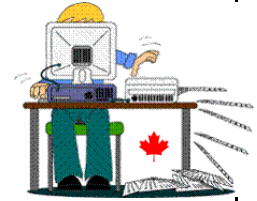


## **Media Watch...**

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

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

**Working collaboratively and efficiently: Scroll down to [Specialist Publications](#) and 'Improving palliative care team meetings: Structure, inclusion, and "team care" (p.7), in *American Journal of Hospice & Palliative Medicine*.**

## **Canada**

### **Doctors worry how organ donations will be affected by Supreme Court ruling on assisted suicide**

*THE NATIONAL POST* | Online – 17 March 2015 – As the nation awaits legalized doctor-assisted death, the transplant community is grappling with a potential new source of life-saving organs – offered by patients who have chosen to die. Some surgeons say every effort should be made to respect the dying wishes of people seeking assisted death, once the Supreme Court of Canada ruling comes into effect next year, including the desire to donate their organs. But the prospect of combining two separate requests – doctor-assisted suicide and organ donation – is creating profound unease for others. Some worry those contemplating assisted suicide might feel a societal pressure to carry through with the act so that others might live, or that it could undermine struggling efforts to increase Canada's mediocre donor rate. "Given the controversy and divided opinion regarding physician-assisted suicide in Canada, I don't think we are anywhere near being ready to procure the organs of patients who might choose this path," said Dr. Andreas Kramer, medical director of the Southern Alberta Organ & Tissue Donation Program in Calgary. "I think there is a legitimate possibility that advocating aggressively for this could compromise the trust that the Canadian public has in current organ-donation processes," Dr. Kramer said. <http://news.nationalpost.com/2015/03/17/doctor-assisted-dying-organ-donations-ethics/>

Noted in Media Watch, 9 February 2015, #396 (p.3):

- CBC NEWS | Online – 6 February 2015 – **'Supreme Court allows doctor-assisted suicide in specific cases.'** The Supreme Court of Canada says a law that makes it illegal for anyone to help a person commit suicide should be amended to allow doctors to help in specific situations. The ruling applies to competent adults with enduring, intolerable suffering who consent to ending their lives. The court has given federal and provincial governments 12 months to craft legislation to respond to the ruling; the ban on doctor-assisted suicide stands until then. <http://www.cbc.ca/news/politics/supreme-court-allows-doctor-assisted-suicide-in-specific-cases-1.2947487>

**N.B.** In this issue of Media Watch is a listing of articles, reports, etc., on the Supreme Court's ruling. See the issue of the weekly report of 16 February 2015, #397 (p.3) for additional press coverage of same.

## U.S.A.

### By sharing death on the Web, dying may not feel so alone

*TIME MAGAZINE* | Online – 17 March 2015 – While it's common to blame the Net and our smart phones for the isolation that does indeed plague our society as a whole, it must be said that in some very important areas, these technologies and platforms are breaking down barriers. <http://time.com/3746236/dying-end-of-life-social-media/>

### Organ donation and end-of-life care

#### As they lay dying

*THE ATLANTIC* | Online – 16 March 2015 – When the term *brain death* was introduced half a century ago, it was meant to provide an objective legal definition for a group of patients whom we might otherwise describe as "unrecoverable." Of course, we also recognize as "unrecoverable" many patients who do not meet the standard for brain death. Those who have suffered devastating strokes or heart attacks, or who have sustained major head trauma, may not be brain-dead even though they have brain injuries that render them unable to survive without life support. A more useful ethical standard could involve the idea of "imminent death." Once a person with a terminal disease reaches a point when only extraordinary measures will delay death; when use (or continued use) of these measures is incompatible with what he considers a reasonable quality of life; and, when he therefore decides to stop aggressive care, knowing that this will, in relatively short order, mean the end of his life, we might say that death is

"imminent." If medical guidelines could be revised to let people facing imminent death donate vital organs under general anesthesia, we could provide patients and families a middle ground – a way of avoiding futile medical care, while also honoring life by preventing the deaths of other critically ill people. Moreover, healthy people could incorporate this imminent-death standard into advance directives for their end-of-life care. They could determine the conditions under which they would want care withdrawn... <http://www.theatlantic.com/magazine/archive/2015/04/as-they-lay-dying/386273/>

#### Specialist Publications

**"But I'm brain-dead and pregnant": Advance directive pregnancy exclusions and end-of-life wishes'** (p.12), in *William & Mary Journal of Women and the Law*.

Selected articles on organ donation in the context of end-of-life care noted in past issues of Media Watch:

- *JOURNAL OF MEDICAL LAW & ETHICS*, 2014;2(2-3):23-35. **'Losing faith in the dead donor rule.'** According to the dead donor rule, vital organs can only be removed from donors who are already dead. Organ procurement ... must not be the cause of their deaths. The rule purports to protect dying and vulnerable individuals from being sacrificed for the benefit of other people who are in need of those organs. [Noted in Media Watch, 22 September 2014, #376 (p.12)] <http://www.ingentaconnect.com/content/plp/jmle/2014/00000002/F0020002/art00002>
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 3 October 2013 – **'The dead-donor rule and the future of organ donation.'** The ethics of organ transplantation have been premised on "the dead-donor rule," which states that vital organs should be taken only from persons who are dead. Yet it is not obvious why certain living patients, such as those who are near death but on life support, should not be allowed to donate their organs, if doing so would benefit others and be consistent with their own interests. [Noted in Media Watch, 7 October 2013, #326 (p.9)] <http://www.nejm.org/doi/full/10.1056/NEJMp1307220>

Cont.

- *END OF LIFE JOURNAL*, 2012;2(2). **'The barriers to organ and tissue donation in palliative care.'** Discussions about organ/tissue donation are now expected to become part of end-of-life care discussions, when appropriate. This article explores the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones, and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. Recommendations for practice will also be made. [Noted in Media Watch, 9 July 2012, #261 (p.9)] <http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care>

## Diagnosis and prognosis

### What patients prefer to know

*THE NEW YORK TIMES* | Online – 16 March 2015 – If you had a serious illness, how much would you want to know about it? Dr. Rachel A. Freedman, an oncologist who specializes in breast cancer at the Dana Farber Cancer Institute in Boston, said she noticed a few years ago that many patients who were referred to her had little understanding of their disease or its treatment. There was hardly any published information on what patients knew about their own cancers, so Dr. Freedman and some colleagues decided to conduct a study. They asked 500 women four questions: Did they know the stage of their tumor, the grade (an indicator of how aggressive a cancer is), and whether it was fed by estrogen or a growth factor called HER-2? "Nobody's ever looked at this before, and it's a simple set of questions," she said. The researchers compared the women's answers with their medical records. The results ... showed that a little more than half of the women knew their cancer's stage and its estrogen and HER-2 status.<sup>1</sup> Only 20% knew the grade. Blacks and Hispanics tended to know less than whites. The study did not determine why the patients knew so little. "It's hard to know if doctors aren't discussing it, or if patients aren't hearing it," Dr. Freedman said. [http://www.nytimes.com/2015/03/17/health/what-patients-prefer-to-know.html?ref=health&\\_r=0](http://www.nytimes.com/2015/03/17/health/what-patients-prefer-to-know.html?ref=health&_r=0)

1. 'Racial/ethnic disparities in knowledge about one's breast cancer characteristics,' *Cancer*, 2015;121(5):724-732. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28977/abstract>

Of related interest:

- NEWSWORKS | Online – 20 March 2015 – **'Keeping "death" out of cancer conversations.'** Turn on the evening news, drive by a cancer center bill board, stop in at a fundraiser and you'll likely catch buzzwords like "cure," "conquer," "breakthrough" and "fight." This language has worked well for medical centers and advocacy groups, bringing in patients and raising billions in research dollars... But there are two terms you probably won't find front and center: "death" and "dying." That's even though cancer is a leading cause of death in the U.S., second only to heart disease. The American Cancer Society ... has not used those terms in major campaigns. The general absence of the term may make sense from a marketing perspective, but some worry the tendency to instead focus on treatment and battle narratives stifles important, tough conversations about the realities of the disease and how to really help those with cancer... <http://www.newsworks.org/index.php/thepulse/item/79592-keeping-qdeathq-out-of-cancer-conversations>
- *THE NEW YORK TIMES* | Online – 19 March 2015 – **'The importance of sitting with patients.'** Surely patients want to be seen and treated in a timely manner, but when we sacrifice empathy for efficiency we fuel what lays at the core of patient – and physician – discontent with modern medicine. We hide behind buzzwords like "patient-centeredness" and "shared decision-making" without being able to offer the time that gives these terms true weight. [http://well.blogs.nytimes.com/2015/03/19/the-importance-of-sitting-with-patients/?ref=health&\\_r=0](http://well.blogs.nytimes.com/2015/03/19/the-importance-of-sitting-with-patients/?ref=health&_r=0)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CONNECTICUT | FOX News (Hartford) – 15 March 2015 – **'Hearing planned on latest Connecticut doctor assisted suicide bill.'** Lawmakers are revisiting legislation that would allow physicians to prescribe medication to help terminally ill patients to end their lives. Similar proposals have died in the legislature's Public Health Committee in past two legislative sessions. <http://foxct.com/2015/03/15/hearing-planned-on-latest-connecticut-doctor-assisted-suicide-bill/>
- THE NEW YORK TIMES | Online – 15 March 2015 – **'Offering a choice to the terminally ill.'** Currently, only Oregon, Washington, Vermont, New Mexico and Montana allow health care providers, under strict guidelines, to hasten the death of terminally ill patients who wish to spare themselves and their loved ones from the final, crippling stages of deteriorating health. Lawmakers in 15 other states and the District of Columbia have introduced so-called aid in dying bills... [http://www.nytimes.com/2015/03/15/opinion/sunday/offering-a-choice-to-the-terminally-ill.html?\\_r=0](http://www.nytimes.com/2015/03/15/opinion/sunday/offering-a-choice-to-the-terminally-ill.html?_r=0)
- MONTANA | The Montana Standard (Butte) – 13 March 2015 – **'House deadlocks on bill to outlaw doctor-assisted suicide.'** The Montana House deadlocked 50-50 on a bill outlawing physician-assisted suicide in Montana, possibly killing the measure one day after appearing to approve it. The House had voted 51-49 on Thursday to give preliminary approval to House Bill 477. On Friday's final and binding vote Representative Bruce Meyers changed his "yes" vote to a "no," forging the 50-50 vote that will kill the measure unless the House decides to reconsider. [http://mtstandard.com/news/local/house-deadlocks-on-bill-to-outlaw-doctor-assisted-suicide/article\\_512f9beb-4af8-5c54-827b-789e139ebdf9.html](http://mtstandard.com/news/local/house-deadlocks-on-bill-to-outlaw-doctor-assisted-suicide/article_512f9beb-4af8-5c54-827b-789e139ebdf9.html)

## International

### End-of-life care in Australia

#### **More than 60% senior Australians use aged care programs before they die: Report**

AUSTRALIA | The Canberra Times – 18 March 2015 – More than 60% of senior Australians die in aged care programs with a further 75% accessing services in the 12 months before their death, according to a new national report.<sup>1</sup> The report ... found 116,500 Australians aged 65 years or older died during 2010-2011 with women dying at an average age of 85.2 years compared with 81.5 years for men. The report found residential aged care was the final program used by more than half of the deceased and a further 36% passed away while receiving community care. The average age of death for those aged over 65 years was 83.4 years old with men more likely to die before women. Those who did not access aged care services died six years earlier on average at 78 years old. The report found that 62% of people studied were a client of an aged care program when they died. <http://www.canberratimes.com.au/act-news/more-than-60-per-cent-of-senior-australians-use-aged-care-programs-before-they-die-aihw-report-20150317-1m0zvm.html>

1. 'Use of Aged Care Services Before Death,' Australian Institute of Health & Welfare, March 2015. <http://www.aihw.gov.au/publication-detail?id=60129550413>

Of related interest:

- AUSTRALIA | ABC News – 20 March 2015 – **'Disadvantaged Australians missing out on end-of-life planning and care: Research.'** Homeless and chronically mentally ill people are missing out on end-of-life planning and care, according to research commissioned by support service Footprints. The research highlights the cares of Australia's most marginalised people. The research found that homeless people living at boarding houses were at risk of being moved on if they were diagnosed with a terminal illness. <http://www.abc.net.au/news/2015-03-20/disadvantage-does-not-end-with-death/6336932>

Cont.

- AUSTRALIA (Queensland) | My Sunshine Coast – 20 March 2015 – **'Extended palliative care services for Queenslanders.'** Patients and their families now have greater access to support thanks to an extension of Queensland's palliative care helpline, PalAssist. The service, operated by Cancer Council Queensland, is now being offered 24 hours a day, 7 days a week... This is a no cost telephone and online service which offers immediate advice and emotional support for patients, carers, family and friends. <http://mysunshinecoast.com.au/articles/article-display/extended-palliative-care-services-for-queenslanders,37702>
- AUSTRALIA | Palliative Care Australia – 19 March 2015 – **'Indigenous access to palliative care services in Australia.'** Indigenous access to palliative care services remains a concern, with continued gaps in access for rural and remote communities across Australia. Research shows that 73% of city dwellers accessed palliative care before they died compared with only 52% of people from the bush. <http://pallcare.org.au/Default.aspx?tabid=1114>

#### House of Commons Health Committee on end-of-life care

#### **Fears over death wish databases that doctors say mean elderly could be left to die at home rather than saved at hospital**

U.K. (England) | *The Daily Mail* – 14 March 2015 – A "worrying" scheme to construct a series of computer databases containing the details of how every elderly person wants to die is being recommended by MPs. They are pressing Ministers to push ahead with a universal system for recording people's death wishes – despite fears people could be denied life-saving hospital treatment. Doctors or nurses would ask elderly patients where they want to die and whether they would prefer treatment to be withheld if all appears lost. Their wishes would then be added to databases to be shared with GPs, hospital staff and ambulance crews. The Health Select Committee wants to reduce the number of dying patients being ferried to hospital for "unnecessary" reasons. While around 7 in 10 people say they want to die in their own homes, only 2 in 10 actually do. Too often, according to a report from the committee today,<sup>1</sup> doctors carry information about where and how their patients want to die "in their heads." Under the new system, if a patient has indicated they want to die at home, this information will be passed to paramedics called to an emergency. There are concerns hard-pressed National Health Service bosses may be in favour of home deaths for financial reasons. Nationwide use of "electronic palliative care co-ordination schemes" could save £50 million a year, it is estimated. <http://www.dailymail.co.uk/news/article-2995242/Fears-death-wish-databases-doctors-say-mean-elderly-left-die-home-saved-hospital.html>

#### **Nobody wants to insure themselves against the cost of end-of-life care**

*THE ECONOMIST* | Online – 14 March 2015 – The average stay in a nursing home lasts 17 months and costs £57,000 (\$85,000) according to the Centre for Economics & Business Research, a think-tank. People with assets under £23,250 get most of their residential care paid for but everyone else is more-or-less on their own, with the unluckiest facing bills as high as £200,000. Ever-attuned to the plight of elderly voters, the government is moving to change that. Next year it will put a cap of £72,000 on the sum that a person will have to pay towards care, and will raise the means-testing threshold from £23,250 to £118,000. The government had hoped that this reform would not just soothe elderly nerves but also stimulate an insurance market for end-of-life care. Unfortunately, that is not happening. <http://www.economist.com/news/britain/21646238-nobody-wants-insure-themselves-against-cost-end-life-care-forever-young>

#### **Specialist Publications**

***'Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death'*** (p.11), posted by the Resuscitation Council (U.K.), British Cardiovascular Society & National Council for Palliative Care.

Cont.



1. 'End-of-Life Care,' Fifth Report of Session 2014-2015, House of Commons Health Committee, 15 March 2015. [Noted in Media Watch, 16 March 2015, #401 (p.4)] <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>

Representative sample of media coverage on the Health Committee's report

- U.K. (England) | *The Daily Mail* – 16 March 2015 – '**Plans to let critically ill die at home may repeat flaws of "death pathway," warns leading neurologist.**' A plan to draw up a "death list" of how every ill or elderly person wants to die has been criticised as a dangerous and worrying idea. Patrick Pullicino, a leading neurologist, said the plan simply perpetuates the "central flaw" of the discredited Liverpool Care Pathway. The professor, who was the first senior doctor to expose the failures of the pathway three years ago, said such a register carried huge risks. <http://www.dailymail.co.uk/news/article-2996368/Plans-let-critically-ill-die-home-repeat-flaws-death-pathway-warns-leading-neurologist.html>
- U.K. (England) | BBC News – 15 March 2015 – '**Improve end-of-life care for all, say MPs.**' Social care should be free to everyone at the end of life, says a report by the Commons Health Committee which calls for better recording of what people want in their last days. The MPs' report said there was "unacceptable variation" in the care received by people in England. Care minister Norman Lamb said the government was looking carefully at a policy of free end-of-life social care. End-of-life care is defined as people expected to die within 12 months. Most have incurable or progressive illnesses. <http://www.bbc.com/news/health-31871482>
- U.K. (England) | *The Independent* – 15 March 2015 – '**MPs' report calls for "kinder, cheaper" state-funded end-of-life care.**' The Health Select Committee said social care for dying patients should be free, ensuring no one dies in hospital for want of a care package at home... Families seeking free care for a dying relative at home currently have to go through a complex process of means testing and assessment, and although around two-thirds of people say they would prefer to die at home, more than half of deaths still occur in National Health Service [NHS] hospitals. The MPs' report also recommended that NHS trusts should have a senior member of staff responsible for monitoring the quality of end-of-life care, adding hospitals and care organisations should provide round-the-clock access to specialist palliative care. <http://www.independent.co.uk/life-style/health-and-families/health-news/mps-report-calls-for-kinder-cheaper-statefunded-endoflife-care-10108818.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | Associated Press – 17 March 2015 – '**Study: Euthanasia cases more than double in Northern Belgium.**' Almost one in 20 people in northern Belgium died using euthanasia in 2013, doubling the numbers in six years...<sup>1</sup> The universities of Ghent and Brussels found that since euthanasia was legalized in 2002, the acceptance of ending a life at the patient's request has greatly increased. While a 2007 survey showed only 1.9% of deaths from euthanasia in the region, the figure was 4.6% in 2013. <http://abcnews.go.com/Health/wireStory/study-euthanasia-cases-double-northern-belgium-29696631>
  1. 'Recent trends in euthanasia and other end-of-life practices in Belgium,' *New England Journal of Medicine*, 17 March 2015. <http://www.nejm.org/doi/full/10.1056/NEJMc1414527>
- FRANCE | Reuters – 17 March 2015 – '**French parliament passes "deep sleep" bill for end of life.**' France's lower house of parliament passed a bill ... allowing patients near the end of their lives to stop medical treatment and request deep sedation until they die, a move that critics say is effectively a form of euthanasia. The draft law, which polls show is backed by most French, passed in the lower house of parliament with 436 members voting in favour and 34 voting against. It is expected to get the final approval from the upper house in May or June. <http://www.reuters.com/article/2015/03/17/france-euthanasia-idUSL6N0WJ3UH20150317>

Cont.

- AUSTRALIA (New South Wales) | ABC News – 14 March 2015 – '**Almost three quarters of voters support euthanasia...**' An overwhelming majority of New South Wales voters are in favour of voluntary euthanasia, according to the ABC's Vote Compass survey. The findings were based on more than 34,000 respondents to the statement: "Terminally ill patients should be able to legally end their own lives with medical assistance." A total of 72% of people strongly agreed or agreed with the proposition, compared with 16% of respondents who did not. Eleven per cent of people said they were neutral. <http://www.abc.net.au/news/2015-03-15/nsw-voters-support-euthanasia-vote-compass-finds/6313864>

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

#### **Improving palliative care team meetings: Structure, inclusion, and "team care"**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 March 2015 – Increasing demands on palliative care teams point to the need for continuous improvement to ensure teams are working collaboratively and efficiently. This quality improvement initiative focused on improving interprofessional team meeting efficiency and subsequently patient care. Meeting start and end times improved from a mean of approximately 9 and 6 minutes late in the baseline period, respectively, to a mean of 4.4 minutes late (start time) and ending early in our sustainability phase. Mean team satisfaction improved from 2.4 to 4.5 on a 5-point Likert-type scale. The improvement initiative clarified communication about patients' plans of care, thus positively impacting team members' ability to articulate goals to other professionals, patients, and families. The authors propose several recommendations in the form of a team meeting "toolkit." <http://ajh.sagepub.com/content/early/2015/03/19/1049909115577049.abstract>

#### **Lived experience of parents of children with life-limiting and life-threatening disease**

*CENTRAL EUROPEAN JOURNAL OF NURSING & MIDWIFERY*, 2015;6(1):209-217. The aim of the research was to identify and describe the problems and experiences of family members caring for children with life-threatening or life-limiting diseases from diagnosis to the eventual death of the child. Four main categories and subcategories were defined: 1) onset of the disease (diagnosis, prognosis and awareness); 2) therapeutical phase (demands of care, the impact of disease and treatment on the family); 3) the acceptance of life with disease (feelings and emotions, coming to terms with disease); and, 4) dying and death (dignified dying, the period after death). Serious disease in a child is a difficult life situation for parents, associated with changes in their personal and family life. Carers need psychosocial support, especially in the form of advice, and require the exercise of empathy and open communication. <http://periodika.osu.cz/cejnm/dok/2015-01/4-buzgova-palenikova.pdf>

Of related interest:

- *CRITICAL CARE*, 2015;19(Suppl 1):572. '**Parents' return to the hospital after the death of their children: Importance of palliative care after death.**' The ability to return to the hospital and talk to medical assistants was considered by parents as a positive and enlightening opportunity. <http://ccforum.com/content/19/S1/P572>
- *PEDIATRIC BLOOD & CANCER* | Online – 18 March 2015 – '**Persistent racial and ethnic differences in location of death for children with cancer.**' Racial and ethnic differences persist in end-of-life care for children with cancer with white non-Hispanic children being most likely to die at home. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25479/abstract>

#### [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.13.

## Reengineering advance care planning to create scalable, patient- and family-centered interventions

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2015;313(11):1103-1104. The Institute of Medicine report, 'Dying in America,'<sup>1</sup> concluded that patients near the end of life often receive undesired, burdensome treatments and called for improvements in advance care planning to ensure that patients' values guide medical care. There is no clear path to accomplish this because there are major shortcomings to existing advance care planning. First, traditional advance directives are often narrowly focused on treatment preferences that are difficult to apply in many clinical situations. The second approach, facilitated advance care planning, is resource intensive and thus difficult to scale up to meet increasing demand. The authors propose two interrelated strategies to create the next generation of advance care planning tools: 1) leveraging web-based technologies to create online interventions; and, 2) using the science of user-centered design to ensure that advance care planning meets the needs of patients, families, and clinicians. <http://jama.jamanetwork.com/article.aspx?articleid=2203806>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

## Hinduism and death with dignity: Historic and contemporary case examples

*JOURNAL OF CLINICAL ETHICS*, 2015;26(1). An estimated 1.2 to 2.3 million Hindus live in the U.S. End-of-life care choices for a subset of these patients may be driven by religious beliefs. In this article, we present Hindu beliefs that could strongly influence a devout person's decisions about medical care, including end-of-life care. The authors provide four case examples (one sacred epic, one historical example, and two cases from current practice) that illustrate Hindu notions surrounding pain and suffering at the end of life. Chief among those is the principle of karma, through which one reaps the benefits and penalties for past deeds. Deference to one's spouse or family is another important Hindu value, especially among Hindu women, which can impact the decision-making process and challenge the Western emphasis on autonomy. In addition, the Hindu embrace of astrology can lead to a desire to control the exact time of death. Confounding any generalizations, a Hindu patient may reject or accept treatments based on the individual patient's or family's interpretation of any given tradition. Through an awareness of some of the fundamental practices in Hinduism and the role of individual interpretation within the tradition, clinicians will be better able to support their Hindu patients and families at the end of life. <http://www.clinicalethics.com/>

Noted in Media Watch, 23 September 2013, #324 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 September 2013 – 'End-of-life care beliefs among Hindu physicians in the U.S.' Studies from the U.S. and Europe show physicians' religiosity is associated with their approach to end-of-life care. No such studies have focused on Hindu physicians practicing in the U.S. Most [survey] participants believed their religious beliefs do not influence their practice of medicine and do not interfere with withdrawal of life support. The practice of discussing end-of-life issues with the patient, rather than primarily with the family, seems to have been adopted by Hindu physicians in the U.S. <http://ajh.sagepub.com/content/early/2013/09/16/1049909113505138.abstract>

**N.B.** Several articles on Hindu perspectives on dying and death are noted in Media Watch, 2 September 2013, #321 (p.9).

### [Back Issues of Media Watch](#)

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



## Closing the divide: The Harvard Global Equity Initiative-Lancet Commission on global access to pain control and palliative care

*THE LANCET* | Online – 8 March 2015 – Universal health coverage ... must include access to pain control and palliative care with financial protection as a fundamental goal. However, health entitlements and essential packages typically do not include drugs and other interventions to alleviate pain and suffering. As a result, many opportunities to provide access to palliative care through health-system reform and national insurance have been missed. In low-income and middle-income countries regulations hampering opioid accessibility, combined with the scarcity of trained doctors and other health professionals, has stymied delivery of pain treatment and palliative care. But these barriers are not insurmountable. Integration of pain control and palliative care into health provision is a quintessential example of a diagonal strategy that can strengthen health systems through positive externalities for disciplines as diverse as surgery and social work. Novel initiatives from developing regions provide valuable lessons to share... Comprehensive pain control and palliative care are embedded into the **Costa Rican** health system. Several countries, including **Albania, Colombia, Mexico, India** and **Rwanda**, have implemented palliative-care laws or national plans. **Uganda** and **Nepal**, despite high levels of poverty, are establishing national oral morphine production programmes. Innovative models for training of clinicians at all levels of the health-care system in palliative care have been piloted in several low-income and middle-income countries. The Harvard Global Equity Initiative-Lancet Commission on Global Access to Pain Control & Palliative Care will build on previous work to harness these opportunities. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60289-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60289-6/fulltext)

### Palliative care and pain treatment in the global health agenda

*PAIN*, 2015;156(Suppl):S115-S118. The Global Atlas of Palliative Care at the End of Life, published by the Worldwide Palliative Care Alliance jointly with the World Health Organization estimated that every year 20 million patients need palliative care (PC) at the end of life. Six percent of these are children. According to the Atlas, in 2011, approximately 3 million patients received PC and only 1 in 10 people in need is currently receiving it. Although most PC is provided in high-income countries, almost 80% of the global need is in low- and middle-income countries. Only 20 countries have PC well integrated into their health-care systems. In regards to opioids, 5 billion people (83% of the world's population) live in countries with low to nonexistent access, 250 million (4%) have moderate access, and only 460 million (7%) have adequate access. In order for PC and pain treatment strategies to be effective, they must be incorporated by governments into all levels of their health care systems. In 1990, the WHO pioneered a public health strategy to integrate PC into existing health care systems which includes four components: 1) appropriate policies; 2) adequate availability of medications; 3) education of health care workers and the public; and, 4) implementation of PC services at all levels throughout the society. This review describes the current status of the field, and presents several initiatives by the UN organizations and the civil society to improve access to PC and to pain treatment for patients in need. <http://www.ncbi.nlm.nih.gov/pubmed/25789428>

**N.B.** Current issue (January 2014) of the Global Atlas of Palliative Care at the End of Life: [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)

Of related interest:

- *ANNALS OF GLOBAL HEALTH*, 2015;81(1):156-157. **'Palliative care education in Belarus: Development and delivery of a cost-efficient, streamlined and targeted palliative care curriculum.'** Worldwide, only ten percent of the 20.4 million people who need palliative care currently receive it. A major barrier in lower and middle-income countries is insufficient knowledge of – and the experience in – palliative care for healthcare workers. The authors report on the development and implementation of a first-in-country palliative care curriculum in **Belarus**. [http://www.annalsofglobalhealth.org/article/S2214-9996\(15\)00863-2/abstract](http://www.annalsofglobalhealth.org/article/S2214-9996(15)00863-2/abstract)

Cont.

- *INTERNATIONAL JOURNAL OF SCIENCE & RESEARCH*, 2015;4(3):469-470. **'Ethical and economic issues in terminal health care.'** Terminal care requires an active and compassionate approach that treats comforts and supports individuals, living with or dying with progressive life threatening conditions. Such care has to be sensitive to the personal, cultural and spiritual values, religious beliefs and practices of an individual and the community he/she belongs to. There is an urgent need to address ethical and economic issues and to bring appropriate legislation to better manage end-of-life care in our country. Ethical dilemma in terminal health care has been a matter of great debate in recent times. It has to be emphasized that withdrawing or withholding life prolonging treatment has to be differentiated from euthanasia. Euthanasia implies ending life in certain terminal and often painful and distressing situations. <http://www.ijsr.net/archive/v4i3/SUB151937.pdf>

**N.B.** The authors are members of the faculty at the Government Medical College, Srinagar, in the Indian state of **Jammu & Kashmir**.

### End-of-life care in Australia

#### **Community-based palliative care is associated with reduced emergency department use by people with dementia in their last year of life**

*PALLIATIVE MEDICINE* | Online – 17 March 2015 – Community-based palliative care [PC] of people who die with or of dementia is relatively infrequent, but associated with significant reductions in hospital emergency department use in the last year of life. More than 70% of both the dementia and comparative cohorts [in this retrospective population-based study] attended hospital emergency departments in the last year of life. Only 6% of the dementia cohort used community-based PC compared to 26% of the comparative cohort. Decedents with dementia who were not receiving community-based PC attended hospital emergency departments more frequently than people receiving community-based PC. The magnitude of the increased rate of emergency department visits varied over the last year of life from 1.4 ... times more often in the first 3 months of follow-up to 6.7 ... times more frequently in the weeks immediately preceding death. <http://pmj.sagepub.com/content/early/2015/03/17/0269216315576309.abstract>

Noted in Media Watch, 17 February 2014, #345 (p.6):

- *AUSTRALIAN AGEING AGENDA* | Online – 12 February 2014 – **'Knowledge lacking on end-of-life rights.'** The end-of-life wishes of people with dementia are not being met and this is partly due to a lack of knowledge among care professionals about a person's right to refuse treatments, according to a report by Alzheimer's Australia and Palliative Care Australia. <http://www.australianageingagenda.com.au/2014/02/12/knowledge-lacking-end-life-rights/>

#### **An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death**

*PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE* | Online – 11 March 2015 – This paper explores definitions of death from the perspectives of several world and indigenous religions,<sup>1</sup> with practical application for health care providers in relation to end-of-life decisions and organ and tissue donation after death. It provides background material on several traditions and explains how different religions derive their conclusions for end of life decisions from the ethical guidelines they proffer. <http://www.peh-med.com/content/pdf/s13010-015-0025-x.pdf>

1. Buddhism, Christianity, Hinduism, Islam, Judaism

#### [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>

## **Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death**

RESUSCITATION COUNCIL (U.K.), BRITISH CARDIOVASCULAR SOCIETY & NATIONAL COUNCIL FOR PALLIATIVE CARE | Online – Accessed 17 March 2015 – Each year, many thousands of people have electronic devices implanted, including pacemakers, implantable defibrillators and small recorders to monitor the heart's rhythm. The reason for each device is individual to the person and their particular medical problem. The increasing use of such devices has provided huge benefit but also has created new challenges for patients and those close to them, and for healthcare professionals. Clear challenges arise when people with an implanted device approach or reach the end of their life. What many people want in that situation is care and treatment to maintain their comfort and quality of life for whatever time they have left. Receiving treatment (for example electric shocks from an implanted defibrillator) as they are dying may provide no benefit but may cause them pain and may cause distress both to them and to those who care about them. [https://www.resus.org.uk/pages/CIEDs\\_Guidance.pdf](https://www.resus.org.uk/pages/CIEDs_Guidance.pdf)

**N.B.** Available is a guide for health professionals, 'Deactivation of Implantable Cardioverter-Defibrillators Towards the End of Life' (at [https://www.resus.org.uk/pages/CIEDs\\_Deactivation.pdf](https://www.resus.org.uk/pages/CIEDs_Deactivation.pdf)); and, also an information leaflet for patients and carers, 'A Guide for Patients & Carers' (at [https://www.resus.org.uk/pages/CIEDs\\_Leaflet.pdf](https://www.resus.org.uk/pages/CIEDs_Leaflet.pdf)).

Noted in Media Watch, 23 February 2015, #398 (p.14):

- **PACING & CLINICAL ELECTROPHYSIOLOGY** | Online – 14 February 2015 – '**Defibrillator deactivation against a patient's wishes: Perspectives of electrophysiology practitioners.**' Survey respondents were from Europe, Asia, Australia, South American and Africa. The majority were from North American (78%), were academically affiliated (64%), and practiced in an urban setting (67.8%). The majority responded that it was not ethical/moral for doctors to deactivate ICDs against patients' wishes or against family/surrogates' wishes, even in the context of medical futility. <http://onlinelibrary.wiley.com/doi/10.1111/pace.12614/abstract>

**N.B.** See Media Watch dated 12 January 2015, #392 (p.9) for a listing of selected articles on defibrillator deactivation in the context of end-of-life care noted in past issues of the weekly report.

## **"Death is part of the job" in long-term care homes: Supporting direct care staff with their grief and bereavement**

SAGE OPEN | Online – 10 March 2015 – For long-term care (LTC) home staff who work directly with residents, death, dying, and grief are day-to-day experiences in their working life. However, staff are often overlooked for grief and bereavement support. This exploratory research used a qualitative approach to understand LTC staff's grief and bereavement experience and to identify the perceived support needs of nurses and personal support workers who work in two faith-based non-profit care homes in Thunder Bay, Ontario, Canada. Findings indicated that participants' experiences are complex, shaped by the emotional impact of each loss, the cumulative burden of ongoing grief, an organizational culture in LTC where death is hidden, and the lack of organizational attention to staffs' support and education needs. Eight recommendations were developed from the findings. <http://sgo.sagepub.com/content/5/1/2158244015573912>

### **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>



## "But I'm brain-dead and pregnant": Advance directive pregnancy exclusions and end-of-life wishes

*WILLIAM & MARY JOURNAL OF WOMEN AND THE LAW* | Online – Accessed 19 March 2015 – Marlise Muñoz was approximately 14 weeks pregnant when she suffered a pulmonary embolism, and two days later doctors declared her brain-dead. Knowing Marlise's end-of-life wishes, her husband ... asked her doctors to withdraw or withhold any "life-sustaining" medical treatment from his brain-dead wife. The hospital refused, and it relied on a Texas statute that automatically invalidates a woman's advance directive in the event she is pregnant. Ultimately, the trial court held that the Texas statute does not apply to a woman who is brain-dead and pregnant. This tragic situation warrants action to ensure a woman's end-of-life wishes are honored by family members, health care providers, and the state. In response to the Muñoz case, in June 2014 the Louisiana legislature amended the state's advance directive statute. Yet, based on the plain language of the statutes in Texas and Louisiana, the pregnancy exclusions do not apply to a situation in which a woman is brain-dead and pregnant, and this holds true for other state statutory pregnancy exclusions. Even if the pregnancy exclusions do apply to a pregnant woman who is brain-dead, they arguably violate a woman's constitutional rights, including the right to terminate a pregnancy and the right to refuse medical treatment. Therefore, state legislatures should propose a statute or amend the language in their current pregnancy exclusions to clarify the applicability to a woman who is brain-dead and pregnant. [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2560306](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2560306)

Noted in Media Watch, 3 February 2014, #343 (p.3):

- TEXAS | *The Boston Globe* (Massachusetts) – 26 January 2014 – '**Brain-dead Texas woman off life support.**' A brain-dead, pregnant Texas woman's body has been removed from life support as the hospital keeping her on machines against her family's wishes acceded to a judge's ruling that it was misapplying state law. The hospital's decision brings an end to a case that became a touchstone for national debates about the beginning and end of life... <http://www.bostonglobe.com/news/nation/2014/01/26/texas-hospital-end-care-for-brain-dead-woman/kWeC6X3f69gJMRaAPbInGI/story.html>

### Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy 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.

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/03/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 | 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>

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