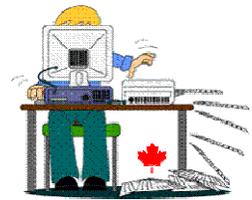


## **Media Watch...**

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.

**16 December 2013 Edition | Issue #336**



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

**The illness experience: Scroll down to [Specialist Publications](#) and 'Hidden patients: The relatives of patients in need of palliative care' (p.13), in *Journal of Palliative Medicine*.**

## **Canada**

### **How surprisingly cheerful pediatric hospices help sick children enjoy the last days of their short lives**

*THE NATIONAL POST* | Online – 6 December 2013 – In stand-alone, homey buildings in Ontario, Quebec, Alberta and B.C., pediatric hospices are dedicating themselves in part to patients many would have trouble even contemplating: children living out the last stages of disease-shortened lives. Hospices also provide respite care for parents whose children have a "life-limiting" illness or condition and require intensive, sometimes "exhausting" care at home, but are not at imminent risk. Still, the concept has been relatively slow to take off and even now the half-dozen Canadian hospices depend largely on private donations to flesh out limited government funding. A recent medical journal article questioned whether they were a wise use of scarce health-care dollars.<sup>1</sup> A survey of oncologists and parents whose children had died of cancer at Toronto's Sick Kids Hospital found that home was the first choice as the place for their kids' to end their lives, followed by hospital, with free-standing hospices last. The study ... was conducted before Toronto actually had a pediatric hospice, however, gave only a brief description of the concept and didn't address respite

care. The idea of pediatric hospices was born in Britain in the 1980s, and that country now has over 40. North America has taken time to follow suit, with just a couple in the U.S. In Canada, facilities have opened over the last eighteen years in Ottawa [and] Milton [in Ontario], Montreal, Calgary and Vancouver, whose Canuck House was the continent's first pediatric hospice. Its medical care also sets it apart from hospitals, bending the usual rules to improve life for children with limited quantities of it left...  
<http://news.nationalpost.com/2013/12/06/how-surprisingly-cheerful-pediatric-hospices-help-sick-children-enjoy-the-last-days-of-their-short-lives/>

### **Specialist Publications**

**'The importance of place and time in translating knowledge about Canada's Compassionate Care Benefit to informal caregivers' (p.14), in *Journal of Social Work in End-of-Life & Palliative Care*.**

Cont.

1. 'Parent and clinician preferences for location of end-of-life care: Home, hospital or freestanding hospice?' *Pediatric Blood & Cancer*, 21 November 2013. [Noted in Media Watch, 22 November 2013, #333 (p.8)] <http://onlinelibrary.wiley.com/doi/10.1002/pbc.24872/abstract>

Noted in Media Watch, 20 May 2013, #306 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 May 2013 – '**The ambiguities of free-standing pediatric hospices.**' Options for location of end-of-life care and death for children with serious illness are not standardized. Possibilities for location of care include home, hospital, and free-standing pediatric hospices; however, access to these choices varies greatly depending on geographical location. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.9500>

## [U.S.A.](#)

### **A federal proposal for paid family leave**

*THE NEW YORK TIMES* | Online – 13 December 2013 – The federal Family & Medical Insurance Leave Act, introduced in Congress, would provide paid leave for workers who need time off to care for family members with serious health conditions, to care for a newborn, or to recover from health problems, including pregnancy and childbirth. It wouldn't solve every problem for working caregivers, but its passage would certainly help. Don't we already have a Federal Family & Medical Leave Act? We do, enacted in 1993, but "it was always intended to be a first step, not the last," says Debra L. Ness, president of the National Partnership for Women & Families, which drafted that measure. [http://newoldage.blogs.nytimes.com/2013/12/13/a-federal-proposal-for-paid-family-leave/?ref=health&\\_r=0](http://newoldage.blogs.nytimes.com/2013/12/13/a-federal-proposal-for-paid-family-leave/?ref=health&_r=0)

### **Medicare has chained us together, reliant on end-of-life government rationing**

*FORBES* | Online OpEd – 12 December 2013 – As 25-30% of Medicare spending occurs in the last year of life, end-of-life care has become a rising issue in health care policy debates. End of life scenarios often place the ICU physician in the position of persuading designated surrogates of the patient to – after consulting the patient's living will and stated wishes – withdraw care and allow the patient to succumb to their illness. When these processes occur physicians often feel a sense of accomplishment because they have ended the needless suffering of their terminal patient with no hope of recovery. Additionally, physicians may also laud the fact that they have stopped the costly provision of futile care, which threatens the fiscal solvency of Medicare. <http://www.forbes.com/sites/ameshadalja/2013/12/12/medicare-has-chained-us-together-reliant-on-end-of-life-government-rationing/>

#### [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.17.

## Why are Americans scared to talk about dying?

THE NATIONAL JOURNAL | Online – 10 December 2013 – Imagine you're brain-dead. There was an accident, and your loved ones have gathered at your hospital bed to hear the doctors say there's not much else they can do. What would you want to happen? It's a scenario that's as terrifying as it is unpredictable. The thought of it pushes some people to iron out end-of-life decisions long before it's too late, some when they're still healthy. They sign advance directives, legal documents, which include living wills and do-not-resuscitate orders, that outline what families and doctors can and can't do when people become patients. In the U.S., dying inside a hospital rather than at home may be more realistic than we'd care to admit. Still, many Americans tend to avoid talking about their own end-of-life wishes, according to new research.<sup>1</sup> Of 7,946 people

polled in a national health survey, just 26% had completed an advance directive. Those who had ... tended to be older and with more education and higher incomes. White people, women, and married people were more likely to have the documents. So were, unsurprisingly, those who reported having a chronic disease and receiving regular care. <http://www.nationaljournal.com/health-care/why-are-americans-scared-to-talk-about-dying-20131210>

### Specialist Publications

'Society of Hospital Medicine backs Medicare reimbursement for end-of-life care counseling' (p.12), in *The Hospitalist*.

1. 'Completion of advance directives among U.S. consumers,' *American Journal of Preventive Medicine*, 2014;46(1):65-70. This study indicates racial and educational disparities in advance directive completion and the need for education on their role in facilitating end of life decisions. [http://www.ajpmonline.org/webfiles/images/journals/amepre/AMEPRE\\_3917-stamped-121013.pdf](http://www.ajpmonline.org/webfiles/images/journals/amepre/AMEPRE_3917-stamped-121013.pdf)

## Debate over Catholic directives that affect 13% of U.S. hospitals

ABC NEWS | Online – 9 September 2013 – Hospitals that serve one in six Americans adhere to Catholic doctrine that threatens the lives of patients, the American Civil Liberties Union [ACLU] claims in a court case filed on behalf of a Michigan woman. The ACLU is suing the U.S. Conference of Catholic Bishops for issuing guidelines the group claims led to substandard medical care for the pregnant woman in Michigan. The guidelines are called the *Ethical & Religious Directives for Catholic Health Care Services* and every Catholic hospital and Catholic healthcare institution must adhere to them or risk losing their classification as a Catholic institution. The guidelines cover such issues as end-of-life care to merging with secular organizations to the kind of patient who should be prescribed birth control. Medical ethicists say patients should be made aware of how the directives can affect their treatment at Catholic hospitals compared with secular hospitals especially in terms of abortion options or end of life care. <http://abcnews.go.com/Health/catholic-bishops-influence-healthcare-catholic-hospitals/story?id=21123027>

Noted in Media Watch, 21 March 2011, #189 (p.9):

- *THE HASTINGS REPORT*, 2011;41(2):28-29. 'Making sense of the Roman Catholic directive to extend life indefinitely.' In November 2009, the U.S. Conference of Catholic Bishops issued *Ethical & Religious Directives for Catholic Health Care Services*, requiring that all patients ... be provided with artificial hydration and nutrition if such care could extend life indefinitely.<sup>1</sup> <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5164>
1. *Ethical & Religious Directives for Catholic Health Care Services*, U.S. Conference of Catholic Bishops, November 2009. <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>

## State initiatives to address aging prisoners

CONNECTICUT | Office of Legislative Research of the Connecticut General Assembly – Accessed 9 December 2013 – This report provides examples of how other States have addressed the problem of dealing with aging and medically infirm prisoners. The report provides examples from California, Florida, Louisiana, Nevada, New York, Pennsylvania, Virginia, and Washington State. California contracts with private providers to establish and operate skilled nursing facilities to incarcerate and care for aging and ill prisoners. The State of Florida operates several facilities specifically designed for elderly as well as palliative care inmates. Louisiana has established a partnership between Louisiana State Penitentiary and University Hospital Community Hospice in New Orleans to provide care for sick and infirm inmates. The State of Nevada has established the Senior Structured Living Program to serve aging offenders, while New York's Unit for the Cognitively Impaired primarily serves prisoners with dementia. In Pennsylvania, sick and elderly inmates are housed at Laurel Highlands, a minimum security facility. In the State of Virginia, most older prisoners are housed at the Deerfield Correctional Center, a one-story, handicap-accessible facility able to address inmates' mobility needs. In Washington State, an assisted-living unit was established at the Coyote Ridge Correctional facility to address the needs of the State's elderly inmates. <http://www.cga.ct.gov/2013/rpt/pdf/2013-R-0166.pdf>

### No matter the species

## Veterinarians launch hospice and palliative care organization

MICHIGAN | *DVM360 Magazine* – 3 December 2013 – Veterinarians Page Yaxley and Katherine Goldberg recently founded the Veterinary Society for Hospice & Palliative Care to advance the practice and knowledge of veterinary hospice and palliative care through professional education, community engagement and research. With the exponential expansion of palliative and hospice care in the past few years, it is emerging as a distinct discipline of veterinary medicine. <http://veterinarynews.dvm360.com/dvm/Veterinary+news/Veterinarians-launch-hospice-and-palliative-care-o/ArticleStandard/Article/detail/830029?contextCategoryId=378>

**N.B.** Additional articles that draw an interesting parallel between end-of-life care for animals and humans are noted in Media Watch, 2 December 2013, #334 (p.4).

## Fetters case shows prison health challenges

IOWA | *The Des Moines Register* – 10 December 2013 – The issues raised by ... [the Kristina Fetters] ... case aren't just about one young inmate with terminal cancer. Her story is a reminder of the bigger challenges faced by a corrections system responsible for the health care needs of 8,000 inmates ... 1,200 over the age of 50. Many of the hundreds of inmates serving life sentences will grow old and die behind bars. They may need dementia care or end-of-life services. Prisons are not only responsible for keeping offenders off the street. They are also health care facilities and must provide everything from medications and mental health treatment to dental care and hospice services to thousands of lowans. Iowa lawmakers should remember that when providing funding for prisons. Because the parole board can't send everyone with a terminal illness to a non-profit hospice facility in the community. <http://www.desmoinesregister.com/article/20131211/OPINION03/312100132/?odyssey=nav%7Chead>

Noted in Media Watch, 9 December 2013, #335 (p.1):

IOWA | *The Washington Post* – 3 December 2013 – **'Terminally ill Iowa inmate gets parole for hospice.'** A dying Iowa inmate who was 15 when she entered prison will spend her final days in a hospice facility, a state board ruled in granting her unprecedented parole. The Iowa Parole Board's decision for Kristina Fetters, 33, means she is the first inmate in the state sentenced to life in prison as a juvenile to be released after a landmark U.S. Supreme Court ruling last year. [http://www.washingtonpost.com/national/health-science/terminally-ill-iowa-inmate-gets-parole-for-hospice/2013/12/03/67cb79ec-5c48-11e3-8d24-31c016b976b2\\_story.html](http://www.washingtonpost.com/national/health-science/terminally-ill-iowa-inmate-gets-parole-for-hospice/2013/12/03/67cb79ec-5c48-11e3-8d24-31c016b976b2_story.html)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | KPAX News (Missoula) – 14 December 2013 – '**Judge dismisses suit against Board of Medical Examiners.**' District Judge Mike Menahan has dismissed a lawsuit brought against the Montana Board of Medical Examiners by a group that opposes physician-assisted suicide. Montanans Against Assisted Suicide charged in court that a 2012 position paper by the Board suggested that assisted suicide was legal in Montana. The board has since rescinded the letter and argued in a hearing that the group was trying to force the issue to the Montana Supreme Court. In an eight-page order, Judge Menahan agreed, saying there was no longer an actual case or controversy for the court to consider and any ruling on it would be based on hypothetical circumstances. <http://www.kpax.com/news/judge-dismisses-suit-against-board-of-medical-examiners/>
- NEW MEXICO | KOB 4 Eyewitness News (Albuquerque) – 9 September 2013 – **"Right-to-die" law trial set to begin.**' This week marks the start of a legal battle over the "right to die" in New Mexico. Currently, assisting with suicide is a fourth degree felony in the state. But an Albuquerque doctor is arguing that "physician aid-in-dying" is not the same thing as "assisted suicide." Four states – Oregon, Vermont, Washington and Montana – have legalized assisted suicide. But this lawsuit takes a different approach. The plaintiffs argue that "physician aid-in-dying" is completely different than "assisted suicide." This is the first time that specific argument will be made in court. [http://www.kob.com/article/stories/S3238970.shtml#\\_UqdLi9JDv8k](http://www.kob.com/article/stories/S3238970.shtml#_UqdLi9JDv8k)

## International

### End-of-life care in Russia

#### **Russian Doctor's trial highlights suffering of terminally ill**

RUSSIA | Radio Free Europe – 15 December 2013 – [The case of Viktor Sechin] has ... shone a rare spotlight on the plight of terminally ill patients in Russia, many of whom continue to die in agony amid chronic drug shortages and a general lack of awareness about how to treat pain. Rights advocates and health experts pin much of the blame on the stringent regulations that govern the use of controlled substances in Russia. While the country has an obligation under international law to regulate access to opioid medications, its drug-control regulations are criticized for routinely denying patients adequate pain relief. Rights groups see [Dr. Aleftina] Khorinyak as a victim of these overly strict and bureaucratic policies. "This woman essentially fell through the cracks of the system of drug regulation in Russia," says Tanya Cooper, a researcher at Human Rights Watch. <http://www.rferl.org/content/russia-palliative-care-suffering/25200224.html>

Noted in Media Watch, 27 August 2012, #268 (p.3):

- RUSSIA | *Open Democracy Russia* – 23 August 2012 – '**It's time to stop the suffering.**' In a country of population 140 million, there are still no more than a few palliative care initiatives and hardly any palliative care specialists. <http://www.opendemocracy.net/od-russia/anna-sonkin/palliative-care-in-russia-its-time-to-stop-suffering>

#### Quotable Quotes

*Compassion asks us to go where it hurts, to enter into the places of pain, to share in brokenness, fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human.* **Henri J.M. Nouwen (1932-1996)**

## End-of-life care in Australia

### **Second-class palliative care**

AUSTRALIA (NEW SOUTH WALES) | *The Daily Advertiser* (Wagga) – 12 December 2013 – Palliative care needs in the Murrumbidgee [district] have again been snubbed by NSW [New South Wales] Health in favour of private-public partnerships. Teams of highly-skilled nurses won't find their way to Wagga under a recently announced \$35 million enhancement of community-based palliative care,<sup>1</sup> despite the district having no hospice, public palliative care unit or specialist palliative care physician. Residents shouldn't feel short-changed by the situation, however, according to NSW Minister for Health Jillian Skinner. With Wagga and the Murrumbidgee relying heavily on community-based palliative care as its only present option, the announcement has drawn criticism from the NSW Nurses & Midwives Association over the privatisation of services as well as the delivery of equitable levels of service between rural and metropolitan areas. Under the new funding announcement, northern NSW and Sydney ... will receive

access to clinical nurse consultants who are highly skilled nurses with post-graduate qualifications in speciality clinical areas. It is likely regional palliative patients in the Murrumbidgee district will be treated by palliative care aids, a less qualified option. <http://www.dailyadvertiser.com.au/story/1967406/second-class-palliative-care/?cs=148>

#### **Corrections & Clarifications**

An Australian newspaper report noted in the 2 December 2013 issue of Media Watch (#334, p.6), on the NSW government initiative to increase access to palliative care, was titled 'Pilot palliative care scheme in limbo.' Western NSW Local Health District, however, reports that new community palliative care packages are expected to be available before the end of December, part of the \$35 million statewide palliative care plan announced by NSW Health Minister Jillian Skinner in September 2013.

1. 'The New South Wales Government Plan to Increase Access to Palliative Care, 2012-2016,' Ministry of Health, September 2012. [Noted in Media Watch, 4 November 2013, #330 (p.6)] <http://www.health.nsw.gov.au/publications/Publications/Palliative%20Care%20Plan%202012-2016.pdf>

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

### **Hospital coma guidelines require care for all patients**

U.K. (ENGLAND & WALES) | BBC News – 11 December 2013 – All patients in a coma or vegetative state should have access to specialist care, according to new guidelines.<sup>1</sup> The Royal College of Physicians is keen to address inconsistencies in the level of resources in hospitals around England & Wales. Experts also want a patient register to help gauge numbers of patients with prolonged disorders of consciousness, which include coma, vegetative state and minimally conscious state. There are no official figures on cases. <http://www.bbc.co.uk/news/health-25322894>

1. 'Prolonged disorders of consciousness: National clinical guidelines: Report of a Working Party,' The Royal College of Physicians, December 2013. The guidelines are endorsed by the Association of British Neurologists, Association for Palliative Medicine, British Society of Rehabilitation Medicine, Chartered Society of Physiotherapy, College of Occupational Therapists, Society of British Neurological Surgeons, and Society for Research in Rehabilitation. [http://www.rcplondon.ac.uk/sites/default/files/prolonged\\_disorders\\_of\\_consciousness\\_national\\_clinical\\_guidelines\\_0.pdf](http://www.rcplondon.ac.uk/sites/default/files/prolonged_disorders_of_consciousness_national_clinical_guidelines_0.pdf)

## End-of-life care in Ireland

### **Our citizens will die better in a culture and setting where we can approach, rather than avoid, our mortality**

IRELAND | *The Irish Times* (Dublin) – 10 December 2013 – There is growing literature that points to the fact that death is not a discrete event, and that good end-of-life care is not something that happens in the last few days or weeks of a person's life. The quality of end-of-life care is the result of a much wider cultural stance on death and dying. Over the course of my career as clinical psychologist with cancer patients at St. Vincent's University Hospital in Dublin, I have worked with several hundred patients who have died – and almost without exception, each one has testified that we die as we live. There are very few Hollywood moments at the bedside of those who die. Often what happens is the product of the attitudes and values that we as citizens and governors of the State hold. These, in turn, create a cul-

ture of end-of-life care, and unless we can build a culture that can facilitate these kinds of conversations, we are never going to reach the point where our citizens die well. <http://www.irishtimes.com/life-and-style/health-family/a-life-dedicated-to-dying-well-1.1622018>

#### **Specialist Publications**

**'Universal human rights and end-of-life care'** (p.9), in *Advance Care Decision Making in Germany & Italy*.

**'Evaluation of 12 pilot projects to improve outpatient palliative care'** (p.11), in *Deutsche Medizinische Wochenschrift*.

## End-of-life care in Pakistan

### **Humanity in need: As funds dry, historic hospice needs help**

PAKISTAN | *The Express Tribune* (Islamabad) – 8 December 2013 – For six decades, the destitute and needy in Westridge and the rest of Rawalpindi have had a place where they knew they would be looked after, regardless of caste or creed. However, in a few months, that could all be a thing of the past. Saint Joseph's Hospice in Rawalpindi has been in dire financial straits ever since foreign donors started packing up and leaving the country after 9/11. The decline in foreign donations since then has left the care facility on the brink of closure. The hospice has always provided a place for the sick and elderly, regardless of faith, when they were rejected by their families and refused admission by other hospitals. The 50-bed Saint Joseph Hospice ... was established in 1964... After 2001, when donations started dwindling in, the hospice tried its best to make the most of the available resources. <http://tribune.com.pk/story/642663/humanity-in-need-as-funds-dry-historic-hospice-needs-help/>

Noted in Media Watch, 2 December 2013, #334 (p.5):

- PAKISTAN | Voice of America – 29 November 2013 – **'Pakistan's Christian hospice to close after 50 years.'** In the crowded, winding streets of the Rawalpindi, a small Christian hospice led by Irish nuns has taken care of the destitute and disabled for 50 years. But the hospice that caters mainly to Muslim patients is now being forced to close because of falling donations... <http://www.voanews.com/content/pakistans-christian-hospice-to-ckose-after-fifty-years/1800622.html>

#### **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>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | *The New York Times* – 12 December 2013 – '**Belgian Senate votes to allow euthanasia for terminally ill children.**' Belgium ... [has become] ... the first country to allow euthanasia for incurably ill children, after the upper house of Parliament voted by a large majority [50-71] to extend to minors a 2002 law legalizing the practice for adults. Under the amended law, euthanasia would become legal for children afflicted with "constant and unbearable physical suffering" and equipped "with a capacity of discernment." <http://www.nytimes.com/2013/12/13/world/europe/belgian-senate-votes-to-allow-euthanasia-for-terminally-ill-children.html>
- U.K. | BBC (Democracy Live) – 12 December 2013 – '**Lords clash over assisted dying.**' Peers have disagreed over whether terminally ill patients should be given a right to assisted dying, during a debate on patient choice at the end of life. Labour peer Lord Dubs said "people should have the right to choose to be free from intolerable pain and discomfort – providing it is their free choice. Assisted dying with safeguards is one of the many legitimate choices that dying patients should have." But Conservative peer Lord McColl of Dulwich countered that it was not possible to legislate for "appropriate" safeguards. He believed that legalising assisted dying would "send a message that suicide is a socially acceptable response to terminal or incurable diseases." <http://www.bbc.co.uk/democracylive/house-of-lords-25351366>
- U.K. | *The Times* – 11 December 2013 – '**Disabled back law to allow assisted dying.**' Most disabled people [surveyed] want the law changed to legalise helping the terminally ill to end their lives, according to one of the first polls of their views. Almost 80% of those interviewed believe someone who helps a friend or family member who is already terminally ill to die should not face prosecution. However, support for a change in the law falls to a third if the person involved suffers from a non-terminal but incurable condition such as locked-in syndrome, dementia or severe disability. <http://www.thetimes.co.uk/tto/health/news/article3945148.ece>

Noted in Media Watch, 4 January 2010, #130 (p.6):

- *DISABILITY & HEALTH JOURNAL*, 2010;3(1):1-70. '**Physician-assisted suicide: A perspective from advocates for people with disability.**' This special edition examines the issues related to assisted suicide and disability, legal considerations, and the Oregon and Washington experiences. Manuscripts were solicited from disability advocates and disability scholars, most of whom ... oppose assisted suicide; however, the varied approaches of the authors broadens the discussion and each article contains a literature review. The authors include scientists, lawyers, scholars and disability rights advocates. Overview of the contents: [http://www.disabilityandhealthjnl.com/article/S1936-6574\(09\)00190-3/fulltext](http://www.disabilityandhealthjnl.com/article/S1936-6574(09)00190-3/fulltext)

N.B. Contents page with links to each article: <http://www.disabilityandhealthjnl.com/current>

- U.K. (ENGLAND & WALES) | *The Daily Telegraph* – 8 December 2013 – '**Judges to rule on "right to die."**' Britain's most senior judges are preparing to make a landmark ruling over attempts to introduce a "right to die" under human rights legislation. A full panel of nine Supreme Court Justices, headed by Lord Neuberger ... is to be convened next week to hear the culmination of three separate legal challenges to the current ban on assisted suicide. The three cases have been put into one "super-case" to allow a sweeping judgment on the current state of the law in England & Wales. It will see Jane Nicklinson, widow of Tony Nicklinson, the "locked-in syndrome" sufferer who died last year, is joining with two severely disabled men in a concerted attempt to use human rights laws to sweep away the 50-year-old ban on assisted suicide. <http://www.telegraph.co.uk/news/uknews/law-and-order/10502699/Judges-to-rule-on-right-to-die.html>

Noted in Media Watch, 9 December 2013, #335 (p.14):

- *END OF LIFE JOURNAL*, 2013;3(4). '**The judgment of the High Court [of England & Wales] in two right-to-die cases.**' This article summarises the judgment from the High Court cases of Tony Nicklinson and 'Martin.' Both suffered from locked-in syndrome secondary to catastrophic physical disabilities, but their mental processes were unimpaired. <http://endoflifejournal.stchristophers.org.uk/legal-discussions/the-judgment-of-the-high-court-in-two-right-to-die-cases>

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

### Universal human rights and end-of-life care

*ADVANCE CARE DECISION MAKING IN GERMANY & ITALY*, 2013;41:1-37. Universal human rights like dignity, physical integrity, health, and freedom from torture or inhuman treatment have special relevance to the end-of-life debate and form the basis on which is built the emergence of new biorights. Over the last decades, such rights as the right to informed consent, the right to die with dignity, and the right not to suffer have gained increasing importance in the international legal order. These rights have also contributed to the setting of generally accepted human rights standards that offer authoritative guidance to both domestic legislators and judges. This is particularly important in light of the fact that the regulation of legal questions surrounding the end of life is quite different in domestic jurisdictions, even in a rather homogeneous and integrated region like Europe, where the relevant legal frameworks still differ according to cultural, ideological, and religious diversities and the more or less liberal attitude adopted by individual states, as it is the case with Germany and Italy. [http://link.springer.com/chapter/10.1007/978-3-642-40555-6\\_1](http://link.springer.com/chapter/10.1007/978-3-642-40555-6_1)

**N.B.** *Advance Care Decision Making in Germany & Italy* contents page: <http://link.springer.com/book/10.1007/978-3-642-40555-6#>

Noted in Media Watch, 16 September 2013, #323 (pp.14-15):

- *PROGRESS IN PALLIATIVE CARE* | Online – 13 September 2013 – '**Dignity: A unifying concept for palliative care and human rights.**' The concept of human dignity is complex. It is a concept that occupies a central place in two disciplines – palliative care and human rights law. [http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc\\_167](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_167)

Noted in Media Watch, 11 February 2013, #292 (pp.10-11):

- *PALLIATIVE MEDICINE*, 2013;27(2):101-102. '**The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care.**' The European Association for Palliative Care, the International Association for Hospice & Palliative Care, the World Palliative Care Alliance, and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.' <http://pmj.sagepub.com/content/27/2/101.full>

**N.B.** The Prague Charter: <http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx>. Footnoted in this issue of Media Watch are several additional articles on palliative care as a human right.

### New horizons in care home medicine

*AGE & AGEING*, 2014;43(1):2-7. Care home medicine has been an under-researched area, but over the last decade there has been a substantial growth in publications. Most of these focused on the "geriatric giants" of falls, incontinence and mental health issues ... as well as other key topics such as medication use and issues related to death and dying. Other areas of recent interest are around access to health services for care home residents, how such services may most effectively be developed and how the quality of life for residents can be enhanced. While many of the reported studies are small and not always well designed, evidence in several areas is emerging which begins to guide service developments. A common

theme is that multi-disciplinary interventions are the most effective models of delivery. The role of care home staff as members of these teams is key to their effectiveness. <http://ageing.oxfordjournals.org/content/43/1/2.abstract>

#### **Extract from *Age & Ageing* article**

End-of-life care planning and delivery is an important part of care in care homes, and there is evidence that integrated pathways can improve care; however, the use of palliative care medications was limited unless specialist care staff were involved.

Cont.

Of related interest:

- *THE GERONTOLOGIST*, 2013;53(6):919-927. '**Voices on relocation and aging in place in very old age – a complex and ambivalent matter.**' Reasons to move reflect the urge to maintain independence, to stay in control, and to avoid loneliness. This is mainly expressed reactively. Reasons not to move reflect a strong attachment to the home and neighborhood. <http://gerontologist.oxfordjournals.org/content/53/6/919.abstract>
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 12 December 2013 – '**Carers' quality of life and experiences of adult social care support in England.**' The authors found that carers' quality of life is affected by social care support directed at carers and support directed at those they care for, as well as access to services, the experience of stigma in communities, and in how individual needs and preferences are considered when making decisions about care. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12089/abstract>

#### Care of elderly surgical patients inextricably linked to considerations about end-of-life care

#### **Ethical and legal aspects of anaesthesia for the elderly**

*ANAESTHESIA*, 2014;69(Supplement):45-53. The elderly have the ethical and legal equivalence of younger adults, yet are treated differently by society. Numerous recent reports have exposed poor inpatient care resulting in part from institutional ageism, which has moral and legal implications for healthcare providers. Morally, there is an argument for positive "exceptionalism" in elderly peri-operative care, pursuing quality improvement through use of a dignity agenda. Legally, numerous changes in human rights, equality, consent, capacity, and end-of-life laws and professional guidance have consistently re-emphasised the need for greater communication between doctors, patients, their relatives and carers. This review describes current ethical thinking and legal precedent (in England & Wales), and directs readers to consider areas in which the law might change in the near future, particularly with regard to the end-of-life care of elderly surgical patients. <http://onlinelibrary.wiley.com/doi/10.1111/anae.12519/full>

Of related interest:

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2013;27(4):389-391. '**The impact of an aging population on palliative care.**' By 2050, it is predicted that 26% of the population will be aged 80 and over. Palliative care is now included as part of the care pathway of a wide variety of non-malignant diseases. The European Association for Palliative Care and the European Union Geriatric Medicine Society have jointly called for every older citizen with chronic disease to be offered the best possible palliative care approach wherever they are cared for. <http://informahealthcare.com/doi/abs/10.3109/15360288.2013.847517>

#### Withdrawing life-sustaining treatment

#### **Acting to let someone die**

*BIOETHICS* | Online – 10 December 2013 – This paper examines the recent prominent view in medical ethics that withdrawing life-sustaining treatment (LST) is an act of killing. The author traces this view to the rejection of the traditional claim that withdrawing LST is an omission rather than an act. Although that traditional claim is not as problematic as this recent prominent view suggests, his main claim is that even if we accepted that withdrawing LST should be classified as an act rather than as an omission, it could still be classified as letting die rather than killing. Even though omissions are contrasted with acts, letting die need not be, for one can let die by means of acts. The remainder of the paper is devoted to establishing this claim and addresses certain objections to it. <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12072/abstract>

Cont.

Noted in Media Watch, 28 October 2013, #329 (p.9):

- *HELLENIC JOURNAL OF SURGERY*, 2013;85(5):296-300. **'Making the decision to withdraw or withhold life support: Thoughts and questions.'** Doctors must have the conscience or the "courage" to stop a treatment which no longer makes sense, provides no further benefit to the patient, causes discomfort or pain, and prolongs the use of limited resources. Although doctors may stop active treatment, they must never stop patient care; withdrawal of therapy does not mean withdrawal of care. <http://link.springer.com/article/10.1007/s13126-013-0055-z#>

#### End-of-life care in Japan

##### **Defining futile life-prolonging treatments through Neo-Socratic Dialogue**

*BMC MEDICAL ETHICS* | Online – 9 December 2013 – In Japan, people are negative towards life-prolonging treatments. Laws that regulate withholding or discontinuing life-prolonging treatments and advance directives do not exist. Physicians, however, view discontinuing life-prolonging treatments negatively due to fears of police investigations. Although ministerial guidelines were announced regarding the decision process for end-of-life care in 2007, a consensus could not be reached on the definition of end-of-life and conditions for withholding treatment. The authors used the Neo-Socratic Dialogue (NSD) method which promotes philosophical discussion based on a case-study to address a question and formulate a consensus and answer in a group. <http://www.biomedcentral.com/content/pdf/1472-6939-14-51.pdf>

Noted in Media Watch, 14 October 2013, #327 (p.4)

- JAPAN | *The Japan News* (Tokyo) – 13 October 2013 – **'81% don't want life-prolonging treatments.'** More than 80% of people surveyed said they would not want to receive life-prolonging treatments in the terminal phase of an illness. Results show many people want to face the final stage of their life in a natural way, part of a trend of people making preparations for death while they are still fairly healthy. <http://the-japan-news.com/news/article/0000719262>

#### End-of-life care in Germany

##### **Evaluation of 12 pilot projects to improve outpatient palliative care**

*DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2013;138(50):2585-2591. The German Cancer Aid supported the development of quality-assured outpatient palliative care to cover the whole country. The projects, funded with the aim to improve outpatient palliative care in different models and different frameworks, were concurrently monitored and evaluated. The participants of a project-completion meeting emphasized the need to carry ... analysis before starting palliative care organizations considering the different regional structures and target groups of patients. Education, training and continuing education programs contribute significantly to the network. A reliably funded coordination center/case management across all institutions is extremely important. <http://europepmc.org/abstract/MED/24301491/reload=0;jsessionid=MfpihHfwPyMAB4AfzTR7.0>

#### End-of-life care in pluralistic and multicultural societies

##### **Advance care planning for Māori, Pacific and Asian people: The views of New Zealand healthcare professionals**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 12 December 2013 – Despite the benefits of advance care planning (ACP), international research has suggested that in pluralistic and multicultural societies such as New Zealand, significant differences exist in the uptake of ACP between European-based populations and other cultural groups. Challenges [identified in this study] were related to a number of issues based on culture, including family decision-making style, a need to "do everything" and a reluctance to discuss issues surrounding dying and death. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12081/abstract>

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

### **Society of Hospital Medicine backs Medicare reimbursement for end-of-life care counseling**

*THE HOSPITALIST* | Online – 10 December 2013 – For hospitalists and other care providers, conversations about the end of life with families and caregivers can be fraught with emotion. The fact that something is uncomfortable does not mean it is not useful or valuable, however. Patients must be able to vocalize end-of-life wishes and should feel confident that the healthcare system is able to respond. To help with this effort, the Society is supporting legislation that would encourage voluntary end-of-life conversations between patients and their healthcare providers. Sponsored by U.S. Representative Earl Blumenauer (Democrat-Oregon), the Personalize Your Care Act of 2013 would make Medicare reimbursement available for advance-care planning consultations, establish grants for state-level Physician Orders for Life-Sustaining Treatment (POLST) programs, and require that advance directives be honored across state lines. [http://www.the-hospitalist.org/details/article/5572331/SHM\\_Backs\\_Medicare\\_Reimbursement\\_for\\_End-of-Life\\_Care\\_Counseling.html](http://www.the-hospitalist.org/details/article/5572331/SHM_Backs_Medicare_Reimbursement_for_End-of-Life_Care_Counseling.html)

**N.B.** This issue of *The Hospitalist* includes several articles on different aspects of end-of-life care. Journal contents page: <http://www.the-hospitalist.org/view/0/currentPrintIssue.html>

Cont. next page

### **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.

Noted in Media Watch, 29 July 2013, #316 (p.2):

- U.S. (CALIFORNIA) | *The Los Angeles Times* – 22 July 2013 – '**Bring back the "death panel" bill.**' Probably nothing causes members of Congress more unease than having to talk about death. There are several representatives from both parties who do want to discuss it. <http://www.latimes.com/news/opinion/opinion-la/la-ol-we-congress-death-panels-health-care20130722.0,3716779.story>

Noted in Media Watch, 20 May 2013, #306 (p.13):

- *THE LINACRE QUARTERLY*, 2013;80(2):103-138. '**The POLST paradigm and form: Facts and analysis.**' This white paper provides a commentary on Physician Orders for Life-Sustaining Treatment as well as on its model (or "paradigm") for implementation across the U.S. <http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000002/art00002>

### **It is possible: Quality measurement during serious illness**

*JAMA INTERNAL MEDICINE*, 2013;173(22):2080-2081. Palliative care is specialized medical care for people with serious illnesses. It is focused on giving patients relief from the symptoms, pain, stress, and treatments of a serious illness – whatever the diagnosis. The goal is to provide the best possible quality of life for the patient and the family. Although 66% of large hospitals have a palliative care program, there is significant variation in the types of programs and services offered, giving rise to concern regarding variation in the quality of care provided by these programs. <http://archinte.jamanetwork.com/article.aspx?articleid=1748826>

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

### **Hidden patients: The relatives of patients in need of palliative care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 December 2013 – When identifying patients for palliative care, medical specialists find it necessary to disclose "hidden" patients: the patient's relatives. The issue has been discussed sporadically in Bulgaria; the present study was part of a larger investigation that examined the opinion of medical specialists, patients, and their relatives. Relatives providing care were predominantly women, two-thirds over 60 years of age. There was a one-to-one ratio between caregivers for oncological and non-oncological patients. The duration of care was more than one year in 53% of cases. Most relatives reported their loved ones found physical suffering "very hard to bear" (53%), while approximately 17% could not assess the extent of psychological suffering. The vast majority stated that they had difficulties in providing care, and 68% had financial problems in that respect. Including relatives as users and part of the palliative care team has been discussed in the literature. In Bulgaria, participation is solely due to the lack of organized services for palliative care. Relatives participate in activities that are performed by trained staff in countries with developed palliative care; these activities, along with negative emotional experiences and economic difficulties, overburden these caregiving relatives significantly. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0333>

Noted in Media Watch, 14 February 2011, #188 (p.11, under 'Worth Repeating'):

- *CANADIAN JOURNAL OF PSYCHIATRY*, 2004;49(6):359-365. '**Palliative care for families: Remembering the hidden patients.**' This article briefly synthesizes empirical work that suggests how to best support families in a palliative care context. The authors discuss how to define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. <https://ww1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf>

## **The importance of place and time in translating knowledge about Canada's Compassionate Care Benefit to informal caregivers**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(4):289-307. Canada's Compassionate Care Benefit (CCB), an employment insurance program designed to allow Canadian workers time off to care for a dying relative or friend,<sup>1</sup> has had low uptake since its inception. Due to their role in working with family caregivers, social workers are one group of primary health care professionals who have been identified as benefiting from a knowledge translation campaign. Knowledge tools about the CCB have been developed through social worker input in a prior study. This article presents the findings of a qualitative exploratory intervention. Social workers utilized the tools for 6 months and discussed their experiences with them. Data analysis revealed references to time and space constraints in using the tools, and demonstrated the impact of time geography on knowledge translation about the CCB. The results suggest that knowledge translation about the CCB could be targeted toward caregivers earlier on in the disease progression before the terminal diagnosis, and knowledge tools must be disseminated to more locations. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.846888>

1. Employment Insurance Compassionate Care Benefits, Service Canada. [http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)

Noted in Media Watch, 12 November 2012, #279 (p.9):

- *INTERNATIONAL JOURNAL FOR EQUITY IN HEALTH* | Online – 1 November 2012 – '**Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit.**' Findings [of this study] reveal experiences of caregiving are not homogenous and access to services and supports are not universal across Canada. Five axes of difference were commonly raised by front-line palliative care providers when discussing important differences in family caregivers' experiences: culture, gender, geography, life course stage, and material resources. The authors' findings reveal inequities with regard to accessing needed caregiver services and resources, including the CCB, based on these axes of difference. <http://www.equityhealthj.com/content/pdf/1475-9276-11-65.pdf>

**N.B.** Additional articles on the implementation and accessing Canada's Compassionate Care Benefit are noted in Media Watch, 2 April 2012, #247 (p.8).

## **Early specialty palliative care – translating data in oncology into practice**

*NEW ENGLAND JOURNAL OF MEDICINE* | Online – 12 December 2013 – Palliative care suffers from an identity problem. Seventy percent of Americans describe themselves as "not at all knowledgeable" about palliative care, and most health care professionals believe it is synonymous with end-of-life care.<sup>1</sup> This perception is not far from current medical practice, because specialty palliative care ... is predominantly offered through hospice care or inpatient consultation only after life-prolonging treatment has failed. Limiting specialty palliative care to those enrolled in hospice or admitted to the hospital ignores the majority of patients facing a serious illness, such as advanced cancer, who have physical and psychological symptoms throughout their disease. To ensure that patients receive the best care throughout their disease trajectory, the authors believe that palliative care should be initiated alongside standard medical care for patients with serious illnesses. [http://www.nejm.org/doi/full/10.1056/NEJMs1305469?query=featured\\_home](http://www.nejm.org/doi/full/10.1056/NEJMs1305469?query=featured_home)

1. '2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies,' Center to Advance Palliative Care, 2011. [Noted in Media Watch, 4 July 2011, #208 (p.7)] <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

Cont.

Of related interest:

- *PSYCHO-ONCOLOGY*, 2014;197(1):59-72. **'The oncological patient in the palliative situation.'** It is the strength of palliative care to complement the diagnosis driven approach of medical cancer care by a problem and resources-based assessment, participatory care plan, and patient-directed interventions. Interventions need to reflect timely prognosis, target population (the patient, the family carer, the professional), and level of trust and remaining energy. In palliative care the relevance of psycho-oncological aspects in the care of the terminally ill is considerable in the understanding of the overall suffering of patients approaching death and their loved ones, and in their care and support. There is little evidence to date in terms of clinical benefit of specific psycho-oncological interventions in the last months or weeks of life, but there is evidence on effects of stress reduction and reduced anxiety if locus of control can stay within the patient as long as possible. [http://link.springer.com/chapter/10.1007/978-3-642-40187-9\\_5](http://link.springer.com/chapter/10.1007/978-3-642-40187-9_5)

Noted in Media Watch, 25 November 2013, #333 (p.11):

- *EPIDEMIOLOGY BIOSTATISTICS & PUBLIC HEALTH* | Online – Accessed 19 November 2013 – **'Pain management and outcomes in cancer patients: Comparison between oncological and palliative sets of care.'** This study indicates how much oncologists and palliative care physicians differ in managing cancer pain. The observational nature of this study reflects the natural and unaffected choice of the professionals. The study only describes their behaviors without a stringent comparative evaluation. <http://ebph.it/article/view/8698/8206>

### **A survey of prognosis discussions held by healthcare providers who request palliative care consultation**

*PALLIATIVE MEDICINE* | Online – 10 December 2013 – Of the 65 ... [respondents to a telephone survey], 45 (69.2%) ... reported that a prognosis discussion had occurred, while 15 (23.1%) reported that a prognosis discussion had not taken place. Among the surveys reporting a discussion, a majority of providers responded that most aspects of prognosis were discussed, with the exceptions of life expectancy, survival rates/statistics, and psychosocial concerns. When the prognosis discussion had not occurred, the most common reasons for omitting the prognosis discussion included difficulty in determining prognosis, the perception that the patient already knew his or her prognosis, and the belief that the prognosis discussion was better suited for a different specialty. The results of this study highlight the uncertainty that primary team providers in the academic hospital environment have with prognostication, which is a complex process for which this set of providers, composed primarily of medical trainees and nurses, may not have had sufficient training. <http://pmj.sagepub.com/content/early/2013/12/09/0269216313514126.abstract>

Noted in Media Watch, 2 December 2013, #334 (p.11):

- NATIONAL INSTITUTE OF HEALTH RESEARCH JOURNALS LIBRARY | Online – Accessed 28 November 2013 – **'Failure to discuss prognosis is detrimental for patients nearing the end of their life.'** A ground-breaking study conducted into the provision of palliative and end of life care at two hospitals in England, found there was a significant gap between National Health Service palliative care policy and current practice. Researchers discovered a lack of communication between medical staff and patients, and their families, with regards to their prognosis which severely limits their ability to be involved in important decisions about their care and treatment. <http://www.sheffield.ac.uk/news/nr/palliative-care-research-1.330456>

Noted in Media Watch, 10 June 2013, #309 (p.9):

- *PSYCHO-ONCOLOGY* | Online – 18 March 2013 – **'If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis.'** Among 9344 respondents [to this population based survey], data revealed an international preference (73.9%) to always be informed in the scenario of having a serious illness, such as cancer, with less than a year to live. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3283/abstract>

## Bereavement and palliative care: A public health perspective

*PROGRESS IN PALLIATIVE CARE* | Online – 3 December 2013 – In recent years there has been an increasing emphasis upon public health perspectives that place palliative care in the context of end-of-life services across whole populations. There is little corresponding public health interest in bereavement. Yet if we have to develop relevant, coherent, and comprehensive end-of-life care policies and practices, public health approaches to palliative care need to be accompanied by public health approaches to bereavement care. The authors argue that palliative care services should match their commitment to providing a good death with a commitment to supporting good grief, and that this means investing their efforts principally in developing community capacity for bereavement care rather than seeking to deliver specialized bereavement services to relatives and friends of those who have received palliative care services. [http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc183](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc183)

Noted in Media Watch, 25 November 2013, #333 (p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 November 2013 – '**Few U.S. public health schools offer courses on palliative and end-of-life care policy.**' Palliative care has been identified by the WHO as a critical policy element for the relief of suffering, yet palliative care policy receives minimal attention in mainstream U.S. public health journals, conferences, or textbooks. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0161>

Noted in Media Watch, 18 November 2013, #332 (p.3):

- GOVERNMENT HEALTH IT | Online – 11 November 2013 – '**American Public Health Association seeks to improve and rebrand public health.**' The American Public Health Association is envisioning public health models of palliative care that incorporate patient-centered medical home design, investments in the palliative care workforce, and public education campaigns... <http://www.govhealthit.com/news/improving-and-rebranding-public-health>

## Communication about existential issues with patients close to death – nurses' reflections on content, process and meaning

*PSYCHO-ONCOLOGY* | Online – 9 December 2013 – Encountering dying patients with implicit existential questions requires the nurses to have positive and comfortable attitude to talking about existential issues. This paper describes the nurses' reflections on existential issues in their communication with patients close to death. Three domains and nine themes emerged. The content domain of the existential conversation covered living, dying and relationships. The process domain dealt with using conversation techniques to open up conversations, being present and confirming. The third domain was about the meaning of existential conversation for nurses. The group reflections revealed a distinct awareness of the value of sensitivity and supportive conversations. This study supports the assertion that experience of talking about existential issues and supporting environment make nurses comfortable when counselling patients close to death. It was obvious from this study that having the courage to be present and confirming, having time and not trying to "solve" every existential problem were the most important factors in conversations with the patients close to death. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3456/abstract>

Noted in Media Watch, 10 September 2012, #270 (p.4):

- *ARCHIVES OF INTERNAL MEDICINE* | Online – 3 September 2012 – '**The relief of existential suffering.**' Physicians need a typology of existential distress to aid its recognition and improved management. The major forms of existential challenge include 1) death anxiety; 2) loss and change; 3) freedom with choice or loss of control; 4) dignity of the self; 5) fundamental aloneness; 6) altered quality of relationships; 7) our search for meaning; and, 8) mystery about what seems unknowable. <http://archinte.jamanetwork.com/article.aspx?articleid=1356535>

Cont.

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online – 13 December 2013 – '**A fifth of Dutch support assisted suicide for people "tired of living."**' A substantial minority of the Dutch public thinks that doctors should be able to help older people to die even if they are not seriously ill but simply tired of living. <http://www.bmj.com/content/347/bmj.f7483>

### Media Watch Online

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/12/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 | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> [Click on 'Current Issue' under 'Media Watch']

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

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']

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events> [Scroll down to 'Media Watch']

#### 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

### **End-of-life care: Lessons from other nations**

*JOURNAL OF PALLIATIVE MEDICINE*, 2005;8(Supplement):s161-s173. Palliative care and hospice services have evolved across the globe in different contexts and in different ways, although many of the challenges faced are similar. Comparison between countries helps to identify the best solutions for individual patients and their families, who have complex needs and problems. This paper describes the globally shared challenges and beginnings in hospice and palliative care. It reviews evolution of services and approaches. It compares the models of hospice and palliative care in the United States and the United Kingdom, where pioneer hospices were developed through the work of Dame Cicely Saunders, and then seeks to highlight ways to learn from the different approaches to address common questions. Several research recommendations result from this review. In many countries the research agenda in palliative and end-of-life care must move from describing need (where there are ample studies) to understanding how and determining whether services and interventions work, for whom, and when. Studies should consider the whole trajectory of illness, particularly in slowly progressive or relapsing conditions (including neurological conditions). Future studies should work toward the use of a similar set of core outcome measures, as well as take advantage of the opportunity to undertake "natural experiments" by comparing and contrasting care systems developed in different contexts around the world. <http://online.liebertpub.com/doi/pdf/10.1089/jpm.2005.8.s-161>

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