECTATIONS** | Online – 19 November 2014 – '**The perceived impact of public involvement in palliative care in a provincial palliative care network in The Netherlands: A qualitative study.**' The perceived impact of public involvement in palliative care in terms of citizen control and partnership is greatest with regard to quality of care, information development and dissemination, and in terms of policymaking with regard to the preparation and implementation phases of decision making. Improving public involvement in palliative care requires positive attitudes, open communication, sufficient resources and long-term support to build a solid basis for pursuing meaningful involvement in the entire decision-making process. <http://onlinelibrary.wiley.com/doi/10.1111/hex.12308/abstract>

#### American Board of Hospice & Palliative Medicine Competencies Work Group

#### **Developing competencies for pediatric hospice and palliative medicine**

**PEDIATRICS** | Online – 17 November 2014 – In 2006, hospice and palliative medicine (HPM) became an officially recognized subspecialty. This designation helped initiate the Accreditation Council of Graduate Medical Education Outcomes Project in HPM. As part of this process, a group of expert clinician-educators in HPM defined the initial competency-based outcomes for HPM fellows (General HPM Competencies). Concurrently, these experts recognized and acknowledged that additional expertise in pediatric HPM would ensure that the competencies for pediatric HPM were optimally represented. To fill this gap, a group of pediatric HPM experts used a product development method to define specific Pediatric HPM Competencies. This article describes the development process. With the ongoing evolution of HPM, these competencies will evolve. <http://pediatrics.aappublications.org/content/early/2014/11/12/peds.2014-0748.abstract>

Of related interest:

- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 20 November 2014 – '**Comparison of pediatric and adult hospice patients using electronic medical record data from nine hospices in the U.S., 2008-2012.**' Among 126,620 hospice patients, 986 (0.8%) were 18 years of age or younger. Pediatric patients were less likely to have an admitting diagnosis of cancer... Although children were less likely to use oxygen at enrollment ... they were more likely to have an enteral feeding tube... Pediatric patients were half as likely as adults to have a do-not-resuscitate order upon hospice enrollment...The average hospice length of stay for pediatric patients was longer than that of adults... Children were more likely to leave hospice care ... but among patients who died while enrolled in hospice, pediatric patients were more likely to die at home... <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0195>
- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 17 November 2014 – '**Improved quality of life at end of life related to home-based palliative care in children with cancer.**' This is the first North American study to assess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a pediatric palliative care home care program appear to have improved quality of life and are more likely to die at home. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0285>



#### 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>

## Canadian Health care Evaluation Project

### Factors affecting family satisfaction with inpatient end-of-life care

*PLOS ONE* | Online – 17 November 2014 – Little data exists addressing satisfaction with end-of-life care among hospitalized patients, as they and their family members are systematically excluded from routine satisfaction surveys. The Canadian Health care Evaluation Project (CANHELP) Bereavement Questionnaire was mailed to the next-of-kin of recently deceased inpatients to seek factors associated with satisfaction with end-of-life care. Nearly three-quarters of recently deceased inpatients [i.e., respondents] would have preferred an out-of-hospital death. Intensive care units were a common, but not preferred, location of in-hospital deaths. Family satisfaction with end-of-life care was strongly associated with their relative dying in their preferred location. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0110860>

**N.B.** The Canadian Health care Evaluation Project (CANHELP) Bereavement Questionnaire: <http://www.thecarenet.ca/docs/CANHELPBereavementQuestionnaire.pdf>

## Palliative care and rehabilitation

### Goal setting in palliative care: A structured review

*PROGRESS IN PALLIATIVE CARE*, 2014;22(6):326-333. Palliative care and rehabilitation both aim to support patients to live as actively as possible. Goal setting has been identified in health policy and clinical guidelines as a mechanism to achieve this. While goal setting is well established in traditional rehabilitation, it is unclear how it should be implemented within palliative care where people are faced with diminishing abilities. The authors identify and synthesize published literature regarding goal setting in palliative care. Themes identified: 1) definition, process, and functions of goal setting; 2) challenges of delivering goal setting; and, 3) theories underpinning goal setting. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000097>

Noted in Media Watch, 21 July 2014, #367 (p.8):

- *BMJ CASE REPORTS* | Online – 9 July 2014 – '**The role of palliative rehabilitation in the preservation of personhood at the end of life.**' The authors highlight the impact of rehabilitative measures on efforts to preserve the personhood of a patient with metastatic renal cell carcinoma and thus maintain her dignity and quality of life and provide her with appropriate and effective holistic care at the end of life. <http://casereports.bmj.com/content/2014/bcr-2014-204780.full>

Noted in Media Watch, 17 February 2014, #345 (p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – Accessed 12 February 2014 – '**Hope, positive illusions and palliative rehabilitation.**' The author's suggestion is that palliative rehabilitation specialists should resist the temptations of inflation and glamorisation, and begin to use the word [hope] more precisely, modestly, and transparently. There is no such thing as "hope" the life force, "hope" the inner power, "hope" the universal human phenomenon, or "hope" the theological virtue. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000084>



## Ethical dilemmas faced by hospice social workers

*SOCIAL WORK IN HEALTH CARE*, 2014;53(10):950-968. Through in-depth interviews, researchers explored ethical dilemmas faced by 14 hospice social workers and the processes they used to move toward resolution. The dilemmas were integrated into a framework focused on the sources of ethical conflict: the client system, the agency, and the profession. Processes involved in resolving ethical dilemmas included consulting with other professionals, weighing the pros and cons of options, and bringing about desired outcomes. Findings suggest that hospice teams should be provided with opportunities to meaningfully discuss ethical decision making. <http://www.tandfonline.com/doi/abs/10.1080/00981389.2014.950402?queryID=%24%7BresultBean.queryID%7D>

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### Media Watch Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/media-watch/>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

#### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and [www.ipcrc.net/archive-global-palliative-care-news.php](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

#### **Canada**

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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=b623758904ba11300ff652fd7fb9f0c>

Noted in Media Watch, 10 November 2014, #383 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):300-305. '**Core competencies for palliative care social work in Europe: An European Association for Palliative Care White Paper – Part 1.**' This White Paper is the culmination of work undertaken ... to examine the diversity of roles, tasks and education of palliative care social workers in Europe.

**N.B.** Access to this article requires a subscription. *European Journal of Palliative Care* contents: [http://www.haywardpublishing.co.uk/\\_year\\_search\\_review.aspx?JID=4&Year=2014&Edition=519](http://www.haywardpublishing.co.uk/_year_search_review.aspx?JID=4&Year=2014&Edition=519)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 18 November 2014 – '**Euthanasia: Discussion before decision.**' The fact that terminally ill patients in Quebec now have a legal right to physician-led euthanasia doesn't mean doctors in the province are eager to broach the subject. But it does mean they can no longer avoid the topic if a patient brings it up. Under the new law, no physician can be forced to hasten a patient's death, but the treating physician is expected to perform the task. To avoid doing so, a physician must consult the chief of his or her institution to find a solution. It is possible, then, that doctors may earn reputations for refusing to participate actively in euthanasia or, conversely, for participating too often. [http://www.cmaj.ca/site/earlyreleases/18nov14\\_euthanasia-discussion-before-decision.xhtml](http://www.cmaj.ca/site/earlyreleases/18nov14_euthanasia-discussion-before-decision.xhtml)

### 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.

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