

Media Watch...

is intended as an advocacy and research 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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Advance care planning: Scroll down to [Specialist Publications](#) and 'End-of-life wishes often unheeded' (p.9), in *Anesthesiology News*.

Canada

National palliative & end-of-life care strategy

Dad's death showed truth of palliative care

BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 6 April 2014 – This past week, the House of Commons spent one hour debating a motion that calls for the federal government to work with the provinces to establish a national palliative-care and end-of-life strategy.¹ It appears much of the government comment during the debate was an attempt to disconnect itself from any obligations in developing such a strategy. Fair enough, perhaps, since the feds have already prepared an in-depth parliamentary report (2011) and a major Senate report (2005).^{2,3} There have also been progress reports, fact sheets, and \$43 million dedicated to palliative-care research. We don't need more reports or strategies – we just need action. Taking the federal government out of the equation leaves the provinces to devise palliative-care strategies that best suit their individual health networks, facilities and geography. But it can be problematic. <http://www.timescolonist.com/opinion/columnists/susan-martinuk-dad-s-death-showed-truth-of-palliative-care-1.943240>

Extract from *The Times-Colonist* article

I've just spent an extended period of time with my father, watching him waste away from cancer. Last June, my siblings and I determined that he could no longer function on his own and I temporarily moved home to be with him. Based on his condition, we thought it would only be two or three weeks; a month at most. But once I was home, living with him in the empty house where my mom had recently passed away, his health and mental well-being improved. As a result, my two or three weeks became a nine-month journey that ended on 16 February. During that time, we had no access to palliative care or a hospice. In the last weeks of his life, we dealt with a doctor who had recently come to Canada from England. He didn't touch, examine or look at my dad. Instead, he spent 10 minutes telling my sister and me about the fabulous palliative-care facilities that exist in Britain and his shock at not having such care here. Perhaps he missed the irony that his comments about the lack of available care came as he forgot to look at, acknowledge or care for my father and his palliative condition.

Cont.

1. Parliamentary discussion proposing a Pan-Canadian Palliative & End-of-life Care Strategy. [Noted in Media Watch, 7 April 2014, #352 (p.1)] A transcript can be accessed at: <http://openparliament.ca/debates/2014/4/1/charlie-angus-11/only/>
2. *Not to be Forgotten: Care of Vulnerable Canadians*, Ad Hoc (All-Party) Parliamentary Committee on Palliative & Compassionate Care, 17 November 2011. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>
3. *Still Not There: Quality End-of-Life Care*, Hon. Sharon Carstairs, Ottawa, June 2005. The report makes ten new recommendations (at the time) in five areas: 1) National Strategy; 2) Patient and Caregiver Support; 3) Training and Education for Formal and Informal Health Care Providers; 4) Government and Citizens Working Together; and, 5) Planning for the Future. <http://www.sharoncarstairs.ca/StillNotThereJune2005.pdf>

N.B. Several landmark reports, published between 1995 and 2012, on end-of-life care in Canada are listed in the issue of Media Watch, 3 March 2014, #347 (p.2).

Greying inmate population strains Canadian prisons

ONTARIO | *The Toronto Star* – 6 April 2014 – The number of incarcerated individuals 50 and older doubled in the last 10 years. Now, just over 20% of the nearly 15,000 inmates on any given day – one in five – fall into that age range. Experts who work alongside offenders and advocate on their behalf argue the system is struggling to keep up with these inmates' needs. As Canadians get older, so do those inside our prisons. And a significant proportion of the overall prison population is serving life or indeterminate sentences, a result, some observers argue, of the federal government's tough-on-crime stance. Many are dying in custody. According to a mortality review done late last year by the office of prisoners' ombudsman Howard Sapers, fully two-thirds of all deaths (355 of 536) from the years 2003 to 2013 were a result of natural causes, on average about 35 a year.¹ Of those 35 who die, the average age is 62. That's also the average age for the 60 to 80 offenders who die while out on parole. Contrast that to the fact that life expectancy for the average Canadian male is about 79 years, and for women 83. http://www.thestar.com/news/canada/2014/04/06/greying_inmate_population_strains_canadian_prisons.html#

1. 'An Investigation of the Correctional Service's Mortality Review Process,' Office of the Correctional Investigator, Canada, 2013. <http://www.oci-bec.gc.ca/cnt/rpt/pdf/oth-aut/oth-aut20131218-eng.pdf>

Chaplain Dan Haley's house of forgiveness

ONTARIO | *The Toronto Star* – 6 April 2014 – Ronald Gourgon stabbed a man in the chest and was sentenced for a murder that left a baby fatherless. Now walking with a cane, the 67-year-old has a deteriorating valve in his heart, and not much longer to live. Recently paroled from an Ontario prison, he called on Dan Haley, a chaplain in Peterborough who runs a supportive housing centre that offers palliative care for ex-inmates. Gourgon is thankful he's found a quiet resting place to "kick the bucket." Ready to die, he seeks forgiveness from the victim's family. http://www.thestar.com/news/canada/2014/04/06/chaplain_dan_haleys_house_of_forgiveness.html

Specialist Publications

'Who wants to die in here?: Perspectives of prisoners with chronic conditions' (p.10), in *Journal of Hospice & Palliative Nursing*.

Prison Hospice

Articles and reports focused on the provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a fairly regular basis. A compilation of these in a single document is now available at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>. The intent is to update this backgrounder on a regular basis (e.g., quarterly).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE CANADIAN PRESS | Online – 7 April 2014 – **'Doctors need to prepare for eventual legalization of assisted suicide...'** A group of palliative-care doctors says it's time to move beyond the "yes or no" debate about physician-assisted death and begin preparing for its eventual legalization in Canada. The doctors say in a commentary in the *Canadian Medical Association Journal* that physicians need to discuss potential policies and guidelines for legally assisting death. They argue that assisted suicide may become legal if the Supreme Court of Canada overturns a 2012 B.C. court ruling that deemed a ban on the act unconstitutional. Quebec also was looking at legalizing doctor-assisted death with Bill 52, which died on the order paper when the provincial election was called. Commentary co-author Dr. David Downar says practice guidelines to protect patients and to safeguard physicians are among issues that need to be determined. <http://www.ctvnews.ca/health/doctors-need-to-prepare-for-eventual-legalization-of-assisted-suicide-cmaj-1.1764612>
 1. 'Physician-assisted death: time to move beyond Yes or No,' *Canadian Medical Association Journal*, 7 April 2014. Access to this article requires payment or subscription. <http://www.cmaj.ca/content/early/2014/04/07/cmaj.140204.full.pdf+html?sid=5723e774-2846-4fd1-8b9e-8b2648501f59>
- VISION TV | Online – 7 April 2014 – **'The trouble with dying.'** For over 20 years, Canadian citizens and courts have been engaged in a profound and divisive debate surrounding one of the most important moments in an individual's life – the moment that it ends. In 'The Trouble with Dying,' each side of the argument over the right to choose the time and manner of one's death weigh in on both the dangers and benefits of medically assisted dying, and the many ethical considerations that the concept entails. <http://www.visiontv.ca/shows/the-trouble-with-dying/>

U.S.A.

Eco-friendly funerals and death in America today

NATIONAL PUBLIC RADIO | Online – 10 April 2014 – Eco-friendly, personalized funerals. The perfect way to end a low-impact environmentally friendly life. Some are replacing a casket with a burial shroud. Opting to place a family member's cremated remains on the ocean floor. Or going high-tech, putting computer chips in your burial blot. Modernizing the burial ritual reflects the values of an aging baby boomer generation. <http://onpoint.wbur.org/2014/04/10/eco-friendly-funerals-cremation>

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>



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.

A 'code death' for dying patients

THE NEW YORK TIMES | Online – 10 April 2014 – Until the early 20th century, death was as natural a part of life as birth. It was expected, accepted and filled with ritual. No surprises, no denial, no panic. When its time came, the steps unfolded in a familiar pattern, everyone playing his part. The patients were kept clean and as comfortable as possible until they drew their last breath. But in this age of technological wizardry, doctors have been taught that they must do everything possible to stave off death. We refuse to wait passively for a last breath, and instead pump air into dying bodies in our own ritual of life-prolongation. Like a midwife slapping life into a newborn baby, doctors now try to punch death out of a dying patient. There is neither acknowledgement of nor preparation for this vital existential moment, which arrives, often unexpected, always unaccepted, in a flurry of panicked activity and distress. We physicians need to relearn the ancient art of dying. When planned for, death can be a peaceful, even transcendent experience. Just as a midwife devises a birth plan with her patient, one that prepares for the best and accommodates the worst, so we doctors must learn at least something about midwifing death. http://well.blogs.nytimes.com/2014/04/10/a-better-way-to-help-dying-patients/?_php=true&_type=blogs&ref=health&_r=0

Noted in Media Watch, 13 January 2014, #340 (p.5):

- AUSTRALIA (New South Wales) | *The Newcastle Herald* – 11 January 2014 – '**OpEd: Death needs a plan similar to childbirth.**' There is a growing school of thought that suggests we could start accepting that chronic illness and end-of-life occur and plan for them in the way that we currently plan for the start of life. <http://www.theherald.com.au/story/2016237/opinion-death-needs-a-plan-similar-to-childbirth/?cs=308>

Avoiding the nursing home ups the risk of unwanted medical care

CALIFORNIA | South California Public Radio (Pasadena) – 8 April 2014 – Most older people suffer from cognitive impairment or dementia in the year before death, making it more likely that they will get aggressive medical treatments that they don't want. And people with dementia who are cared for at home are more likely to get unwanted treatment than if they are in a nursing home, a study finds.¹ <http://www.scpr.org/news/2014/04/08/43362/avoiding-the-nursing-home-ups-the-risk-of-unwanted/>

1. 'Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia,' *Health Affairs*, 2014;38(4):667-674. <http://content.healthaffairs.org/content/33/4/667.abstract>

Will you "like" the doctor who tells you you're dying?

CABLE NEWS NETWORK (CNN) | Online – 10 April 2014 – Honesty may be the best policy, but when delivering bad news to patients, physicians must prepare to pay a price for that honesty. You simply do not like the doctor who tells you what you are afraid to hear. In this age of greater accountability in health care, the satisfaction of patients and the subtle nuance of likeability is connected directly to doctor payment. And patients who don't like what their doctor tells them won't "like" that doctor on the growing number of physician rating services springing up on the Internet. The complex task of adding unwelcome and difficult content to a conversation may impede physicians from having dialogues about the most sensitive issues. Often these hard conversations arrive as a patient nears the end of life. <http://www.cnn.com/2014/04/10/opinion/mulcahy-doctors-dying-patients/>

Answers to tough questions about dying

THE NEW YORK TIMES | Online – 7 April 2014 – Lots of people want to encourage you to have the Conversation with aging family members about their wishes at the end of life, and then to help you document those preferences in an advance directive. You can log onto the Conversation Project, for example.¹ Established two years ago by the former syndicated columnist Ellen Goodman, it will guide you through discussions of fears, values, medical options. Or you can turn to Prepare, created last year by a geriatrician, Dr. Rebecca Sudore of the University of California, San Francisco.² Readers here have also recommended the Five Wishes document.³ And to be sure doctors follow your or your relatives' wishes precisely, a POLST [Physician Orders for Life-Sustaining Treatment] form is your strongest protection when frailty or illness becomes advanced.⁴ But then what? There is still scant discussion, except from experienced hospice staff members, about what to expect when death comes very close. http://newoldage.blogs.nytimes.com/2014/04/07/answers-to-tough-questions-about-dying/?_php=true&_type=blogs&_r=0

1. The Conversation Project: <http://theconversationproject.org/>
2. Prepare: <https://www.prepareforyourcare.org/>
3. Five Wishes: http://www.agingwithdignity.org/catalog/product_info.php?products_id=28
4. 'Comparison of methods to communicate treatment preferences in nursing facilities: Traditional practices versus the Physician Orders for Life-Sustaining Treatment program,' *Journal of the American Geriatrics Society*, 2010;58(7):1241-1248. [Noted in Media Watch, 5 July 2010, #156 (p.8)] <http://www3.interscience.wiley.com/journal/123572530/abstract>

Extract from *The New York Times* article

How do you deal with pain, everyone's great fear? What is dyspnea (answer: shortness of breath), and what can be done to ease it? How is palliative care different from hospice care, and which do you need? What are the actual signs, physical and emotional, of approaching death? Families and friends need to know these things, especially when they are trying to help a loved one die at home — where most people say they want to die, although only a minority do.

Specialist Publications

'End-of-life wishes often unheeded' (p.9), in *Anesthesiology News*.

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

The bottom line on hospice care

NEVADA | Vegas Inc (Henderson) – 6 April 2014 – For years, private hospice providers in the Las Vegas Valley have built a profitable business model around easing terminally ill patients toward a comfortable death. The drill seemed simple enough, with noble intent: Set up an office; brand a soothing name; hire or contract doctors, nurses, social workers and religious counselors to visit patients at their homes or care facilities; and, get reimbursed by Medicare. The profit would rise or fall depending on the needs of the patients. Those who demanded less attention would offset the cost of serving those who needed a higher level of care. But because of the demands of additional federal quality-control reporting requirements and shrinking Medicare reimbursements for patient care and pharmaceuticals, companies that take care of the dying are learning the business isn't as simple or as financially rewarding as it once was. Because Las Vegas isn't lacking for an elderly population approaching death, investors on the hunt for profitable businesses still are attracted to the hospice industry. Between 40 and 50 hospice providers – most of them for-profit organizations – operate in Southern Nevada. <http://www.inbusinesslasvegas.com/business/2014/apr/06/bottom-line-hospice-care/>

Noted in Media Watch, 10 March 2014, #348 (p.5):

- *THE NEW YORK TIMES* | Online – 3 March 2014 – '**Differences in care at for-profit hospices.**' People who pay attention to hospice care, so often a godsend for the dying and their families, have noticed and wondered about two trends in recent years: 1) What began as a grass-roots movement to improve end-of-life care is becoming a business; and, 2) We've also seen hospice patients are increasingly likely to be disenrolled before they die. Patients are getting bounced as corporate bottom lines come to matter more. A study has found for-profit hospices have significantly higher disenrollment rates than non-profits, among other disparities. http://newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/?_php=true&_type=blogs&_r=0

1. 'National hospice survey results: For-profit status, community engagement, and service,' *JAMA Internal Medicine*, 24 February 2014. [Noted in Media Watch, 3 March 2014, #347 (p.9)] <https://archinte.jamanetwork.com/article.aspx?articleid=1832198>

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

Bounced from hospice

THE NEW YORK TIMES | Online – 7 April 2014 – It didn't come as a complete surprise when a Pennsylvania hospice told Phyllis Fine's family last year that she was no longer eligible to receive care. Mrs. Fine, 84, enrolled in hospice in June 2012. After supposedly routine heart valve surgery, she suffered a major stroke, leaving her unable to walk, speak much or feed herself. For months, hospice staffers cared for her... The hospice had admitted Mrs. Fine for 90 days, then another 90. After that, Medicare rules required recertification every 60 days, meaning that a physician must attest she is likely to die within six months if her disease runs its normal course. In May, when Mrs. Fine was no longer losing weight or showing other signs of decline, the hospice apologetically said she no longer qualified. http://newoldage.blogs.nytimes.com/2014/01/07/bounced-from-hospice/?_php=true&_type=blogs&_r=0

Specialist Publications

'Patients who lack capacity and lack surrogates: Can they enroll in hospice?' (p.11), in *Journal of Pain & Symptom Management*.

International

End-of-life care in Australia

Draft advance care directive do-it-yourself kit to explain legal and medical wishes for people while dying is confusing

AUSTRALIA (South Australia) | News.com – 11 April 2014 – An eight year battle to produce a do-it-yourself kit designed to help people explain their legal and medical wishes while they are dying, has led to more complaints and confusion. Critics have complained the 72-page document is onerous, and too much for the terminally ill or terminally diagnosed to digest, as evidence by the encouragement on page 33: "Good news ... you are nearly finished, just a few more things to do." The Law Society is one group not happy with the final draft, which it says will cost patients far more to implement and is far too complicated for people to handle at an already difficult time. <http://www.news.com.au/national/south-australia/draft-advance-care-directive-diy-kit-to-explain-legal-and-medical-wishes-for-people-while-dying-is-confusing/story-fnii5yv4-1226880340092>

1. 'Draft Advance Care Directive DIY Kit,' Health & Ageing, Government of South Australia, 2013. http://saplan.org.au/media/W1siZilsjIwMTQvMDEvMjkwMDRfNTRfNDhfOTA4X0FDRF9LaXRfRkIOQUwucGRmI1d/ACD_Kit%20FINAL.pdf

N.B. The Advance Care Directives Act 2013 (SA), commencing 1 July 2014, will empower adults to make clear legal arrangements for their future health care, end of life, preferred living arrangements and other personal matters. The new Advance Care Directive will replace the existing Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction with a single Advance Care Directive.

China's Shanxi Province promotes tree funerals

CHINA TOPIX | Online – 8 April 2014 – China may have found another solution to its shortage of land space for graves other than encouraging citizens to opt for sea burials. Shanxi province has another alternative: tree funerals. In addition to solving the land space problem, it is also frugal and eco-friendly, according to its proponents. The Xianjuyuan Cemetery at Shanxi's capital, Taiyuan, conceptualized the eco-friendly funeral alternative, where ashes of the departed are placed in a biodegradable urn and buried under a tree. The urn and its content eventually decompose into the soil in three to six months. <http://www.chinatopix.com/articles/1684/20140408/china-shanxi-promotes-tree-funerals.htm>

End-of-life care in Singapore

Survey: 77% of Singaporeans wish to die at home

SINGAPORE | National News Agency of Malaysia – 8 April 2014 – Singaporeans want to die at home, die affordably, and not leave financial burdens behind. And it would help to have well-trained doctors and nurses guide them about hospice palliative care. They also want a platform to talk about death in the community – national conversations and public education on hospice palliative care to discuss issues on death and dying. These are ... the findings that have emerged from a survey commissioned by the Lien Foundation to examine death attitudes and perception of hospice palliative care in Singapore.¹ The home has emerged as the preferred place of death for most or 77% of Singaporeans, and the majority or 70% wished to be cared for at home when they reach the end of life. <http://www.bernama.com.my/bernama/v7/wn/newsworld.php?id=1028961>

1. 'Death Attitudes Survey,' Lien Foundation, April 2014. <http://www.lienfoundation.org/pdf/news/2014/Death%20survey%20Presser%20Final%20-%20Combined.pdf>

Cont.

Noted in Media Watch, 12 September 2012, #218 (p.6):

- SINGAPORE | *The Straits Times* – 6 September 2011 – '**Subsidy dearth for end-of-life home care.**' The dying would like to spend their last days at home, but the current health-care system makes it difficult for those without financial means to do so one of the findings of a new study.¹ http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_709910.html

1. *What Doctors Say About Care Of The Dying*, National University of Singapore's Centre for Biomedical Ethics, September 2011. Commissioned by the Lien Foundation. http://www.lienfoundation.org/pdf/news/What_Doctors_Say_About_Care_of_the_Dying.pdf

N.B. Singapore was rated 18th in *The Quality of Death: Ranking End-of-life-Care Across the World*, Economist Intelligence Unit, 2010. Commissioned by the Lien Foundation. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

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

The end of life care strategy: New ambitions

U.K. | National Council for Palliative Care – 8 April 2014 – A strong national vision is required if the care of people at and approaching the end of their lives is not to be put at risk, according to the National Council for Palliative Care (NCPC). The warning comes after it emerged that NHS [National Health Service] England no longer plans to refresh existing national strategy documents, reversing an earlier announcement that it would be refreshing the National End of Life Care Strategy (NEOLCS), which was 5-years-old in 2013. NHS England plans to publish new sets of actions and ambitions, which NCPC has concerns will not carry the same authority as the current strategy. A NCPC report calls for any new actions or ambitions to command the same level of credibility at a national and local level that the NEOLCS has done. The report calls for end-of-life care to be linked to other national

priorities including care for people with dementia and plans for vulnerable older people, as well as for greater priority to be given to developing ways of measuring whether people received good end-of-life care. Developing a measure of this could mean less reliance placed in the future on a commonly used measure, 'Death in the Usual Place of Residence,'¹ which doesn't give insight into people's quality and experience of care. http://www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf

Specialist Publications

'End-of-life issues in U.K. medical schools' (p.9), in *American Journal of Hospice & Palliative Medicine*.

1. 'Death in the Usual Place of Residence,' The Health Foundation. <http://www.qualitywatch.org.uk/indicator/death-usual-place-residence>

Of related interest:

- U.K. (Scotland) | *The Motherwell Times* – 7 April 2014 – '**Hospice care begins at home.**' The hospice at home scheme – the Community Palliative Care project – launched in Cumbernauld in January is set to roll out throughout North Lanarkshire. The partnership ... is part of the nationwide Reshaping Care for Older People programme, which seeks to help growing numbers of people over 65 to continue to live full, positive and independent lives in the community.¹ <http://www.motherwelltimes.co.uk/news/community-news/hospice-care-begins-at-home-1-3356146>

1. 'Reshaping Care for Older People: A Programme for Change, 2011-2021,' The Scottish Government. <http://www.scotland.gov.uk/Resource/0039/00398295.pdf>

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

End-of-life issues in U.K. medical schools

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 April 2014 – All schools offered some exposure to the topic of dying, death and bereavement, and palliative care, although the orientation had increased somewhat from an earlier study in 2000. The palliative medicine specialist and the nurse specialist in palliative care are the most consistent members of the team. Most schools have hospice participation, with time spent with a hospice patient increasing over the period. <http://ajh.sagepub.com/content/early/2014/04/09/1049909114530492.abstract>

Noted in Media Watch, 23 May 2011, #202 (p.11)::

- *THE CLINICAL TEACHER*, 2011;8(2):138-139. '**Dealing with death.**' Twenty-one new doctors from 17 different medical schools in Great Britain were interviewed, in which the emphasis of the interviews includes their learning from medical school, palliative care experiences, and how they learn to care for dying patients. The participants described death as a taboo subject. <http://onlinelibrary.wiley.com/doi/10.1111/j.1743-498X.2011.00451.2.x/abstract>

End-of-life wishes often unheeded

ANESTHESIOLOGY NEWS, 2014;40(3). The known wishes of critically ill patients to not be resuscitated or placed on life support following heart failure or stoppage of breathing are frequently ignored, researchers have found. The study, presented at a conference of the Society of Critical Care Medicine, could have implications for end-of-life care throughout the country, suggesting an urgent need for standardized protocols for documenting patients' wishes, making them both easily accessible, and legally binding. The study examined the outcomes of a group at a teaching hospital in California; patients' clearly stated wishes not to be resuscitated or placed on life support were not followed in 21 of 35 cases. The most significant factors in these unwanted intubations were intervention by patients' families to countermand their known wishes (nine cases) and an inability to locate documentation of patients' wishes in a timely manner (eight cases). In three cases, family members or proxies, aware of the patients' wishes not to be resuscitated, were not present at the time the decision to resuscitate was made. In the remaining case, the patient required immediate intubation before being able to discuss the decision with family members. http://www.anesthesiologynews.com/ViewArticle.aspx?d=Policy%2B%26%2BManagement&d_id=3&i=March+2014&i_id=1045&a_id=26087

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 April 2014 – '**The relationship between organizational characteristics and advance care planning practices.**' Organizational characteristics may impede uniform adoption of advance care planning best practices. This study points to the need for consistent educational programs and policies on, and examination of, values, beliefs, and resources that account for organizational differences. <http://ajh.sagepub.com/content/early/2014/04/04/1049909114530039.abstract>
- *BMC PALLIATIVE CARE* | Online – 10 April 2014 – '**Intervention thresholds: A conceptual frame for advance care planning choices.**' People display transitions between wanting or not wanting interventions based on scenarios. Further research is needed to determine effective ways to identify, measure, and represent the components of an individual's intervention threshold in order to facilitate informed decision making during future incapacity. <http://www.biomedcentral.com/1472-684X/13/21/abstract>

Cont.

- *IRISH MEDICAL TIMES* | Online – 11 April 2014 – **'Doctors' concerns over living wills expressed to Department of Health.** The development of an advance healthcare directive should require consultation with a healthcare professional, with the directive containing certain minimum information, the Royal College of Physicians of Ireland believes. A healthcare professional is not legally obliged to provide a treatment not clinically indicated, and an advance healthcare directive should not be allowed to mandate provision of a specific intervention that is not clinically indicated, in the College's view. Health professionals also need to be protected from liability if they stop or do not initiate treatment that they reasonably believe has been refused by a valid and applicable advance decision... Health professionals should also be protected from liability if they provide treatment when they have taken reasonable steps to find out if an advance decision exists but are unable to satisfy themselves that there is a valid and applicable advance decision. <http://www.imt.ie/features-opinion/2014/04/doctors-concerns-over-living-wills-expressed-to-doh.html>

Noted in Media Watch, 7 April 2014, #352 (p.9):

- *IRISH MEDICAL TIMES* | Online – 2 April 2014 – **'Directives to clarify advanced care protocol.'** The Irish Medical Organization (IMO) considers that patients might make an advance care plan (ACP) rather than a legally-binding directive. An ACP can provide valuable insights into patients' pre-morbid views and wishes at a time of great distress for the patient and their family, the IMO believes. In its submission, the union warned that a situation may arise where a patient-designated healthcare representative contests the decision made in the advanced care document. The capacity of the patient to make that decision at that time may be contested. Equally, it may be argued that the patient changed their decision. <http://www.imt.ie/news/latest-news/2014/04/directives-to-clarify-advanced-care-protocol.html>

Pre-death grief in the context of dementia caregiving: A concept analysis

JOURNAL OF ADVANCE NURSING | Online – 6 April 2014 – Pre-death grief in the context of dementia caregiving is a meaningful concept found in the popular media. From a scholarly point of view, it is an emerging concept. A definition is offered to advance conceptual clarity. Discussion focuses on advancing the concept into a situation-specific middle-range theory of pre-death grief in family caregiving. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12411/abstract>

Hospice care for patients who choose to hasten death by voluntarily stopping eating and drinking

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(3):126-131. Some hospice and palliative care organizations are considering the merits of creating written policies to guide clinicians' responses to patient requests for information and support for a voluntarily stopping eating and drinking (VSED)-related hastened death. How clinicians understand the meaning of a request to hasten dying and the legality and morality of the VSED option will determine their responses. http://journals.lww.com/jhpn/Abstract/2014/05000/Hospice_Care_for_Patients_Who_Choose_to_Hasten.3.aspx

Who wants to die in here?: Perspectives of prisoners with chronic conditions

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(3):173-181. The number of [U.S.] federal and state prisoners 65 years or older is growing rapidly. Older inmates often suffer advanced chronic conditions. Although compassionate release is a possibility, in practice, only a small fraction of prisoners are paroled before their death. The result is more people are spending their final days incarcerated. The purpose of this study was to examine the values, beliefs, and perceptions held by current and potential future consumers of end-of-life care in prisons to highlight facilitators and barriers to providing compassionate care for those dying in prison. Themes identified: 1) Seeking human interaction; 2) Accessing material resources; 3) Obtaining compassionate care; 4) Seeking equitable care; 5) addressing physiological needs; and 6) facing death. http://journals.lww.com/jhpn/Abstract/2014/05000/Who_Wants_to_Die_in_Here_Perspectives_of.11.aspx

Improving the evidence base in palliative care to inform practice and policy: Thinking outside the box

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 April 2014 – The aim of this narrative review is to explore the debate about the use of current evidence-based approaches for conducting research, such as randomized controlled trials and other study designs, in palliative care, and more specifically to: a) describe key myths about palliative care research; b) highlight substantive challenges of conducting palliative care research, using case illustrations; and, c) propose specific strategies to address some of these challenges. Myths about research in palliative care revolve around evidence hierarchies, sample heterogeneity, random assignment, participant burden and measurement issues. Challenges arise because of the complex physical, psychological, existential and spiritual problems faced by patients, families and service providers. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00179-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00179-1/abstract)

End-of-life care in Romania

Developing a costing framework for palliative care services

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2014 – The Palliative care services have been reported to be a less expensive alternative to traditional treatment; however, little is known about how to measure the cost of delivering quality palliative care. In this project, a reliable framework for determining the cost of inpatient and home-based palliative care services was developed. Inpatient palliative care cost in Romania was calculated at \$96.58 per day. Home-based palliative care was calculated at \$30.37 per visit, \$723.60 per month, and \$1367.71 per episode of care, which averaged 45 visits. A standardized methodology and framework for costing palliative care is presented. The framework allows a country or provider of care to substitute their own local costs to generate cost information relevant to the health care system. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00154-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00154-7/abstract)

Noted in Media Watch, 8 October 2012, #274 (p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 October 2012 – '**Palliative care in Romania: Between poor resources and poor management.**' Palliative care must compete with other serious healthcare issues, including the highest European Union incidences for tuberculosis, infant mortality, and uterine cervix cancer mortality. Therefore, the evolution of palliative care in Romania was largely the result of important input from non-governmental organizations, now the main providers of palliative care services, including education on the subject. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000030>

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

Patients who lack capacity and lack surrogates: Can they enroll in hospice?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 April 2014 – Patients who lack capacity and lack surrogates are among the most vulnerable patients we care for in palliative care. In the case presented here, the authors consider how to make end-of-life decisions for a patient who lacks capacity and lacks surrogates, who has a terminal illness, and who is not a candidate for disease-modifying treatments. The authors first define and characterize this population of patients through a review of the literature and then explore some decision-making quandaries that are encountered at the end of life. They make recommendations on how best to proceed with decision making for this vulnerable population. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00155-9/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00155-9/abstract)

Cont.

Noted in Media Watch, 30 September 2013, #325 (p.4):

- *THE NEW YORK TIMES* | Online – 23 September 2013 – **'When there's no family.'** Ten years ago, the American Bar Association's Commission on Law & Aging looked into the problem and cited estimates that approximately 4% of older adults are "unbefriended elderly..."¹
<http://newoldage.blogs.nytimes.com/2013/09/23/when-theres-no-family/?ref=health&r=0>
- 1. 'Incapacitated and alone: Healthcare decision making for unbefriended older people,' *Human Rights*, 2004;31(4). Article on Association's Commission on Law & Aging 2003 report.
http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol_31_2004/spring2004/hr_spring04_incapacitated.html

Does decisional conflict differ across race and ethnicity groups? A study of parents whose children have a life-threatening illness

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 April 2014 – This study is the first to describe racial and ethnic differences in decisional conflict of parents of children with life-threatening illnesses. Significant differences exist by race, ethnicity, language spoken, and diagnosis time across several sub-domains of decisional conflict. These differences are important to address when creating clinical care plans, engaging in shared decision-making, and creating interventions to alleviate decisional conflict. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0604>

Rehospitalization of older adults discharged to home hospice care

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 April 2014 – Among those [patients, i.e., study participants] readmitted, 25% had received a palliative care consultation, compared to 47.1% of those not readmitted. Patients without a participating decision-maker involved in their hospice decision had 3.5 times the risk of readmission within 30 days, compared to those with. Patients who had one or more telephone contacts with their primary care physician during week 1 after discharge had 2.4 times the readmission risk within 30 days, compared to patients with no such contacts during this period. Readmission within 30 days of initial discharge to hospice is associated with several measures of care and care planning. Further study of these measures may identify opportunities for interventions to improve the hospital-to-hospice transition and to decrease hospital readmissions. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0224>

Ten common questions (and their answers) on medical futility

MAYO CLINICAL PROCEEDINGS | Online – 10 April 2014 – The term medical futility is frequently used when discussing complex clinical scenarios and throughout the medical, legal, and ethics literature. However, the authors propose that health care professionals and others often use this term inaccurately and imprecisely, without fully appreciating the powerful, often visceral, response that the term can evoke. This article introduces and answers ten common questions regarding medical futility in an effort to define, clarify, and explore the implications of the term. They discuss multiple domains related to futility, including the biological, ethical, legal, societal, and financial considerations that have a bearing on definitions and actions. [http://www.mayoclinicproceedings.org/article/S0025-6196\(14\)00163-3/abstract](http://www.mayoclinicproceedings.org/article/S0025-6196(14)00163-3/abstract)

Noted in Media Watch, 17 February 2014, #345 (p.11):

- *NEW YORK LAW SCHOOL LAW REVIEW*, 2013-2014;58(2):347-368. **'Dispute resolution mechanisms for intractable medical futility disputes.'** Many hospital policies give a central decision making role to the institutional ethics committee. Specifically, these policies give the ethics committee not only a role to mediate, but also a role to adjudicate futility disputes. The traditional hospital ethics committee is not up to this adjudicatory task. It lacks independence, diversity, composition, training or resources. http://www.nylslawreview.com/wordpress/wp-content/uploads/2014/01/NYLS_Law_Review.Volume-58_Issue-2_Pope-article.pdf

Cont.

Noted in Media Watch, 11 November 2013, #331 (p.7):

- *CHEST*, 2013;144(5):1707-1711. **'Medical futility procedures: What more do we need to know?'** Unilateral medical futility policies, which allow health-care providers to limit or withdraw life-sustaining treatment over patient or surrogate objections, are increasingly designed around a procedural approach. Medical or ethics committees follow a pre-specified process, the culmination of which is a justified decision about whether ongoing treatment should be withheld or withdrawn.. <http://journal.publications.chestnet.org/article.aspx?articleid=1761255>

Meeting the needs of siblings of children with life-limiting illnesses

NURSING CHILDREN & YOUNG PEOPLE, 2014;26(3):16-20. Siblings of children with life-threatening or life-limiting illnesses can face a number of challenges, yet this is a group that is often unacknowledged as needing specific support. It is essential that the needs of siblings are recognised and addressed as part of a family-centred approach. This article discusses the experiences and challenges faced by siblings in such families and what children's nurses can do to help. It outlines a group intervention offered by a community children's palliative care service. <http://rcnpublishing.com/doi/abs/10.7748/ncyp2014.04.26.3.16.e349>

Noted in Media Watch, 23 December 2013, #337 (p.10):

- *PSYCHO-ONCOLOGY* | Online – 18 December 2013 – **'They still grieve: A nationwide follow-up of young adults 2-9 years after losing a sibling to cancer.'** A majority (54%) of siblings [i.e., study participants] stated that they had worked through their grief either "not at all" or "to some extent" at the time of investigation. In multiple regression analyses with unresolved grief as the dependent variable, 21% of the variance was explained by lack of social support and shorter time since loss. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3463/abstract>

Noted in Media Watch, 23 July 2012, #263 (p.11):

- *AMERICAN JOURNAL OF EPIDEMIOLOGY* | Online article – 19 July 2012 – **'The forgotten griever: A nationwide follow-up study of mortality subsequent to the death of a sibling.'** The least-studied familial relationship in the bereavement literature is that of siblings, although loss of a sibling may also involve health consequences. An elevated mortality risk associated with a sibling's death was found in all age groups studied, but the association was generally stronger at younger ages and could be observed predominantly after more than one year of follow-up. <http://aje.oxfordjournals.org/content/early/2012/07/19/aje.kws163.abstract>

Physician-reported practices on continuous deep sedation until death: A descriptive and comparative study

PALLIATIVE MEDICINE | Online – 9 April 2014 – The frequency of continuous deep sedation until death among all deaths was 11.3% for GPs and 18.4% for medical specialists [i.e., among physicians in Flanders, Belgium]. GPs reported significantly higher rates of severity and mean intensity of pain, delirium, dyspnea, and nausea in the last 24 hours of life for sedated patients and a higher number of severe symptoms than medical specialists. No differences were found between groups in the drugs used, except in propofol, reported only by medical specialists. Artificial nutrition and hydration was withheld or withdrawn in 97.2% of GPs and 36.2% of medical specialist cases. Explicit life-shortening intentions were reported by both groups. Continuous deep sedation until death was initiated without consent or request of either the patient or the family in 27.9% (medical specialists) and 4.7% (GPs) of the cases reported. Considerable variation, often largely deviating from professional guidelines, was observed in physician-reported performance and decision-making, highlighting the importance of providing clearer guidance on the specific needs of the context in which continuous deep sedation until death is to be performed. <http://pmj.sagepub.com/content/early/2014/04/09/0269216314530768.abstract>

N.B. Recent articles on palliative or terminal sedation noted in Media Watch, 10 February 2014, #344 (pp.10-11).

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMC PALLIATIVE CARE* | Online – 9 April 2014 – '**Motivations of physicians and nurses to practice voluntary euthanasia: A systematic review.**' This paper reviews a total of 27 ... studies out of the 1,703 articles identified... Five studies were in countries where euthanasia is legal and 22 in countries where it is not. Seventeen studies were targeting physicians, 9 targeted nurses and 1 both health professionals. Six studies identified the motivations underlying the intention to practice euthanasia, 16 the behavior itself and 5 both intention and behavior. The category of variables most consistently associated with euthanasia is psychological variables. All categories collapsed, the four variables most frequently associated with euthanasia are past behavior, medical specialty, whether the patient is depressed and the patient's life expectancy. The present review suggests that physicians and nurses are motivated to practice voluntary euthanasia especially when they are familiar with the act of euthanasia, when the patient does not have depressive symptoms and has a short life expectancy and their motivation varies according to their medical specialty. Additional studies among nurses and in countries where euthanasia is legal are needed. <http://www.biomedcentral.com/content/pdf/1472-684X-13-20.pdf>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/4/media-watch/>

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

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

Australia

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Worth Repeating

Case studies

Care demands by families and family healthcare proxies: A dilemma for palliative care and hospice care staff

ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING, 2013;21(5):42-46. This article provides two cases of unrealistic care demands... [that] ...highlight the psychosocial needs and methods of communication that families may use to communicate with caregivers about their desires for or concern over their loved one's care at the end of life. These cases illustrate how conflicts may arise when patients' families, including their healthcare proxies, have unrealistic expectations and make inappropriate care demands of the healthcare staff, who then struggle to administer client- or patient-centered care. The provision of high-quality, compassionate palliative and hospice-based care is the goal for healthcare providers who have chosen to provide end-of-life care as their professional focus. For individuals who combine the philosophy of palliative and hospice care with the care of elders, even greater challenges may occur because of the complex nature of family dynamics, relationships, and belief systems, among other factors, which often influence patient care. It can be challenging for healthcare providers to navigate the many potential minefields when such challenges exist. When successfully navigated, however, the satisfaction that results from achieving a clinically compassionate, caring, and comfortable death for the patient as well as solace for the family are worth all of the effort.
<http://www.annalsoflongtermcare.com/article/care-demands-families-and-family-healthcare-proxies-dilemma?i=7e7ddff74b>

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.

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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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