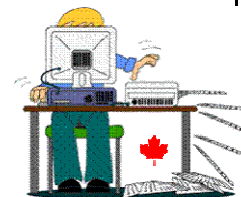


## **Media Watch...**

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.

**15 December 2014 Edition | Issue #388**



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

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

**End-of-life care in nursing homes; Scroll down to [Specialist Publications](#) and 'Developing palliative care practice guidelines and standards for nursing home-based palliative care teams: A Delphi study' (p.12), in *Journal of the American Medical Directors Association*.**

## **Canada**

### **College of Physicians & Surgeons of Ontario**

#### **Doctors need patient or family consent before stopping end-of-life treatment: New Ontario draft policy**

ONTARIO | *The National Post* – 11 December 2014 – Doctors must obtain the consent of patients or their families before deciding to turn off or withhold life-preserving treatments, Canada's largest medical regulator says in a draft new policy that largely reshapes how end-of-life care is decided.<sup>1</sup> The blueprint ... contrasts with the existing advice offered by ... [the] College ... that doctors should avoid treatments they believe will be of no benefit or harmful to a gravely ill patient.<sup>2</sup> Regulators in at least two other provinces and in Britain have similar policies, stipulating essentially physicians have the final word on what kind of end-of-life treatment is most appropriate. Recent legal rulings have raised questions about that approach, however, with one tribunal saying the Ontario guidelines were clearly at odds with the law. The new policy addresses those concerns, but still directs intractable disagreements to an independent board for a ruling and should not mean dying patients are kept alive in vain, said Carol Leet, the college's president. The draft policy also tackles what doctors should do if patients ask for help in committing suicide, arguing they should discuss their concerns about pain and other issues, rather than merely indicating assisted-death is against the law. And it urges doctors to discuss end-of-life issues with patients long before they are at death's door. <http://news.nationalpost.com/2014/12/11/doctors-need-patient-or-family-consent-before-stopping-end-of-life-treatment-new-ontario-draft-policy/>

1. 'Planning for and Providing Quality End-of-Life Care,' College of Physicians & Surgeons of Ontario, December 2014. Draft of proposed policy, for consultation purposes only, available at: [http://policyconsult.cpso.on.ca/wp-content/uploads/2014/12/Draft-Planning-for-and-Providing-Quality-End-of-Life-Care-Policy\\_WP.pdf](http://policyconsult.cpso.on.ca/wp-content/uploads/2014/12/Draft-Planning-for-and-Providing-Quality-End-of-Life-Care-Policy_WP.pdf)
2. 'Decision-Making for the End of Life,' College of Physicians & Surgeons of Ontario, July 2006. <http://www.cpso.on.ca/Policies-Publications/Policy/Decision-making-for-the-End-of-Life>

Cont.

Noted in Media Watch, 10 November 2014, #383 (p.11):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 4 November 2014 – **'Withholding and withdrawing treatment in Canada: Implications of the Supreme Court of Canada's decision in the Rasouli case.'** In Ontario, physicians must obtain consent to withdraw life support in cases like that of Hassan Rasouli, even where such treatment is thought to be non-beneficial. Consent may or may not be required to withdraw other treatment or to withhold treatment. <http://www.cmaj.ca/content/186/16/E622.extract>

Noted in Media Watch, 29 September 2014, #377 (p.1):

- ONTARIO | *The Toronto Star* – 28 September 2014 – **'Stalemate: Deciding life or death.'** The little-known Consent & Capacity Board (CCB) – the only one of its kind in North America – is a working laboratory for the most pressing issue facing Canada's healthcare system: the end of life. When a physician's treatment proposal is challenged by a family member whose loved one can no longer communicate their wishes, doctors can make an application to the CCB. [http://www.thestar.com/news/world/2014/09/26/stalemate\\_deciding\\_life\\_or\\_death.html](http://www.thestar.com/news/world/2014/09/26/stalemate_deciding_life_or_death.html)

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

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – **'The future of decision-making in critical care after *Cuthbertson v. Rasouli*.'** The Supreme Court of Canada ruling on *Cuthbertson v. Rasouli* has implications for all acute healthcare providers. The authors' objective in writing this article is to clarify the implications of this ruling on the care of critically ill patients. <http://link.springer.com/article/10.1007/s12630-014-0215-9>

## End-of-life care in Ontario

ONTARIO | Office of the Auditor General of Ontario – 9 December 2014 – **'2014 Report (Extract).'** Palliative care services in Ontario developed in a patchwork fashion, often being initiated by individuals who had a passion for this area of care, wherever they were located in the province. As a result, although efforts have been made to create an integrated, coordinated system to deliver palliative care, no such system exists. Currently, the Ministry (of Health & Long Term Care] lacks information on the palliative care services that are available, their costs, the patient need for these services or what mix of services would best meet patient needs... Overall, despite its many initiatives, the Ministry does not, as yet, have effective processes in place to ensure that there is sufficient public information on palliative care services, or that patients nearing the end of life have timely and equitable access to palliative care services that meet their needs. [http://www.auditor.on.ca/en/reports\\_en/en14/308en14.pdf](http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf)

Cont.

### Significant areas for improvement in end-of-life care noted by the Ontario Auditor General

Strategic policy framework not in place for palliative care delivery system.

Ministry needs better information for decision-making and planning.

Mix of services should be reviewed to ensure patients' needs are met cost effectively.

Access to palliative care services is not equitable.

Patient care could be improved and health care costs reduced.

Education standards needed for physicians and nurses to help ensure proper patient care.

Most publicly funded services used by cancer patients.

More public awareness and education needed.

### Specialist Publications

**'Factors associated with not receiving home-care, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study'** (p.11), in *Health Policy*.

Of related interest:

- ONTARIO | *Ontario Health Technology Assessment Series*, 2014;14(18):1-70. **End-of-Life Care Interventions: An Economic Analysis.** The annual cost of providing care for patients in their last year of life is estimated to account for approximately 9% of the Ontario health care budget. Access to integrated, comprehensive support and pain/symptom management appears to be inadequate and inequitable. Most people with a terminal illness say they would prefer to die at home, but ... they are more likely to die in hospital. As part of an effort to improve end-of-life care in the Ontario health care system, the authors evaluated the cost-effectiveness of nine quality improvement strategies. They found in-home team care increased people's chances of dying at home, increased the time spent at home in the last year of life, and reduced health care costs by about \$4,400 per patient. The authors could not make firm conclusions about the cost-effectiveness of strategies related to team care, patient care planning discussions, education for patients and caregivers, and support services for caregivers. <http://www.hqontario.ca/Portals/0/documents/eds/ohas/economic-analysis-eol-care-interventions-1411-en.pdf>

N.B. The *Ontario Health Technology Assessment Series* is published by Health Quality Ontario.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | *The Chronicle-Herald* (Halifax) – 11 December 2014 – **'Hospice advocates embrace revived assisted-dying debate.'** Raising funds to build the first free-standing residential hospice in Nova Scotia is dependent on the Halifax Hospice Society's ability to engage the public in open dialogue on death and dying. This is no easy task. Thus, when advocates for assisted dying promote a public debate on whether or not Canadians should have the right to determine their own fate, the Hospice Society recognizes the opening and jumps headlong into the death and dying discussion — albeit from a very different perspective. Respecting the decision-making capacities of autonomous individuals to make informed health-care choices lies at the heart of commonly accepted principles of health-care ethics. This respect for the voluntary rights of the individual suggests everyone should have jurisdiction over his or her own health care. Both hospice and right-to-die advocates would agree that this unalienable right to autonomy should include the dying process. The Halifax Hospice Society neither endorses nor condones an individual's right to die in a manner and a time of his or her choosing. Hospices do not implement processes that either lengthen or shorten the dying process. <http://thechronicleherald.ca/opinion/1257461-hospice-advocates-embrace-revived-assisted-dying-debate>
- *THE NATIONAL POST* | Online – 7 December 2014 – **'End-of-life debate turns to newborns: "Postnatal abortion" morally acceptable in some cases, ethicist says.'** Doctors would be justified to end the lives of some terminally impaired newborn babies, says a prominent Canadian bioethicist in a report that pushes the country's euthanasia debate into provocative new territory. Much of the discussion of physician assisted-death in Canada has centred around adult patients capable of making known how they want to end their lives. <http://news.nationalpost.com/2014/12/07/end-of-life-debate-turns-to-newborns-postnatal-abortion-morally-acceptable-in-some-cases-ethicist-says/>
  1. 'Physicians can justifiably euthanize certain severely impaired neonates,' *Journal of Thoracic & Cardiovascular Surgery*, 11 October 2014. [http://www.itcvsonline.org/article/S0022-5223\(14\)01532-3/abstract](http://www.itcvsonline.org/article/S0022-5223(14)01532-3/abstract)

### Specialist Publications

**'Medical aid in dying in Quebec – legal considerations'** (p.17), in *Journal of Medical Law & Ethics*.

**'Human dignity and medical ethics'** (p.17), in *Journal of Medical Research & Development*.

**'Psychosocial determinants of nurses' intention to practise euthanasia in palliative'** (p.18), in *Nursing Ethics*.

## U.S.A.

### "Warehouses for the dying": Are we prolonging life or prolonging death?

*THE WASHINGTON POST* | Online – 12 December 2014 – For a man at a highly rated hospital surrounded by the technology of medical miracles, [Paul] Marik sounded a note of striking skepticism: Patients too often suffer in vain attempts to prolong life, he said, because of the mandate to "do everything." The urge to deploy every last aggressive medical technique, in other words, was hurting people. "I think if someone from Mars came and saw some of these people, they would say, what have they done to deserve this punishment?" said Marik, gesturing to the surrounding rooms. "People might say we are prolonging life, but we end up prolonging death." Critics of U.S. health care have long marshaled evidence against the overuse of aggressive end-of-life care, but the idea that many Americans are dying badly – subjected to desperate treatments in ways that are not only expensive but painful and medically futile – has gained currency of late. Marik's long-standing argument, which is notable ... for coming from an ICU doctor, is this: The nation has double or triple as many ICU beds *per capita* as other Western nations, it spends inordinate amounts of money in the last months of life, and worst of all, this kind of care isn't what patients want. His doubts about end-of-life care appear to be widely shared among his ICU colleagues. <http://www.washingtonpost.com/news/storyline/wp/2014/12/12/warehouses-for-the-dying-are-we-prolonging-life-or-prolonging-death/>

#### The business of dying

*The Washington Post* article is one in a series on end-of-life care in the U.S.

**Part 1:** 'Terminal neglect? How some hospices treat dying patients,' 3 May 2014. [Noted in Media Watch, 5 May 2014, #356 (p.3)]

[http://www.washingtonpost.com/business/economy/terminal-neglect-how-some-hospices-fail-the-dying/2014/05/03/7d3ac8ce-b8ef-11e3-96ae-f2c36d2b1245\\_story.html](http://www.washingtonpost.com/business/economy/terminal-neglect-how-some-hospices-fail-the-dying/2014/05/03/7d3ac8ce-b8ef-11e3-96ae-f2c36d2b1245_story.html)

**Part 2:** 'Is that hospice safe? Infrequent inspections mean it may be impossible to know,' 26 June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.3)]

[http://www.washingtonpost.com/business/economy/is-that-hospice-safe-infrequent-inspections-means-it-may-be-impossible-to-know/2014/06/26/e258e880-aaa4-11e3-b98c-72cef4a00499\\_story.html](http://www.washingtonpost.com/business/economy/is-that-hospice-safe-infrequent-inspections-means-it-may-be-impossible-to-know/2014/06/26/e258e880-aaa4-11e3-b98c-72cef4a00499_story.html)

**Part 3:** 'Rising rates of hospice discharge in U.S. raise questions about quality of care,' 6 August 2014. [Noted in Media Watch, 11 August 2014, #370 (p.4)]

[http://www.washingtonpost.com/business/economy/leaving-hospice-care-alive-rising-rates-of-live-discharge-in-the-us-raise-questions-about-quality-of-care/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265\\_story.html](http://www.washingtonpost.com/business/economy/leaving-hospice-care-alive-rising-rates-of-live-discharge-in-the-us-raise-questions-about-quality-of-care/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265_story.html)

**Part 4:** 'As more hospices enroll patients who aren't dying, questions about lethal doses arise,' 25 August 2014. [Noted in Media Watch, 25 August 2014, #372 (p.3)]

<http://www.washingtonpost.com/news/storyline/wp/2014/08/21/as-more-hospices-enroll-patients-who-arent-dying-questions-about-lethal-doses-arise/?hpid=z5>

**Part 5:** 'Quality of U.S. hospices varies, patients left in dark,' 26 October 2014. [Noted in Media Watch, 3 November 2014, #382 (p.5)]

[http://www.washingtonpost.com/business/economy/quality-of-us-hospices-varies-patients-left-in-dark/2014/10/26/aa07b844-085e-11e4-8a6a-19355c7e870a\\_story.html](http://www.washingtonpost.com/business/economy/quality-of-us-hospices-varies-patients-left-in-dark/2014/10/26/aa07b844-085e-11e4-8a6a-19355c7e870a_story.html)



#### 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>

## Dying in America: Report sets off discussion in *Annals of Internal Medicine*

*THE WASHINGTON POST* | Online – 8 December 2014 – In September, the Institute of Medicine started what it hoped would become a national conversation on how well we're prepared for dying. It published a 500-page report<sup>1</sup> ... which found neither individuals nor the health-care system are at all ready for the inevitable. The report ... "outlined comprehensive recommendations for tackling an issue that's only getting more pressing as 10,000 baby boomers join Medicare every day." Those recommendations included educating Americans to begin thinking about the end of life early on, along with suggestions for improving access to hospice care, training more doctors in palliative care and compensating health-care professionals for talking to pa-

tients about death. To prompt discussion, the *Annals of Internal Medicine* is publishing four commentaries touching on the issues raised in the report, from cancer treatment to unnecessary end-of-life treatments.<sup>2-5</sup>  
[http://www.washingtonpost.com/national/health-science/dying-in-america-report-sets-off-discussion-in-annals-of-internal-medicine/2014/12/05/43ce9dea-7a73-11e4-84d4-7c896b90abdc\\_story.html](http://www.washingtonpost.com/national/health-science/dying-in-america-report-sets-off-discussion-in-annals-of-internal-medicine/2014/12/05/43ce9dea-7a73-11e4-84d4-7c896b90abdc_story.html)

### **Specialist Publications**

**'Deep-seated barriers to end-of-life-care improvement in the twenty-first century'** (p.16), in *Reviews in American History*.

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
2. 'Dying in America: A constructive step forward and an opportunity to deepen partnerships with patients and families.' There may be no truer test of a health care system than how it supports persons with advanced illness or at the end of life, and the loved ones who care for them. In that regard, our health care system struggles and often fails, and this failure contributes to soaring health care costs that put enormous strain on families and our economy. <http://annals.org/article.aspx?articleid=2020456>
3. 'The doctor: For life and at the end of life.' The co-chair of an IOM committee on care at the end of life discusses changes need-ed in the care of patients approaching death and argues that treating physicians should remain fully present even after their patients enter palliative care or hospice programs. <http://annals.org/article.aspx?articleid=2020455>
4. 'Engaging public health in end-of-life issues: It is time to step up to the plate.' In September 2014, the Institute of Medicine released its fifth full report on end-of-life issues and identified recommendations within five domains. One recommendation is to educate and engage the public by providing fact-based information about the care of persons with advanced serious illness to encourage advance care planning and informed choices based on the needs and values of individuals. <http://annals.org/article.aspx?articleid=2020457>
5. 'Can the U.S. buy better advance care planning?' Since the early 1980s, many aspects of care near the end of life in the U.S. have changed dramatically. Yet, despite nearly 30 years of efforts to get persons ... to engage in advance care planning, few patients do. This commentary discusses the Institute of Medicine report, particularly the committee's recommendation to reimburse physicians for engaging patients in advance care planning. <http://annals.org/article.aspx?articleid=2020454>

### **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.18.

## U.S. life expectancy continues to climb

*THE WASHINGTON POST* | Online – 8 December 2014 – The average life expectancy for people born in 2012 in the U.S. is a record high of 78.8 years, according to the Centers for Disease Control & Prevention. The life expectancy for girls born in 2012 is 81.2 years, vs. 76.4 years for boys. The rate of death in the U.S. reached a record low of 732.8 per 100,000 people in 2012, decreasing 1.1% from 2011. [http://www.washingtonpost.com/national/health-science/us-life-expectancy-continues-to-climb/2014/12/05/9edb2ffe-4fc2-11e4-8c24-487e92bc997b\\_story.html](http://www.washingtonpost.com/national/health-science/us-life-expectancy-continues-to-climb/2014/12/05/9edb2ffe-4fc2-11e4-8c24-487e92bc997b_story.html)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *FORBES* | Online – 8 December 2014 – **'74% support giving terminally ill patients greater end-of life control.'** A new report indicates a surge of public support for giving terminally ill patients greater control of their end-of-life care. According to the results of an online survey ... 74% of American adults believe terminally ill patients who are suffering from severe pain should have the right to choose to end their own lives.<sup>1</sup> 14% of participants oppose this view. <http://www.forbes.com/sites/cjarlotta/2014/12/08/74-percent-support-giving-terminally-ill-patients-greater-end-of-life-control/>

1. 'Most Americans Agree With Right-to-Die Movement,' Harris Poll, October 2014. <http://www.harrisinteractive.com/NewsRoom/HarrisPolls/tabid/447/ctl/ReadCustom%20Default/mid/1508/ArticleId/1531/Default.aspx>

## International

### French MPs release report on end-of-life care

FRANCE | *Euro News* – 12 December 2014 – French MPs have submitted a report to the President on end-of-life care that stops short of euthanasia. The proposals allow the right to "continuous deep sedation" to allow terminally ill patients who request it to lessen their suffering. President François Hollande welcomed the proposals on the controversial issue and said they would form the basis of new laws. "<http://www.euronews.com/2014/12/12/french-mps-release-report-on-end-of-life-care/>

### End-of-life care in Taiwan

### Majority would rather die than receive life support: Web poll

TAIWAN | Focus Taiwan (Taipei) – 11 December 2014 – More than 80% of participants in an Internet survey said they would rather die than be put on life support if they came down with a terminal illness, the Taiwan Healthcare Reform Foundation said Thursday. In the single-question survey ... 86% of 1,099 participants said they would prefer to die in a "dignified manner" than continue to receive dialysis or rely on mechanical ventilators to artificially prolong their lives, said Liu Shu-chiung, executive director of the Taipei-based foundation. Some consider respiratory care wards as cash cows

for hospitals and many believe they prolong pain instead of alleviating it, she said. <http://focustaiwan.tw/news/asoc/201412110030.aspx>

### Specialist Publications

**'Low socio-economic status is associated with more aggressive end-of-life care for working-age terminal cancer patients'** (p.15), in *The Oncologist*.

Cont.



Noted in Media Watch, 8 July 2013, #313 (p.5):

- TAIWAN | *The Taipei Times* – 8 July 2013 – 'Government looks into "futile care.'" With a rapidly aging population and a cash-strapped National Health Insurance system, the government is paying more attention to the issue of "futile medical care," treatment applied only to prolong life without a foreseeable cure or positive outcome, and the prospect of hospice care. <http://www.taipetimes.com/News/taiwan/archives/2013/07/08/2003566617>

### Irish cultural needs "forgotten"

U.K. | *The Daily Mail* – 11 December 2014 – Health workers in Britain "don't bother" to understand Irish patients, who suffer higher levels of long-term illness, death rates from terminal diseases and mental ill-health, the Irish Parliament has heard. A parliamentary watchdog was told very poor health among Irish expatriates ... is not recognised because the community is lumped in with the overall white population in official figures. Dr. Mary Tilki, chair woman of the organisation Irish in Britain, said many who remain cut off after years of discrimination are suffering further from a lack of cultural understanding afforded to other minorities. "There is increasing recognition that people from the Caribbean, India and Pakistan have cultural

needs but the Irish tend to be forgotten," she told Dublin's Oireachtas Joint Committee on Health & Children. This can make for a very lonely and frightening experience in hospital, a care home or in end of life care. <http://www.dailymail.co.uk/wires/pa/article-2870035/Irish-cultural-needs-forgotten.html>

#### Extract from *The Daily Mail* article

Irish people have among the highest levels of long-term illness; the highest death rate from cancer in the population; and, high levels of death rates from coronary heart disease, hypertension, and stroke.

### ***Universal Health Coverage & Palliative Care: Do not leave those suffering behind***

WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE | Online – 11 December 2014 – The report looks at the situation of palliative care in relation to universal health coverage policies, schemes and discourse. It suggests some of the barriers that may have prevented the greater inclusion of palliative care in universal health coverage policies and schemes and looks at case studies in England, Mexico, Singapore, South Africa and the Republic of Ireland highlighting the extent to which palliative care is included. <http://www.thewhpca.org/resources/item/uhc-and-palliativecare>

#### Specialist Publications

'Multinational Association of Supportive Care in Cancer, the European Society of Medical Oncology, and the European Association of Palliative Care survey of palliative programs' (p.17), in *Supportive Care in Cancer*.

#### 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>

## End-of-life care in Mexico

### Important advance in care for incurably ill

MEXICO | Human Rights Watch – 10 December 2014 – The Mexican Health Ministry took an important step ... to ensure access to palliative care for people suffering from pain due to incurable illness. The government released long-awaited guidelines to its healthcare system that will operationalize provisions on end-of-life care outlined in Mexico's 2009 health law. In October, Human Rights Watch highlighted ... the barriers faced by tens of thousands of patients who suffer unnecessarily from severe pain and other symptoms.<sup>1</sup> Although the Health Ministry was supposed to issue the guidance within six months of the 2009 law coming into effect, it was held up for years, delaying the effect of the law. <http://www.hrw.org/news/2014/12/10/mexico-important-advance-care-incurably-ill>

1. 'Care When There Is No Cure: Ensuring the right to palliative care in Mexico,' Human Rights Watch, 28 October 2014. [Noted in Media Watch, 3 November 2014, #382 (p.7)] <http://www.hrw.org/reports/2014/10/28/care-when-there-no-cure>

**N.B.** Palliative care in Mexico is provided mainly by hospital-based teams that operate as part of their organization's pain service. Interest was stimulated in 1990 by the Mexican Declaration on Cancer Pain Relief. During the early part of that decade, palliative care programs became operational at the Civil Hospital of Guadalajara and, in Mexico City, at the National Institute of Nutrition and the National Cancer Institute. Further impetus was provided in 1996 by the Declaration of Guadalajara, and in 2004, the Paliat Institute opened, supported by government funding. That same year, 14 palliative care organizations were identified, which in total provided two hospices, four in-patient units, eight hospital teams, and three home care services...

**Source:** 'Mapping levels of palliative care development: A global view,' *Journal of Pain & Symptom Management*, 2008;35(8):469-485. [http://www.jpsmjournal.com/article/S0885-3924\(07\)00729-4/fulltext](http://www.jpsmjournal.com/article/S0885-3924(07)00729-4/fulltext)

### Half of Yorkshire residents feel "uncomfortable" talking to someone who is grieving

U.K. | *The Yorkshire Post* – 10 December 2014 – Bereavement remains a taboo subject, with almost half of people in Yorkshire saying they feel uncomfortable talking to someone who is grieving, a new study ... has revealed.<sup>1</sup> Across the country the vast majority, 84%, of those who have been bereaved in the past five years thought that people in Britain are uncomfortable talking to those who have recently been bereaved. <http://www.yorkshirepost.co.uk/news/main-topics/general-news/half-of-yorkshire-residents-feel-uncomfortable-talking-to-someone-who-is-grieving-1-6996276>

1. 'Public Attitudes to Bereavement,' Dying Matters Coalition, December 2014. [http://comres.co.uk/polls/NCPC\\_Dying\\_Matters\\_Coalition\\_Bereavement\\_Poll\\_Tables.pdf](http://comres.co.uk/polls/NCPC_Dying_Matters_Coalition_Bereavement_Poll_Tables.pdf)

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ITALY | KVNU News (North Logan, Utah, U.S.) – 11 December 2014 – **'Campaign pushes for right-to-die legislation in Italy.'** A campaign of leading doctors, politicians and those terminally ill in Italy is challenging the country's Vatican-influenced laws that ban euthanasia. The appeal comes a year after the group proposed legislation that would give Italians more control over how they die. That would include both the right to euthanasia and to a living will, where legal instructions are written on what medical assistance a person wants in the future if he or she becomes incapable of communicating. Sixty percent of Italians are in favor of regulated euthanasia and more than 70% would like the right to compose a living will. <http://www.610kvnu.com/world/10e7c2ece4b65e33bcbce99450dd45d6>

Cont.



- U.K. (Wales) | Wales Online – 10 December 2014 – **“Assisted dying” proposal defeated in National Assembly after gaining support of just 12 Assembly Members.** A proposal on the principle of “assisted dying” has been defeated in the National Assembly – after just 12 Assembly Members supported it in a Senedd debate. Although the National Assembly does not have the power to legalise assisted dying ... [it was] ... argued it was appropriate for Wales’ national democratic forum to debate the issue. <http://www.walesonline.co.uk/news/wales-news/assisted-dying-proposal-defeated-national-8268159>
- ISRAEL | *Haaretz* – 9 December 2014 – **‘Unprecedented: Israeli court okays euthanasia for patient who didn’t meet criteria.’** A gag order was lifted on a recent, unprecedented decision by an Israeli court which allowed termination of the life of a patient suffering from a terminal disease who did not meet the criteria of “dying patient” set into legislation in 2005. Two weeks ago, the Tel Aviv District Court approved administering euthanasia to a patient suffering from amyotrophic lateral sclerosis [ALS] ... The patient had suffered from ALS for over nine years. During the past seven years he had been totally paralyzed, except for being able to move his eyes. He was bedridden, unable to speak, and was fed and ventilated artificially. Recently his condition deteriorated and there was a concern that he would also lose his ability to communicate via eye movements. <http://www.haaretz.com/news/national/1.630758>

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

#### **Palliative sedation and what constitutes active dying**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 December 2014 – The authors present the case of a 34-year-old woman with Klippel-Feil syndrome who developed progressive generalized dystonia of unclear etiology, resulting in intractable pain despite aggressive medical and surgical interventions. Ultimately, palliative sedation was required to relieve suffering. Herein, they describe ethical considerations including defining sedation, determining prognosis in the setting of an undefined neurodegenerative condition, and use of treatments that concurrently might prolong or alter end-of-life trajectory. The authors highlight pertinent literature and how it may be applied in challenging and unique clinical situations. Finally, they discuss the need for expert multidisciplinary involvement when implementing palliative sedation and illustrate that procedures and rules need to be interpreted to deliver optimal patient-centered plan of care. <http://ajh.sagepub.com/content/early/2014/12/08/1049909114561997.abstract>

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – **‘Palliative sedation: An analysis of international guidelines and position statements.’** Guidelines were published by American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

#### **Caring for the patient with end-stage dementia**

*ANNALS OF LONG-TERM CARE*, 2014;22(12). This article reviews four key components to ensuring patients with end-stage dementia receive proper care. First, the challenge of prognostication, a leading barrier to hospice care, is reviewed. Second, care planning strategies ... are examined. Third, strategies for managing complications of dementia, such as behavioral problems, sleep disturbances, and pain, are reviewed. Finally, strategies for helping patients and families through the bereavement process are examined, as skillful end-of-life care will leave a legacy of dignity and peace for the family. <http://www.annalsoflongtermcare.com/article/caring-patient-end-stage-dementia>

Cont.

Noted in Media Watch, 18 August 2014, #371 (p.10):

- *JOURNAL OF ALZHEIMER'S DISEASE* | Online – 4 August 2014 – '**Needs of people with severe dementia at the end-of-life: A systematic review.**' Ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned. <http://iospress.metapress.com/content/8wk34806v5630580/>

### **"I'm not the only one": A collaborative approach to developing a children and young person's bereavement group**

*BEREAVEMENT CARE*, 2014;33(3):97-102. This paper describes a collaborative partnership in developing a children and young persons' bereavement group. The course consists of a series of four sessions which encourage children to share and express feelings. The group uses a partnership approach. Whereas previous groups were hospice counsellor-led, the new model is for co-facilitation by the counsellor and a specialist nurse from a regional oncology centre. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2014.980983>

Of related interest:

- *NEW REVIEW OF HYPERMEDIA & MULTIMEDIA*, 2015;21(1). '**New mourners, old mourners: Online memorial culture as a chapter in the history of mourning.**' Pervasive social media in which users generate their own content have significantly shifted mourners' social interactions and the norms that govern them, partly in new directions (such as enfranchising previously stigmatised griefs; more potential for conflict between mourners and others) but partly returning to something more like the relationships of the pre-industrial village (such as everyday awareness of mortality, greater use of religious imagery, more potential for conflict among mourners). <http://opus.bath.ac.uk/42140/>

Noted in Media Watch, 5 March 2012, #243 (p.11):

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;64(4):275-302. '**Does the Internet change how we ... mourn?**' Part 1 [of this article] describes a range of online practices that may affect dying, the funeral, grief and memorialisation, inheritance and archaeology... Part 2 argues new online practices have implications for, and may be illuminated by, key concepts in death studies: the sequestration (or separation from everyday life) of death and dying, disenfranchisement of grief, private grief, social death, illness and grief narratives, continuing bonds with the dead, and the presence of the dead in society. [http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue\\_1\\_6:journal.1.255:linkingpublicationresults.1:300329.1](http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue_1_6:journal.1.255:linkingpublicationresults.1:300329.1)

### **End-of-life care in England**

#### **Advance care planning: An unsuitable subject for Quality & Outcomes Framework?**

*BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 1 December 2014 – Promotional initiatives for ACP [advance care planning] ... have focused on increasing its use, with one guideline advocating integration into the Quality & Outcomes Framework (QOF) as a means of establishing ACP as a "routine" part of care.<sup>1,2</sup> The suggestion that something as complex and sensitive as ACP could be dealt with in a similarly routine and structured way to blood pressure monitoring or cardiovascular risk assessment seems surprising; certainly the possibility should lead to detailed examination of the implications of incentivisation of this process, as well as perhaps to a degree of re-examination of the concept itself. ACP unquestionably has much to recommend it, with the potential to be highly beneficial both for patients and healthcare professionals, and effective use of ACP will in many situations reflect good quality care. However, it is clear that it must be used appropriately, with the ideal being an individualised approach, as part of a personalised therapeutic relationship, to patients who are likely to benefit: a directed approach leading to a box-ticking exercise for all will not sit well with this aim. <http://bjgp.org/content/64/629/649>

Cont.

1. 'Quality & Outcomes Framework: 2013-2014,' The Framework, a voluntary process for all surgeries in England, is the annual reward and incentive programme detailing GP practice achievement results. <http://www.hscic.gov.uk/catalogue/PUB15751>
2. 'Advance Care Planning: National guideline No.12 in the Concise Guidance to Good Practice Series.' Prepared by the British Geriatrics Society, Royal College of Physicians, Royal College of Nursing, Royal College of Psychiatrists, Royal College of General Practitioners, British Society of Rehabilitation Medicine, Alzheimer's Society, Help the Aged and the National Council for Palliative Care. <https://www.rcplondon.ac.uk/publications/advance-care-planning>

#### **Home care in Ontario, Canada**

#### **Factors associated with not receiving homecare, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study**

*HEALTH POLICY* | Online – 3 December 2014 – Publicly funded homecare has been shown to reduce acute care use and improve quality of life for those nearing end-of-life (EOL). Yet despite the known benefits of homecare, many EOL cancer patients never receive these services. The authors used administrative data on all cancer decedents in Ontario, Canada, in 2006 to determine predictive factors of not receiving homecare, not receiving EOL homecare, and late initiation of EOL homecare. 22,262 decedents met the eligibility criteria, 25% of whom never received homecare in the last six months of life. A logistic regression found that cancer disease site, having a co-morbidity, region of residence, shorter cancer survival, being male, lower income, older age, and less prior emergency department use were significant factors associated with not receiving homecare. Individuals with hematological cancer were less likely to receive homecare in their final months. Some of these covariates also predicted not receiving EOL homecare and late referral to these services. [http://www.healthpolicyjrn.com/article/S0168-8510\(14\)00334-0/abstract](http://www.healthpolicyjrn.com/article/S0168-8510(14)00334-0/abstract)

#### **Islamic law and medical decision making**

#### **The growth of patient autonomy in modern medical practice and the defined limitations under the Shari'ah**

*INTERNATIONAL ISLAMIC UNIVERSITY MALAYSIA*, 2014;22(2):77-111. Both Islamic and Western bioethics perceive autonomy as an integral element that must be respected in developing and preserving a positive and ethical doctor patient relationship. The eclipse of paternalism and deference towards greater patient autonomy which currently form the trend in modern medical practice however, have raised a lot of concern among ethicists and doctors alike. There is general agreement that the fundamental liberty of the individual to self-determination cannot and should not be undermined. Allowing unrestricted exercise of this right however would place untenable responsibility on the patient in making complex medical decisions and relegate the doctor's duty to no more than a passive informer, rather than one whose duty is to care for the patient, prevent harm and act in the latter's best interests. In this respect, both Islamic and Western bioethics recognise that patient autonomy is not an absolute or predominant concept and is subject to limitations. There are accordingly both similar and different limitations between the Islamic and Western models with regard to the concept of autonomy, but they attend to the same purpose. Such limitations, instead of infringing the right of autonomy, serve to enhance the content and respect for patient autonomy by ensuring that it is guided and applied appropriately in consonance with other bioethical principles (in the case of Islamic bioethics, the governing principles of the Shari'ah), leading to effective and sound decision making, and an overall improved healthcare environment. Medical decision making should not be a purely medical judgment but a combined opinion between the doctor and the patient. Autonomous medical choices are usually enhanced rather than undermined by a process of shared decision-making that is intrinsically valuable in modern medical practice. <file:///C:/Users/Barry/Downloads/135-439-1-SM.pdf>

Cont.

From the archives:

- *ONLINE JOURNAL OF HEALTH ETHICS*, 2014;10(1). 'End-of-life decisions: An Islamic perspective.' <http://aquila.usm.edu/cgi/viewcontent.cgi?article=1126&context=ojhe>
- *THE LANCET*, 2005;366(9487:774-779). 'End-of-life: The Islamic view.' [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(05\)67183-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(05)67183-8/fulltext)
- *JOURNAL OF SUPPORTIVE ONCOLOGY*, 2005;3(6):432-436. 'Palliative Care for Muslim Patients.' <http://www.oncologypractice.com/jso/journal/articles/0306432.pdf>

### End-of-life care in Australia

#### **The Virtual Hospice: A working, integrated end-of-life care programme**

*INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 3 December 2014 – The Virtual Hospice [VH] is a working integrated end-of-life care programme, in development, for the people of Maitland, New South Wales, Australia. It was "built" in response to: 1) the inequity and inconsistency in the provision of palliative care for people dying at home, in hospital, and in aged care facilities; 2) the apparent disconnectedness experienced by individuals living, working, and dying in our local community; and, 3) the ever increasing medicalization of death and dying in Australian society. Rather than build a hospice out of bricks and mortar, The VH has been founded upon interconnected relationships; maintained by a series of person-centred tools, experiential learning programmes, and community events; and tended by an ethos of compassion and respect. Integration within The VH occurs across geographical locales (homes, aged care facilities and hospital); between all people involved in end-of-life care (patients, caregivers, palliative care staff, health care professionals and the community); and at the interpersonal level (reconciling and acknowledging that death and dying melds fittingly with life and living). The VH works as an agile coordinated organisation, aiming to achieve excellent, affordable, consistent, personalised and compassionate end-of-life care. Over the past five years more than 850 patients have been supported; more than 50% of those dying have died out of hospital; and more than 90 health care professionals have been trained, (and continue to be mentored) to deliver palliation in their place of work. <http://www.ijic.org/index.php/ijic/article/viewFile/1944/2760>

#### **Developing palliative care practice guidelines and standards for nursing home-based palliative care teams: A Delphi study**

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 3 December 2014 – Lack of nursing home (NH)-specific palliative care practice guidelines has been identified as a barrier to improving palliative and end-of-life (EOL) quality of care. The objectives of this study were to 1) assess which of the guidelines developed by the National Consensus Project, and the corresponding preferred care practices endorsed by the National Quality Forum, are important and feasible to implement in NHs; and, 2) identify the operational standards for palliative care teams in NHs. Based on the existing literature, a set of 7 domains with associated 22 palliative practice guidelines was drafted. The authors invited 48 NH leaders, including clinicians, to review the importance ... and the feasibility ... of these guidelines. Participants were also asked about palliative care team composition rounding frequency. The response rate to both rounds was 85%. With regard to importance, the mean rating for all guidelines was 8 or higher (i.e., highly important), but there was variability in agreement with regard to 5 of the guidelines. The same 5 guidelines were also considered more difficult to implement (e.g., costly, unrealistic). Overall, 17 palliative care guidelines were identified for use by NH palliative care teams. Five disciplines (social work, certified nurse assistant, nurse, physician, and nurse practitioner or physician assistant) were identified as comprising a core team and 3 were proposed as extended or ad hoc members. [http://www.jamda.com/article/S1525-8610\(14\)00691-4/abstract](http://www.jamda.com/article/S1525-8610(14)00691-4/abstract)

Cont.

Of related interest:

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 6 November 2014 – '**Hospice use among nursing home and non-nursing home patients.**' For nursing home patients, hospice use and associated costs have grown dramatically. A better understanding of hospice in all care settings, especially how patients move across settings, is needed to inform debates about appropriateness of use and potential policy reform. The impact of changes to the hospice benefit on patients who live or move through nursing homes near the end of life should be carefully considered. <http://link.springer.com/article/10.1007/s11606-014-3080-x>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 December 2014 – '**Diffusion of palliative care in nursing homes: Lessons from the Culture Change Movement.**' Studies have found that nursing homes that rely heavily on Medicaid funding are less likely to implement innovative approaches to care, such as palliative care or resident-centered approaches commonly referred to as "culture change." However, a nationally representative survey the authors conducted found some high Medicaid facilities have implemented these innovative approaches. [http://www.jpsmjournals.com/article/S0885-3924\(14\)00885-9/abstract](http://www.jpsmjournals.com/article/S0885-3924(14)00885-9/abstract)

Selected articles on end-of-life care in nursing homes noted in recent issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 November 2014 – '**Family members' experience with hospice in nursing homes.**' Findings [of this study] highlighted the critical role of communication in supporting residents and their family members. Care coordination, support and oversight, and role confusion also impacted family members' experience of hospice care in the nursing home. [Noted in Media Watch, 1 December 2014, #386 (p.7)] <http://ajh.sagepub.com/content/early/2014/11/24/1049909114560213.abstract>
- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION*, 2014;15(10):744-750. '**Hospice family members' perceptions of and experiences with end-of-life care in the nursing home.**' The family members of nursing home residents reported higher quality of life; however, levels of anxiety, depression, perceptions of pain medicine, and health were similar for hospice family members in the nursing home and in the community. [Noted in Media Watch, 17 November 2014, #384 (p.6)] [http://www.jamda.com/article/S1525-8610\(14\)00340-5/abstract](http://www.jamda.com/article/S1525-8610(14)00340-5/abstract)
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 November 2014 – '**Prevalence and description of palliative care in U.S. nursing homes: A descriptive study.**' There is limited availability of palliative type programs in nursing homes and underutilization in those with programs. [Noted in Media Watch, 17 November 2014, #384 (p.6)] <http://ajh.sagepub.com/content/early/2014/11/12/1049909114558585.abstract>
- *BMC PALLIATIVE CARE* | Online – 23 October 2014 – '**Choosing care homes as the least preferred place to die: A cross-national survey of public preferences in seven European countries.**' As part of a larger study examining preferences and priorities for end of life care, the authors investigated the extent to which care homes are chosen as the least preferred place of death, and the factors associated with this negative preference. Their results suggest it might be difficult to promote care homes as a good place to die. [Noted in Media Watch, 27 October 2014, #381 (p.9)] <http://www.biomedcentral.com/content/pdf/1472-684X-13-48.pdf>

### **Inadequacy of palliative training in the medical school curriculum**

*JOURNAL OF CANCER EDUCATION* | Online – 9 December 2014 – This report examines the literature on palliative training in the current medical school curriculum. Physicians and medical students both report feeling that their training in end-of-life care and in palliative issues is lacking. The literature expresses concerns about the varied and non-uniform approach to palliative care training across medical schools. The authors recommend the development of more palliative training assessment tools in order to aid in the standardization of curriculum involving end-of-life care. In addition, increased exposure to dying patients will aid students in building comfort with palliative care issues. <http://link.springer.com/article/10.1007/s13187-014-0762-3>

Cont.



Noted in Media Watch, 23 December 2013, #337 (p.15):

- *MEDICAL EDUCATION*, 2014;48(1):59-66. **'Palliative care education in U.S. medical schools.'** Medical educators in the U.S. perceive teaching of palliative care [PC] competencies as important, medical students experience it as valuable and effective, and demographic and societal forces fuel its necessity. A review of U.S. medical school surveys ... reveals varied and uneven approaches... PC competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures, and the hidden curriculum. <http://onlinelibrary.wiley.com/doi/10.1111/medu.12292/abstract;jsessionid=2FBCD9A6EFEAB3DC99DF08C1D05F1770.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *ANNALS OF INTERNAL MEDICINE*, 2013;159(12):848-849. **'The role of palliative care in medical education.'** This commentary discusses palliative care and argues that it teaches good medical practice and the art of medicine and should be an essential and longitudinal component of medical education and training. <http://annals.org/article.aspx?articleid=1789252>

From the archives:

- *JOURNAL OF PALLIATIVE CARE*, 1993;9(4):5-10. **'The problematic nature of education in palliative care.'** There are many aspects of palliative care that are problematic: a) lack of a long tradition and adequate conceptualization of palliative care; b) significance of psychological, emotional, and spiritual aspects; c) importance of but inadequate understanding of symptom control; d) fact that palliative care is not curative in the accepted sense; e) its multi-professional nature; f) range of different settings of palliative care; and, g) palliative caregivers have to perform their duties in situations where the emotional and psychological demands on them may be immense. <http://www.ncbi.nlm.nih.gov/pubmed/7510805>

### **Quality of life and cost of care at the end of life: The role of advance directives**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 December 2014 – Advance directives (ADs) are expected to improve patients' end-of-life outcomes, but retrospective analyses, surrogate recall of patients' preferences, and selection bias have hampered efforts to determine ADs' effects on patient outcomes. Most patients [i.e., study participants] did not want heroic measures (76%). Do-not-resuscitate (DNR) orders were associated with higher quality of life across the entire sample. There were no statistically significant relationships between DNR orders and outcomes among patients when the authors stratified by patient preference, or between living wills/durable powers of attorney and outcomes in any of the patient groups. The associations between DNR orders and better quality of life in the week before death indicate that documenting preferences against resuscitation in medical orders may be beneficial to many patients. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00886-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00886-0/abstract)

### **Providers' beliefs about expressing condolences to the family of a deceased patient: A qualitative and quantitative analysis**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 December 2014 – Most providers do not receive training in expressing condolences to bereaved families, and most health care institutions do not have policies in place encouraging expression of condolences. Physicians may fail to meet the expectations of bereaved families. Four hundred ninety-seven of 1063 providers (47%) responded to the survey. Of 432 respondents who provide direct patient care, 375 answered the question, "Excluding condolences offered when notifying someone of a death, how often do you express your condolences to the family after the death of [a patient]?" Two hundred eight of the 375 (55%) responded "always" or "often." Providers who only provide inpatient care were significantly less likely to express condolences than those who provide some or only outpatient care. Providers in practice for 20 or more years were more likely to write letters than less experienced providers. Qualitative data suggested that respondents want institutional support for expressing condolences. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0217>



### **Physician and parent perceptions of prognosis and end-of-life experience in children with advanced heart disease**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 December 2014 – Nearly half of parents and physicians [i.e., survey respondents] felt that patients suffered "a great deal," "a lot," or "somewhat" at EOL [end-of-life], but there was no agreement between them. At diagnosis, parents more often expected complete repair and normal lifespan while the majority of physicians expected shortened lifespan without normal quality of life. Parents who expected complete repair with normal life were more likely to report "a lot" of suffering at EOL. In 43% of cases, physicians reported that the parents were prepared for the way in which their child died, while the parents reported feeling unprepared. Both parents and physicians perceive suffering at EOL in patients who die of AHD [advanced heart disease]. Moreover, parent expectations at diagnosis may influence perceptions of suffering at EOL. Physicians overestimate the degree of parent preparedness for their child's death. Physicians overestimate the degree of parent preparedness for their child's death. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0305>

### **How Dutch neurologists involve families of critically ill patients in end-of-life care and decision-making**

*NEUROLOGY* | Online – Accessed 9 December 2014 – When critically ill neurologic patients are cognitively incapacitated, decisions about treatment options are delegated to surrogates, usually family members. The authors conducted qualitative interviews with twenty Dutch neurologists and residents in neurology varying in age, work experience, and workplace to investigate how they involve their patients' family members in decision-making. Their reports revealed that they ascribed three different, yet tightly interwoven roles to families: 1) informants about values and preferences of patients; 2) participants in care and care planning; and, 3) sufferers themselves. Neurologists regarded decision-making as an integral part of end-of-life care rather than an isolated process, changing the meaning of what decision-making entails. All different roles of family members were important in end-of-life care and decision-making, instead of the single one of legal surrogate. <http://cp.neurology.org/content/early/2014/12/05/CPJ.000000000000091.abstract>

Of related interest:

- *HEALTH COMMUNICATION*, 2015;30(2):144-153. '**Communication non-accommodation in family conversations about end-of-life health decisions.**' Furthering our understanding of how communication can improve end-of-life decision making requires a shift in focus from whether people talk to how people talk about end-of-life health decisions. This study used communication accommodation theory to examine the extent to which communication non-accommodation distinguished more from less successful end-of-life conversations... [http://www.tandfonline.com/doi/abs/10.1080/10410236.2014.974128#.Vlbmq9LF\\_YQ](http://www.tandfonline.com/doi/abs/10.1080/10410236.2014.974128#.Vlbmq9LF_YQ)

### **End-of-life care in Taiwan**

#### **Low socio-economic status is associated with more aggressive end-of-life care for working-age terminal cancer patients**

*THE ONCOLOGIST* | Online – Accessed 8 December 2014 – This study assessed the association between aggressive end-of-life (EOL) care and SES [Socio-economic status] in working-age cancer decedents from Taiwan between 2009 and 2011. The findings show that patients of low SES experienced more aggressive EOL care (chemotherapy, more than one emergency room visit, intensive care unit admission, and death in an acute care hospital) than high-SES patients. Public health strategies are needed to ensure low-SES patients receive high-quality EOL cancer care, and to better allocate health care resources for a sustainable health care system. <http://prostatecancer.theoncologist.com/article/low-socioeconomic-status-associated-more-aggressive-end-life-care-working-age-terminal>

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

### **Deep-seated barriers to end-of-life-care improvement in the twenty-first century**

*REVIEWS IN AMERICAN HISTORY*, 2014;42(4). By the late nineteenth century, the people of Europe and North America were living longer and had rising expectations of health and well-being, but with the benefits of longevity and the diminished threat of early death came other consequences. The predominant causes of death started to shift ground – from sudden demise brought on by infection, disaster and plague to protracted dying associated with the emerging chronic diseases of the modern era – not least cancer and tuberculosis. Mid–nineteenth-century popular culture presented idealized images of a slow and controlled farewell to the world, with family members gathered around and confidence in a passage to another and better world. But, by the close of the century, preoccupations were emerging about the manner of dying – now coming to be seen not only as a social and cultural event but also as potentially a medical process. This brought growing unease in the disposition towards dying. Changing personnel around the deathbed, secrecy about the imminence of death, as well as the desire to quell the threat of pain and suffering – all reveal a new anxiety that opened up a space for medical intervention. <http://eprints.gla.ac.uk/99729/1/99729.pdf>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 December 2014 – '**Just ask: Hospice familiarity in Asian and Hispanic adults.**' [Survey] respondents were mostly female, average age 53 years. Familiarity with hospice varied significantly among the groups, and was lower in the Hispanic (16%) and higher in the Chinese (45%) and Korean (56%) groups. Personal experiences with hospice were low (8-16%) in all groups. A majority (75-94%) responded they would share hospice information with loved ones, but the Hispanic group was significantly less likely to do so, compared with Chinese and Korean Americans. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00891-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00891-4/abstract)

### **Media Watch: Editorial Practice**

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

### **Distribution**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### **Links to Sources**

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

### **Something Missed or Overlooked?**

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

## Drugs, cancer and end-of-life care: A case study of pharmaceuticalization?

*SOCIAL SCIENCE & MEDICINE* | Online – 3 December 2014 – There is evidence from some countries of a trend towards increasingly aggressive pharmacological treatment of patients with advanced, incurable cancer. To what extent should this be understood as a progressive development in which technological innovations address previously unmet needs, or is a significant amount of this expansion explained by futile or even harmful treatment? In this article it is argued that while some of this growth may be consistent with a progressive account of medicines consumption, part of the expansion is constituted by the inappropriate and overly aggressive use of drugs. Such use is often explained in terms of individual patient consumerism and/or factors to do with physician behaviour. This paper, drawing on empirical research conducted in the U.S., the European Union and the U.K., examines the extent to which upstream factors shape expectations and drive pharmaceuticalisation, and explores the value of this concept as an analytical tool. <http://www.sciencedirect.com/science/article/pii/S0277953614007965>

## Multinational Association of Supportive Care in Cancer, the European Society of Medical Oncology, and the European Association of Palliative Care survey of palliative programs

*SUPPORTIVE CARE IN CANCER* | Online – 12 December 2014 – Sixty-two program leaders completed the survey. Most programs had been in existence greater than 5 years and were led by oncology trained physicians who had an additional specialty. Most programs had consultative services and outpatient clinics with fewer having inpatient beds and institutionally associated hospices ... [and] ... provided patient continuity. Patients were generally seen late in the course of illness with the average survival of 23 days when seen as inpatients and 40 days when seen as outpatients. Less than half had palliative care fellowship training programs. Most had research structures in place. These findings differ from results reported in a previous survey which may reflect a European palliative care program structure. However, there were similarities which include a high inpatient palliative care unit mortality and short survival of patients seen as outpatients, indicating that referrals to palliative care occur late in the course of cancer. <http://link.springer.com/article/10.1007/s00520-014-2543-2>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JOURNAL OF MEDICAL LAW & ETHICS*, 2014;2(4):109-121. **'Medical aid in dying in Quebec – legal considerations.'** In Quebec, euthanasia and physician assisted suicide are labelled as medical aid in dying and perceived as part of healthcare. However, in Canada, at the federal level, euthanasia and physician assisted suicide remain punishable under the Canadian Criminal Code. This article reviews Quebec's legal approach to medical aid in dying, highlights some of the legal challenges and discusses the need to handle them. <http://www.ingentaconnect.com/content/plp/jmle/2014/00000002/00000004/art00001>
- *JOURNAL OF MEDICAL RESEARCH & DEVELOPMENT*, 2014;3(4). **'Human dignity and medical ethics.'** An eloquent example of fallacies exploiting the many-meanings of such keywords or expressions in medical ethics as human dignity and individual autonomy, was recently provided by the Royal Society of Canada Expert Panel...<sup>1</sup> That Report claimed that "while the language of human dignity is seemingly universal, there is currently no consensus on the moral basis or on the precise meaning of human dignity," concluding that "the concept of human dignity is an unsuitable tool for settling normative questions pertaining to end-of-life decision making." This stratagem enabled them to hold that there must be a moral right to assist suicide, in view of what they deem "the paramount status of the value of individual autonomy." <http://www.academicpub.org/JMRD/paperInfo.aspx?paperid=15437#Abstract>

1. *The Royal Society of Canada Expert Panel: End of Life Decision Making* (pp.51-52), The Academies of Arts, Humanities & Sciences of Canada, November 2011. [Noted in Media Watch, 21 November 2011, #228 (p.3)] <https://rsc-src.ca/en/expert-panels/rsc-reports/end-of-life-decision-making>

Cont.

- *MEDICAL EXPRESS* | Online – 12 December 2014 – '**The state of euthanasia in Europe.**' This article provides a round-up of the state of current euthanasia regulations in Europe. <http://medicalxpress.com/news/2014-12-state-euthanasia-europe.html>
- *NURSING ETHICS* | Online – 8 December 2014 – '**Psychosocial determinants of nurses' intention to practise euthanasia in palliative.**' To the authors' knowledge, this is the first study to identify nurses' motivations to practise euthanasia in palliative care... It also has the distinction of identifying the ethical principles underlying nurses' moral norm and intention. Overall, nurses [i.e., survey respondents] have a slightly positive intention to practise euthanasia. <http://nej.sagepub.com/content/early/2014/12/06/0969733014557117.abstract>

### Media Watch Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/12/media-watch/>

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

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

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

#### **Asia**

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

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

#### **Australia**

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

#### **Canada**

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

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

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

#### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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

**Barry R. Ashpole**  
Guelph, Ontario CANADA

'phone: 519.837.8936  
e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)