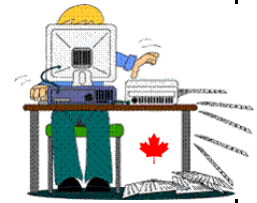


## **Media Watch...**

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

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

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

**Beyond patient autonomy: Scroll down the [Specialist Publications](#) and 'From informed consent to shared decision-making' (p.14), in *South African Medical Journal*.**

## **Canada**

### **Baby boomers call for national seniors care strategy**

CTV NEWS | Online – 18 August 2014 – In the Canadian Medical Association's 2014 National Report Card on health issues, 95% of Canadians aged 45 years and over identified the need for a national strategy for seniors care. The report also found that 81% of these Canadians are concerned with the quality of health care they can expect in the future. As well, 78% are concerned about their ability to afford quality home and long-term care during their retirement. According to the report, about 26% of baby boomers are currently providing care for an elderly relative, which may be giving them a first-hand look at the state of seniors health services and facilities. <http://www.ctvnews.ca/health/baby-boomers-call-for-national-seniors-care-strategy-1.1964183>

1. 2014 National Report Card, Canadian Medical Association, August 2014 press release: [https://www.cma.ca/En/Lists/Medias/2014-National-Report-Card-Media-Releas\\_Final-e.pdf](https://www.cma.ca/En/Lists/Medias/2014-National-Report-Card-Media-Releas_Final-e.pdf)

**N.B.** Canadians are living longer, in 2011 an average of 81.7 years. For many adults, the ability to perform key health functions declines as they age. Decline in functional health accelerates after age 65, with more severe disability occurring, on average, around age 77. (Statistics Canada: <http://www.statcan.gc.ca/daily-quotidien/140717/dq140717d-eng.pdf>)

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

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 22 August 2014 – '**The path from physician assisted suicide to involuntary euthanasia.**' The public debate on this issue belies a commitment to rational argument. <http://fullcomment.nationalpost.com/2014/08/22/jackson-doughart-the-path-from-physician-assisted-suicide-to-involuntary-euthanasia/>

Cont.

- CTV NEWS | Online – 20 August 2014 – '**12 Canadians among suicide tourists to Switzerland, study finds.**' Swiss researchers say that doctor-assisted deaths doubled between 2008 and 2012, when 611 foreign nationals travelled to Switzerland to die. Residents of 31 different countries travelled there within the four-year period, the researchers say, for euthanasia at one of four right-to-die organizations that provide such services to non-Swiss nationals. The vast majority of so-called "suicide tourists" came from Germany (268) and the U.K. (126). Other countries that saw residents travel to Switzerland to end their lives included France (66), Italy (44), U.S. (21), Austria (14), Canada (12), and Spain and Israel (each with 8). <http://www.ctvnews.ca/health/health-headlines/12-canadians-among-suicide-tourists-to-switzerland-study-finds-1.1968785>
  1. 'Suicide tourism: A pilot study on the Swiss phenomenon,' *Journal of Medical Ethics*, 20 August 2014. <http://jme.bmj.com/content/early/2014/07/03/medethics-2014-102091.abstract>
- CTV NEWS | Online – 19 August 2014 – '**Doctors debate end-of-life care...**' Doctors tackled the delicate question of medically assisted death at a session devoted to end-of-life care at the annual conference of the Canadian Medical Association... The session ended with an overwhelming vote – 90% – in favour of an advisory resolution that supports "the right of all physicians, within the bonds of existing legislation, to follow their conscience when deciding whether to provide so-called medical aid in dying." The CMA defines "medical aid in dying" as, essentially, euthanasia or physician-assisted suicide. <http://www.ctvnews.ca/health/doctors-debate-end-of-life-care-at-cma-meeting-1.1966254>

**Specialist Publications**

'Conscience should guide doctors at end-of-life' (p.17), in *Canadian Medical Association Journal*.

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

### **Food and the dying patient**

*THE NEW YORK TIMES* | Online – 21 August 2014 – Contrary to popular belief, a feeding tube does not prolong life in a patient with dementia. It actually increases suffering. A stomach full of mechanically pumped artificial calories puts pressure on an already fragile digestive system, increasing the chance of pushing stomach contents up into the lungs. And surgically implanted tubes are a setup for complications: dislodgments, bleeding and infections that can result in pain, hospital admissions and the use of arm restraints in already confused patients. But maybe most important, the medicalization of food deprives the dying of some of the last remnants of the human experience: taste, smell, touch and connection to loved ones. So why do so many demented patients die with feeding tubes? Food is how we know best to care for one another, from breast to deathbed. And thus it runs contrary to every impulse we have as humans to stop feedings. As a dying person becomes unable to process food on her own, our tendency is to plug life into her with a tube pumping artificial nutrition. <http://well.blogs.nytimes.com/2014/08/21/food-and-the-dying-patient/>

#### **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>

## As more hospices enroll patients who aren't dying, questions about lethal doses arise

THE WASHINGTON POST | Online – 21 August 2014 – The hospice industry in the U.S. is booming and for good reason, many experts say. Hospice care can offer terminally ill patients a far better way to live out their dying days, and many vouch for its value. But the boom has been accompanied by what appears to be a surge in hospices enrolling patients who aren't close to death, and at least in some cases, this practice can expose the patients to more powerful painkillers routinely used by hospice providers. Hospices see higher revenues by recruiting new patients and profit more when they are not near death. There are no statistics on how often such abuses may be occurring. But complaints from around the country illustrate the potential dangers of enrolling patients in hospice even though they are not near death, the families involved say. <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>

### Specialist Publications

'Knowledge about hospice: Exploring misconceptions, attitudes, and preferences for care' (p.8), *American Journal of Hospice & Palliative Medicine*.

'Increasing rates of advance care planning through interdisciplinary collaboration,' (p.13), in *American Journal of Medicine*.

'A statewide survey of adult and pediatric outpatient palliative care services' (p.12), in *Journal of Palliative Medicine*.

**N.B.** This article is part of an ongoing *Washington Post* series on the hospice industry 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)

Of related interest:

- REUTERS | Online – 18 August 2014 – '**Cancer screenings common among older, sick Americans.**' Despite potential risks and limited benefits, many Americans are still screened for cancers toward the end of their lives, according to a new study.<sup>1</sup> Up to half of older people in the U.S. received cancer screenings even though there was a high likelihood that they would die within nine years without cancer... Several professional societies have updated their cancer screening guidelines to suggest that people who aren't expected to live another 10 years should not be screened for certain cancers. <http://www.reuters.com/article/2014/08/18/us-screening-life-study-idUSKBN0G11VT20140818>

1. 'Cancer screening rates in individuals with different life expectancies,' *JAMA Internal Medicine*, 18 August 2014. A substantial proportion of the U.S. population with limited life expectancy receive prostate, breast, cervical, and colorectal cancer screening that is unlikely to provide net benefit. <http://archinte.jamanetwork.com/article.aspx?articleid=1897549>

## Family caregivers providing complex chronic care to people with cognitive and behavioral health conditions

AARP NEWS | Online – 19 August 2014 – This paper reports on results from a national survey showing that caregivers of family members with challenging behaviors were more likely to perform more than one medical/nursing task, such as managing medications, and often do so with resistance from the person they are trying to help. Yet they receive little or no instruction or guidance on how to do this important work. This analysis offers recommendations for assisting family caregivers who play this dual role.<sup>1</sup> <http://www.aarp.org/about-aarp/press-center/info-08-2014/new-report-documents-impact-on-family-caregivers.html>

1. *Family Caregivers Providing Complex Chronic Care to People with Cognitive & Behavioral Health Conditions*, American Association for Retired Persons Public Policy Institute, 2014. [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/2014/family-caregivers-cognitive-behavioral-AARP-ppi-health.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-cognitive-behavioral-AARP-ppi-health.pdf)

Of related interest:

- CAREGIVER ACTION NETWORK | Online – 19 August 2014 – **'A new survey of in-home family caregivers reveals challenges and rewards of caregiving.'** Caregivers often put the needs of their loved ones before themselves, and over time that selflessness has an impact – both inspirational and challenging. Eighty percent of caregivers believe that their role has given them more meaning in their lives, but most of them have also felt exhausted (85%), frustrated (82%) and overwhelmed (79%), according to the 'When Care Comes Home' survey. [http://www.caregiveraction.org/news/?news\\_id=74](http://www.caregiveraction.org/news/?news_id=74)

## Arizona same-sex couple wants marriage recognized due to terminal illness

ARIZONA | LGBTQnation – 18 August 2014 – A same-sex couple from southern Arizona wants a federal judge to immediately order the state to recognize their marriage because one of the men is terminally ill. Lawyers for George Martinez and Fred McQuire of Green Valley say the order is needed so McQuire can be recognized as Martinez's survivor when he dies. That will allow him to take care of his affairs and collect larger Veterans Affairs and other benefits. <http://www.lgbtqnation.com/2014/08/ariz-same-sex-couple-want-marriage-recognized-due-to-terminal-illness/>

Noted in Media Watch, 12 May 2014, #357 (p.2):

- INDIANA | Buzz Feed – 8 May 2014 – **'Judge: Indiana must continue to recognize out-of-state marriage of terminally ill woman and her wife.'** The Indiana attorney general's office will appeal a federal court ruling that forces the state to continue recognizing the out-of-state marriage of a lesbian couple because one of the women was diagnosed with a terminal illness. <http://www.buzzfeed.com/tonymerevick/judge-indiana-must-continue-to-recognize-out-of-state-marria>

Noted in Media Watch, 30 September 2013, #325 (p.3):

- OHIO | 10TV News (Columbus) – 25 September 2013 – **'Gay marriage lawsuit expansion could impact local families.'** The judge handling a case involving end-of-life issues for gay spouses expanded the suit to apply to any lesbian, gay, bisexual and transgender couples in similar situations. <http://www.10tv.com/content/stories/2013/09/25/reynoldsburg-gay-marriage-lawsuit-impact.html>

### [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.

## Care aides get little to no training for life-and-death tasks

MINNESOTA | *The Star Tribune* (Minneapolis) – 17 August 2014 – Each day, thousands of home-based caregivers ... are thrust into ... life-and-death situations with little training and virtually no direct supervision. They perform a dizzying array of complex medical tasks – from inserting feeding tubes and cleaning infections to monitoring intravenous fluids – that once were provided only in hospitals or nursing homes by medical professionals. Many say they feel overwhelmed and unqualified as they struggle to help patients with serious illnesses and disabilities. Of more than two dozen personal care attendants interviewed by the *Star Tribune* in the past two months, only one

had received more than an hour's training from their agencies. Many said they appealed to their agencies for more training and oversight but were told that state payments were too low to cover the expense. <http://www.startribune.com/lifestyle/health/271534921.html>

### Extract from *The Star Tribune* article

In Minnesota ... all it takes to be certified as a home caregiver is a brief online quiz with questions such as, "When talking to a 911 operator, do not hang up. True or false?"

## International

### End-of-life care in England

#### **Elderly patients asked during home visits by nurses: Would you want to be resuscitated?**

U.K. (England) | *The Daily Telegraph* – 20 August 2014 – Elderly patients have been asked whether they would agree to a "do not resuscitate" order, instructing medics to let them die if their heart stopped, during home visits from nurses, it [has] emerged. Nurses who have met the patients for the first time have questioned them about sensitive medical issues including whether they would want doctors to restart their heart if it stopped beating. The surveys are given to nurses in the form of National Health Service employer's template documents which outline questions they may wish to ask their patients where appropriate. But in some cases nurses have asked patients they have just met if they wish to sign the "do not resuscitate" order. The move has been criti-

cised by some medics who claim frail older patients may feel under pressure to say yes. <http://www.telegraph.co.uk/health/nhs/11044923/Elderly-patients-asked-during-home-visits-by-nurses-Would-you-want-to-be-resuscitated.html>

### Specialist Publications

'Are end-of-life practices in Norway in line with ethics and law?' (p.8), in *Acta Anaesthesiologica Scandinavica*.

'Spiritual care in the training of Bavarian hospice volunteers' (p.16), *Zeitschrift für Palliativmedizin*.

Of related interest:

- U.K. (England) | *The Star* (Sheffield) – 19 August 2014 – **'Marie Curie to end home nursing service for dying patients in Sheffield.'** Marie Curie is to stop providing home nursing services to dying patients in Sheffield following planned changes to National Health Service funding. The charity says it can no longer afford to provide visits to terminally-ill patients under the terms of a new contract from Sheffield Clinical Commissioning Group. Under the current contract, Marie Curie pays half the cost of running the service. The new contract would mean it paying almost 90% of the costs. <http://www.thestar.co.uk/news/health/local-health/marie-curie-to-end-home-nursing-service-for-dying-patients-in-sheffield-1-6790646>

Cont.

- U.K. (England) | National Health Service – 15 August 2014 – **'Lessons learned – implementing an electronic palliative care coordination system.'** This document provides useful tips and information which has been collated from the NHS intelligence networks and from working with sites who are currently implementing an electronic palliative care coordination system. Project leads provided insight from their experience and reflections on what they should or could have done. It also provides a number of links to useful resources that have supported their learning. [http://www.nhs.uk/media/2511469/epaccs\\_lessons\\_learned.pdf](http://www.nhs.uk/media/2511469/epaccs_lessons_learned.pdf)

#### Elder care in the U.K.

##### **Care choice plan "could fail" as councils stick to European Union rules**

U.K. (Scotland) | *The Herald* (Edinburgh) – 18 August 2014 – Charities have warned policies designed to let older people choose their own care will fail if councils insist on following European [Union] rules on tendering. Personalisation policies, which have near-universal support from the government, councils and care providers, are meant to give elderly and disabled people and their carers a choice of the services they receive, and help keep them in their own homes. But care providers have long warned there is a basic incompatibility between this choice and procurement rules councils follow when commissioning services. When they are given budgets for self-directed support, many families have been dismayed to find they cannot use them to buy the care they want because the charity or company providing it is not on an approved list. Sometimes an older person has been getting care at home or other help for years and must change providers against their wishes. <http://www.heraldscotland.com/news/health/care-choice-plan-could-fail-as-councils-stick-to-eu-rules.25059501>

Of related interest:

- U.K. (Wales) | BBC News – 17 August 2014 – **'Care homes face nurse recruitment "crisis," claims forum.'** Urgent action is needed to attract more nurses into Wales' independent care sector so it can relieve pressure on hospital bed use... Care Forum Wales chair Mario Kreft said a shortage of care home nurses was at risk of becoming a "crisis." He spoke out after it emerged two homes in the Bridgend area were to close, citing nurse recruitment problems. <http://www.bbc.com/news/uk-wales-28822454>

#### End-of-life care in Wales

##### **Terminally ill North Wales mum can get life prolonging drug... but only in England**

U.K. (Wales) | *The Daily Post* (Llandudno Junction, Conwy) – 18 August 2014 – A terminally ill mum will be given a drug which could prolong her life – but only if the National Health Service [NHS] in England are willing to fund it. Cheryl Sheard, of Dyserth, is currently waiting to hear if she will be able to receive a £24,000 course of Avastin treatment, which has been made available over the border for people with advanced cervical cancer. Studies have shown that the drug – unavailable on the NHS in Wales – could extend women's lives by an extra four months. The mother-of-two will find out in four weeks if Wirral-based Clatterbridge Cancer Centre has been able to access the funding so she can have the drug alongside her chemotherapy. <http://www.dailypost.co.uk/news/health/terminally-ill-north-wales-mum-7630160>

Noted in Media Watch, 31 March 2014, #351 (p.4):

- U.K. (England) | *The Daily Mail* – 27 November 2014 – **'Thousands of elderly cancer victims could be denied drugs: New NICE rules set to downgrade treatment for terminally ill.'** Thousands of seriously ill cancer patients could be denied treatment under changes to the way drugs are funded on the NHS. Campaigners are warning that proposals from the National Institute for Health and Care Excellence (NICE) will end the priority given to terminally ill patients. <http://www.dailymail.co.uk/news/article-2590340/Thousands-elderly-cancer-victims-denied-drugs-New-NICE-rules-set-downgrade-treatment-terminally-ill.html>

Cont.

Of related interest:

- U.K. (Wales) | ITV News (Cardiff) – 18 August 2014 – **'£6.4 million of funding for specialist end-of-life care.'** The new funding for hospices and health boards will ensure specialist consultant, nurse and other health support for palliative care is available in all parts of the country. <http://www.itv.com/news/wales/update/2014-08-18/6-4-million-of-funding-for-specialist-end-of-life-care/>

#### End-of-life care in Scotland

#### **Terminally ill man denied free care again "for applying too early"**

U.K. (Scotland) | BBC News – 15 August 2014 – A terminally ill man who was told he wasn't close enough to death to qualify for free personal care has been refused support for a second time. Andy Masterton, who is in the final stages of motor neurone disease, was told by East Ayrshire Council that he applied too early for the benefit. The council says the benefit is only for people who are four weeks from death at the point they are referred. Only over-65s are currently entitled to free help with washing and dressing. Council [sic] of Scottish Local Authorities recommends that people under 65 should be given free personal care if they have a terminal illness. Mr. Masterton is bedridden, but is still being refused the benefit. <http://www.bbc.com/news/uk-scotland-glasgow-west-28802491>

**N.B.** 'End of life: A guide for People with Motor Neurone Disease,' Motor Neurone Disease Association. <http://www.mndassociation.org/news-and-events/Latest+News/end+of+life+guide+launched>

Noted in Media Watch, 23 June 2014, #363 (p.7):

- U.K. (Scotland) | LocalGov – 16 June 2014 – **'Councils charging terminally ill for personal care, says charity.'** Local authorities are wrongly charging terminally ill people for personal care, according to a report from MND [Motor Neurone Disease] Scotland.<sup>1</sup> The charity is warning that many people under 65 years with motor neurone disease are being charged by their local council for personal care, despite Convention of Scottish Local Authorities guidance stating those with a terminal illness should not have to pay... <http://www.localgov.co.uk/Councils-charging-terminally-ill-for-personal-care-says-charity/36522>

1. 'Scottish local authorities' personal care charging for under 65s who are terminally ill,' MND Scotland, June 2014. <http://www.mndscotland.org.uk/personal-care-charges/>

Noted in Media Watch, 18 November 2013, #332 (p.10-11):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(6):286-289. **'What palliative care can do for motor neurone disease patients and their families.'** The involvement of the specialist palliative care team may be episodic, occurring at times of change, crisis or decision-making; for example, at diagnosis, when discussing gastrostomy or ventilatory support, when there are cognitive changes and at the end of life. End-of-life care planning – and reassurance that, with good palliative care, death is usually peaceful – is a crucial part of care.

**N.B.** Access to the *European Journal of Palliative Care* requires a subscription. Contents: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?pageid=58&JID=4&Year=2013&Edition=488](http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488)

#### **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>



## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (Scotland) | *The Herald* (Edinburgh) – 19 August 2014 – '**Assisted suicide law backed.**' Support for legalising assisted suicide in Scotland has risen since the death of the popular MSP [Member of the Scottish Parliament] who championed the law change, analysis of a public consultation has found. Three-quarters of responses to a consultation on the Assisted Suicide (Scotland) Bill undertaken by Holyrood's Health & Sport Committee backed the proposed legislation, the My Life, My Death, My Choice campaign group said. The Bill was introduced by independent MSP Margo MacDonald, and Green MSP Patrick Harvie took it over after her death in April. Of 830 individual submissions, 79% were in favour. When the 70 responses from groups and organisations were factored in, the total fell to 75%. A previous poll put support for the Bill at 69%. <http://www.heraldscotland.com/news/home-news/assisted-suicide-law-backed.25083608>

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

### **Knowledge about hospice: Exploring misconceptions, attitudes, and preferences for care**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 August 2014 – Despite relatively high hospice awareness and favorability, myths and misperceptions about hospice still abound – and may drive ethnic disparities in end-of-life care. Educational interventions and future study are needed. 106 [survey respondents] (86%) had heard about hospice, 65 (54%) of whom had a personal experience with hospice. Participants had an average hospice knowledge test score of 18 indicating moderate knowledge of hospice. A majority of respondents (62%) did not know that hospice cannot provide concurrent cure-oriented care. Misperceptions about eligibility, coverage of hospice, the provision of hospice in nursing homes or to persons who live alone were not uncommon. Greater knowledge of hospice was associated with more favorable attitudes about the hospice philosophy of care and a greater preference for hospice. Respondents who were more educated, worked in the medical field, were non-Hispanic White, and had direct experience with hospice were also more likely to be more knowledgeable about hospice. <http://ajh.sagepub.com/content/early/2014/08/14/1049909114546885.abstract>

### **Are end-of-life practices in Norway in line with ethics and law?**

*ACTA ANAESTHESIOLOGICA SCANDINAVICA* | Online – 14 August 2014 – Forgoing life-prolonging treatment at the request of the family may be more frequent in Norway than the law permits. A very small minority of doctors has hastened the death of a patient, and most cases involved non-competent patients. Male doctors below 50 seem to have a more liberal end-of-life practice. End-of-life decisions, including limitation of life prolonging treatment, may be emotionally, ethically and legally challenging. Euthanasia and physician-assisted suicide (PAS) are illegal in Norway. A study from 2000 indicated that these practices occur infrequently in Norway. Forty-four per cent of the [survey] respondents reported that they had terminated treatment at the family's request not knowing the patient's own wish, doctors below 50 and anaesthesiologists more often. Anaesthesiologists more often reported to have terminated life-prolonging treatment because of resource considerations. Six doctors reported having hastened the death of a patient the last 12 months, one by euthanasia, one by PAS and four had hastened death without patient request. Male doctors and doctors below 50 more frequently reported having hastened the death of a patient. <http://onlinelibrary.wiley.com/doi/10.1111/aas.12384/abstract>

Cont.



Noted in Media Watch, 7 May 2012, #252 (p.12):

- *RESUSCITATION* | Online – 26 April 2012 – '**Law, ethics and clinical judgment in end-of-life decisions: How do Norwegian doctors think?**' According to Norwegian law, an autonomous patient has the right to refuse life-prolonging treatment. If the patient is not defined as dying ... health personnel are obliged to instigate life-saving treatment in an emergency situation even against the patient's wishes. This study investigated how doctors' attitudes and knowledge agree with these legal provisions, and how the statutory provision on emergency situations influences the principle of patient autonomy for severely ill, but not dying, patients. [http://www.resuscitationjournal.com/article/S0300-9572\(12\)00219-5/abstract](http://www.resuscitationjournal.com/article/S0300-9572(12)00219-5/abstract)

### **A confined encounter: The lived experience of bereavement in prison**

*BEREAVEMENT CARE*, 2014;33(2):56-62. The powerful socio-cultural prescriptions of the prison environment can cause the grief of prison inmates to be profoundly disenfranchised and demonstrates how this can impact negatively on their coping ability. The paper calls for development of support systems to ensure a level of bereavement care attuned to the needs of imprisoned persons. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2014.933572?queryID=%24%7BresultBean.queryID%7D>

### **The opportunity cost of futile treatment in the ICU**

*CRITICAL CARE MEDICINE*, 2014;42(9):1977-1982. When used to prolong life without achieving a benefit meaningful to the patient, critical care is often considered "futile." Although futile treatment is acknowledged as a misuse of resources by many, no study has evaluated ... how it affects care for others. The authors evaluated delays in care when futile treatment is provided [and conclude in this study] that futile critical care was associated with delays in care to other patients. [http://journals.lww.com/ccmjournal/Abstract/2014/09000/The\\_Opportunity\\_Cost\\_of\\_Futile\\_Treatment\\_in\\_the.2.aspx](http://journals.lww.com/ccmjournal/Abstract/2014/09000/The_Opportunity_Cost_of_Futile_Treatment_in_the.2.aspx)

Of related interest:

- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2014;6(5):301-307. '**Futile care: Concept analysis based on a hybrid model.**' Futile care is a concept affected by a host of factors including: cultural, ethical and religious issues; lack of coordination within the therapeutic personnel, patient and families; lack of communal training; commitment of human errors; unclear pre-awareness of diseases; lack of clear instructions; and, finally work conditions. <file:///C:/Users/Barry/Downloads/35787-135133-1-PB.pdf>
- *WORLD HEALTH & POPULATION*, 2014;15(2):4-13. '**End-of-life decisions: Some international comparisons.**' As health systems worldwide confront diminishing resources and endless questioning on expenditures, the concept of medical futility has taken on increasing prominence. Medical professionals know intuitively that certain interventions near the end of life can neither extend life nor improve the quality of life remaining. In addition to medical futility, concerns about international economic pressures and enhanced recognition of patient autonomy lead to questions as to the appropriateness of withdrawing life-sustaining treatment, assisted suicide and euthanasia. <http://www.ncbi.nlm.nih.gov/pubmed/25144785>

### **Needs assessment of palliative care education in gynecologic oncology fellowships: We're not teaching what we think is most important**

*GYNECOLOGIC ONCOLOGY* | Online – 15 August 2014 – Gynecologic oncology fellowship directors [i.e., survey respondents] prioritize communication topics as the most important palliative care (PC) topics for fellows to learn. There is no correlation between which PC topics are currently being taught and which are considered most important. Interest in new PC curricular materials is high, representing an opportunity for curricular development and dissemination. Future efforts should address identification of optimal methods for teaching communication to gynecologic oncology fellows. <http://www.sciencedirect.com/science/article/pii/S0090825814012694>

## End-of-life care in Australia

### **Australian palliative care better than the U.S.**

*HOSPITAL & AGED CARE* | Online – 18 August 2014 – The palliative care movement in Australia is about a decade more advanced than the U.S. sector, a U.S. palliative care pioneer told ... [a recent] ... Palliative Care Victoria... Director of Doctor-Patient Communication at the University of Pittsburgh Palliative & Supportive Institute, Dr. Robert Arnold, complimented the Australian palliative care sector for recent progress made to enable communities and health professionals to have the "difficult conversations we have to have." "In the U.S. it's predominantly a hospital-based specialty," said Dr. Arnold, who is also the Professor and Medical Director of the Pittsburgh Institute. "Partly because you have a health care system you do better – with continuity and integration between outpatient and inpatient programs – than we do." Dr. Arnold said he was impressed by the degree to which palliative care in Australia is integrated into government. "In the U.S., you wouldn't have the head of Health (Minister) show up and talk knowledgeably about how important it is and clearly showing that he believes in it. We see the government as a problem not as a partner." He also said he was impressed by how Australia aims to provide good palliative care regardless of where patient is. <http://www.hospitalandagedcare.com.au/news/australian-palliative-care-better-than-the-us>

Of related interest:

- *AUSTRALIAN FAMILY PHYSICIAN*, 2014;43(8):514-519. **'End-of-life care for patients with cancer.'** Not all GPs are willing to undertake palliative care, often because of a sense of inadequate knowledge, confidence and support. The more palliative care is undertaken, however, the more confident practitioners feel. Therefore, starting to treat end-of-life patients early in a GP's career is important, and making use of the considerable resources available will assist in building knowledge and confidence. <http://www.racgp.org.au/afp/2014/august/end-of-life-care-for-patients-with-cancer/>
- *AUSTRALIAN FAMILY PHYSICIAN*, 2014;43(8):526-528. **'Advance care planning.'** There has been an increased focus on advanced care planning and advance care directives in Australia, partly driven by the ageing population and technological advances, as well as the principle of patient-centred care. GPs have an important role in initiating and facilitating advance care planning. <http://www.racgp.org.au/afp/2014/august/advance-care-planning/>
- *AUSTRALIAN SOCIAL WORK* | Online – 14 August 2014 – **'Cultural meaning-making in the journey from diagnosis to end of life.'** The authors make recommendations for greater involvement of social workers in palliative care, and for more attention to supporting dying people and their families to make culturally meaningful decisions in the journey toward death. [http://www.tandfonline.com/doi/abs/10.1080/0312407X.2014.939668#.U\\_NQS8VdX8k](http://www.tandfonline.com/doi/abs/10.1080/0312407X.2014.939668#.U_NQS8VdX8k)
- *BMC PALLIATIVE CARE* | Online – 18 August 2014 – **'Is a good death possible in Australian critical and acute settings?: Physician experiences with end-of-life care.'** Regardless of specialty, all physicians [i.e., study participants] identified the problematic nature of providing expert palliation in critical and acute settings. Strategies for integrating specialised palliative and intensive care were offered with corresponding directions for future research and clinical development. <http://www.biomedcentral.com/content/pdf/1472-684X-13-41.pdf>

**N.B.** Australia was rated 2nd and the U.S. 9th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by The Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)] [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

## Communication as an expression of humanized end-of-life care: A systematic review

*JOURNAL OF NURSING*, 2014;8(8):2845-2853. The articles selected demonstrated the urgent need to acquire specific skills in the field of communication, in order to promote a dignified end of life. Regardless of experience, or even the ability to deal with the proximity of death, it is extremely important to develop strategies that are not exclusively based on verbal expression, but also on non-verbal signals, in order to promote a positive health care experience. [http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/6030/pdf\\_5957](http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/6030/pdf_5957)

**N.B.** English and Portuguese language article.

Noted in Media Watch, 5 November 2012, #278 (p.9):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 25 October 2012 – '**The importance of patient-provider communication in end-of-life care.**' A narrative of a man with schizophrenia who wished to forgo hemodialysis – a study in the ethical importance of attention to non-verbal communication. <http://www.springerlink.com/content/x621n738448481p3/>

## An examination of global and regional opioid consumption trends 1980-2011

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 19 August 2014 – Most of the world's population lacks adequate availability of opioids. Great disparities in availability of opioids continue to exist between higher- and lower-to-middle-income countries. This study examined more than 30 years of consumption data reported to the International Narcotics Control Board ... for five opioids that are indicated for the treatment of moderate to severe pain: fentanyl, hydromorphone, morphine, oxycodone, and pethidine. As such, this study offers a regional and global perspective on opioid consumption, providing an indication of preparedness for treating moderate to severe pain. Countries are categorized according to the World Health Organization's six geographical regions. Morphine equivalence (ME) statistics were calculated for each study drug, allowing for equianalgesic comparisons between consumption of the study opioids and well as the ability to aggregate all study opioids. The ME statistic is adjusted for country population, which allows for uniform global-, regional-, and country-level equianalgesic comparisons of consumption of morphine with other opioids. Although overall trend lines revealed general increases by region, profound inequities in opioid consumption continue to abound globally. <http://informahealthcare.com/doi/abs/10.3109/15360288.2014.941132>

Noted in Media Watch, 3 February 2014, #343 (p.10):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 28 January 2014 – '**The Global Opioid Policy Initiative: A wealth of information, but what is next?**' This study shows by country which opioid medicines are available, what they cost to the patient, and investigates the presence of barriers for access to these medicines. Data from the project will be an important resource for those who advocate for improved access to opioid analgesics. <http://informahealthcare.com/doi/abs/10.3109/15360288.2013.873513>

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

- HUMAN RIGHTS WATCH | Online – 24 January 2014 – '**WHO boosts hope on pain relief, palliative care.**' World Health Organization has adopted a groundbreaking resolution urging countries to ensure access to pain medicines and palliative care for people with life-threatening illnesses. The resolution addresses the needs of the 20 million people who die each year suffering from moderate or severe pain and other symptoms due to cancer, HIV and other conditions, and the 40 million each year who require palliative care for relief of pain and other symptoms. <http://www.hrw.org/news/2014/01/24/un-who-boosts-hope-pain-relief-palliative-care>

Cont.

Of related interest:

- *SUPPORTIVE CARE IN CANCER* | Online – 20 August 2014 – '**Exploring the myths of morphine in cancer: Views of the general practice population.**' The public view of morphine to emerge from this study is markedly different from that discussed in the myths of morphine. It is viewed as a medication that has the ability to provide peace and control both pain and the course of cancer. The participants in this study described a wish for greater involvement in pain control decisions, perceiving morphine as a facilitator rather than a barrier to good cancer care. <http://link.springer.com/article/10.1007/s00520-014-2379-9>

### **Dying in the hospital: What happens and what matters, according to bereaved relatives**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 August 2014 – Relatives rated quality of death (QOD) as sufficient. A majority of patients and relatives were not sufficiently prepared for imminent death and relatives experienced many problems. QOD appears to be a multi-dimensional construct, strongly affected by medical care and staff attentiveness. Two hundred forty-nine relatives participated [in this study] and rated overall QOD at 6.3. According to relatives, patients suffered from 7.0 of 22 symptoms, and were at peace with imminent death in 37%. Patients had been aware of imminent death in 26%, relatives in 49%. Further, 39% of patients and 50% of relatives had said goodbye, and 77% of patients died in the presence of a relative. Symptom alleviation was sufficient in 53%, and in 75%, sufficient efforts had been made to relieve symptoms. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00406-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00406-0/abstract)

### **A statewide [California] survey of adult and pediatric outpatient palliative care services**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 August 2014 – Few California hospitals offer outpatient palliative care services. This finding has remained consistent over time. Adult and pediatric outpatient palliative care services care primarily for patients with cancer, operate part-time with modest staffing, and are funded primarily by their institution. Making the case for value to engender more institutional support, increasing billing revenue, system initiatives, and partnering with insurers may lead to the establishment of more outpatient palliative care services. Of the 136 hospitals with an adult palliative care service, 18% reported an outpatient palliative care service with a mean age of 3.7 years. Of the 42 hospitals offering pediatric palliative care services, 19% reported an outpatient palliative care service with a mean age of 3.4 years. On average, adult outpatient palliative care services see 159 new patients per year with 722 follow-up visits. Pediatric outpatient palliative care services see 10 new patients per year with 28 follow-up visits. Few services provided 24/7 coverage (25% adult, 38% pediatric). Wait times for newly referred patients were 11 days for adults and 9 days for pediatrics. Most referrals are received from oncology. Funding for outpatient palliative care ser-

vices is largely through institutional support, followed by foundations, billing, and philanthropy. Compared to similar data from 2007, the prevalence of outpatient palliative care services affiliated with hospitals in California has not changed significantly. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0144>

#### **An emerging field of research: Challenges in pediatric decision making**

*MEDICAL DECISION MAKING* | Online – 21 August 2014 – There is growing interest in pediatric decision science spurred by policies advocating for children's involvement in medical decision making. Challenges specific to pediatric decision research include the dynamic nature of child participation in decisions due to the growth and development of children, the family context of all pediatric decisions, and the measurement of preferences and outcomes that may inform decision making in the pediatric setting. The objectives of this article are to describe each of these challenges, to provide decision researchers with insight into pediatric decision making, and to establish a blueprint for future research... <http://mdm.sagepub.com/content/early/2014/08/20/0272989X14546901.abstract>

Cont.

Of related interest:

- *JOURNAL FOR SPECIALISTS IN PEDIATRIC NURSING* | Online – 17 August 2014 – **'Who are the children using hospice care?'** The predisposing, enabling, and need characteristics of children [i.e., study participants] were identified. Children who used hospice were a diverse group with community resources that enabled them to access care while presenting with serious health needs. Children enrolled in hospice were more likely older (15-20 years of age), resided nearer a pediatric hospice, and had a serious health condition such as neuromuscular disease with multiple co-morbidities. With this knowledge, pediatric nurses can improve their clinical practice by targeting conversations with families and children most in need of hospice care. <http://onlinelibrary.wiley.com/doi/10.1111/jspn.12085/abstract>

### **When they don't die: Prognosis ambiguity, role conflict and emotion work in cancer caregiving**

*JOURNAL OF SOCIOLOGY* | Online – 14 August 2014 – Analysis indicates a clearly terminal (negative) prognosis facilitates clear priorities, unambiguous emotion management and improved social bonds. A more ambiguous (positive) prognosis, that includes a greater chance of survival, fosters role conflict, clashing feeling rules and ongoing guilt within spousal carers. This highlights the importance of a prognosis to emotion management, underscoring a phenomenon that is likely to grow as survival rates continue to improve and explaining some of the variation in carers' experiences. <http://jos.sagepub.com/content/early/2014/08/14/1440783314544996.abstract>

### **"Moral luck" and the question of autonomy, choice, and control in end-of-life decision making**

*PROGRESS IN PALLIATIVE CARE* | Online – 19 August 2014 – It is commonly assumed that, in the realm of ethical decision making at the end-of-life, "luck" and "risk" do not intrude. Nonetheless "moral luck" (where happenstance makes a moral difference) does intrude and can have an unanticipated impact on the ultimate moral outcomes of end-of-life care. This essay explores the relevance and possible implications of moral luck in end-of-life decision making and care. A key conclusion of the paper is that the notion of moral luck needs to be taken seriously in end-of-life care contexts since it can have an unanticipated impact on the outcomes of the decisions that are made and thereby on the moral interests of patients facing the end of their lives. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000101>

Of related interest:

- *AMERICAN JOURNAL OF MEDICINE* | Online – 19 August 2014 – **'Increasing rates of advance care planning through interdisciplinary collaboration.'** In 2014, 24% of the U.S. population is 50 and over and 17 million are between 75 and 85. By 2044, the 17 million U.S. elders just between 75 and 85 is estimated to grow to 30 million. These unprecedented numbers of aging adults in the U.S. present major challenges for the healthcare system as well as the economy. For example, 18% of the U.S. gross national product is spent on healthcare. Of that total, Medicare accounts for 21% or \$554 billion. Most alarmingly, of the \$554 billion spent on Medicare, 28%, or about \$170 billion, is spent on healthcare during the last 6 months of life. [http://www.amjmed.com/article/S0002-9343\(14\)00676-7/abstract](http://www.amjmed.com/article/S0002-9343(14)00676-7/abstract)
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 August 2014 – **'Doctors' decisions when faced with contradictory patient advance directives and health care proxy opinion: A randomized vignette-based study.'** Written advance directives and proxy opinions significantly influenced doctors' decision making. When both were available and concordant, they reinforced each other. When the directive and the proxy disagreed, the resulting effect was to forgo the intervention. Contradictions between advance directives and proxy opinions result in a weak preference for abstention from treatment, and increase the difficulty of the decision. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00405-9/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00405-9/abstract)

## From informed consent to shared decision-making

*SOUTH AFRICAN MEDICAL JOURNAL*, 2014;104(8):561-562. Morality in medicine was long dominated by paternalism: the belief, based on the principles of beneficence (best interests) and non-maleficence (no harm), that doctors knew best and only shared information with patients that the doctor felt was necessary. Attitudes have shifted and there is a recognition that doctors don't "know best." Patients are entitled to choose for themselves, and respect for patient autonomy (self-determination) is now dominant. Shared decision-making, an approach whereby doctors and patients make decisions together using the best available evidence, extends the respect for patient autonomy beyond the narrow legalistic confines of informed consent. Patient autonomy is respected and patients have the opportunity to engage with the healthcare process. Shared decision-making has become more prominent partly because there is an ethical imperative to involve patients properly in decisions about their care, and partly because there is increasing evidence that this approach has benefits. <http://www.samj.org.za/index.php/samj/article/view/8287>

Selected articles on shared decision-making noted in past issues of Media Watch:

- *PATIENT EDUCATION & COUNSELING* | Online – 21 July 2014 – '**Understanding patient perceptions of shared decision making.**' There is no one-size-fits all process that leads patients to label a decision as shared. Rather, the outcome of "agreement" may be more important than the actual decision-making process for patients to label a decision as shared. [Noted in Media Watch, 28 July 2014, #368 (p.12)] [http://www.pec-journal.com/article/S0738-3991\(14\)00291-2/abstract](http://www.pec-journal.com/article/S0738-3991(14)00291-2/abstract)

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### 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.

- *JAMA INTERNAL MEDICINE*, 27 May 2013 [Noted in Media Watch, 3 June 2013, #308 (p.4)]:
  - a. 'How patient centered are medical decisions? Results of a national survey.' Discussions about common tests, medications, and procedures as reported by patients do not reflect a high level of shared decision making. <http://archinte.jamanetwork.com/article.aspx?articleid=1691770>
  - b. 'Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists.' Patients' expectations about 1-year survival are more accurate than those of their nephrologists, but their longer-term survival expectations dramatically overestimated even their 2-year survival rates. <http://archinte.jamanetwork.com/article.aspx?articleid=1691764>
  - c. 'Association of patient preferences for participation in decision making with length of stay and costs among hospitalized patients.' Patient preference to participate in decision making concerning their care may be associated with increased resource utilization among hospitalized patients. <http://archinte.jamanetwork.com/article.aspx?articleid=1691765>
  - d. 'Decision-making preferences among patients with an acute myocardial infarction.' Despite numerous calls for greater participation by patients in the medical decision-making process, shared decision-making is not yet integrated into routine medical care, perhaps because of a perception that patients wish to defer to their physicians. <http://archinte.jamanetwork.com/article.aspx?articleid=1691767>
- *THE HASTINGS REPORT*, 2013;43(4):13-16. **'What's not being shared in shared decision-making?'** What's not to like about shared decision-making? These programs employ specially crafted decision aids to educate patients about their treatment options and then merge the newly informed patient preferences, both general and treatment-specific, with guidance from physicians to optimize medical decisions. Sounds great, right? Even better, recent evidence indicates that shared decision-making programs may also help bend the proverbial cost curve by reducing the use of medical interventions that patients, now properly educated about their options, often say they do not want. [Noted in Media Watch, 15 July 2013, #314 (p.7)] <http://onlinelibrary.wiley.com/doi/10.1002/hast.188/abstract>

### **Length of home hospice care, family-perceived timing of referrals, perceived quality of care, and quality of death and dying in terminally ill cancer patients who died at home**

*SUPPORTIVE CARE IN CANCER* | Online – 21 August 2014 – A significant number of bereaved families regarded the timing of referrals to home hospices as late, and the perceived timing was associated with the family-perceived quality of care and quality of death and dying. Patients [i.e., survey respondents] received home-based hospice care for a median of 35.0 days, and 8.0 % received home hospice care for less than 1 week. While 1.5 % of the families reported the timing of referrals as early, 42 % reported the timing as late or too late. The families of patients with a length of care of less than 4 weeks were more likely to regard the timing of referrals as late or too late. The patients of family members who regarded the timing of referrals as late or too late had a significantly lower perceived quality of care and lower quality of death and dying. Independent determinants of higher likelihoods of perceived late referrals included: frequent visits to emergency departments, patient being unprepared for worsening condition, and patient having concerns about relationship with new doctor. Systematic strategies to overcome the barriers related to perceived late referrals are necessary. <http://link.springer.com/article/10.1007/s00520-014-2397-7>

Of related interest:

- *JOURNAL OF MEDICAL HUMANITIES* | Online – 20 August 2014 – **'Hospice comics: Representations of patient and family experience of illness and death in graphic novels.'** Non-fiction graphic novels about illness and death created by patients and their loved ones have much to teach all readers. However, the bond of empathy made possible in the comic form may have special lessons for healthcare providers who read these texts and are open to the insights they provide. <http://link.springer.com/article/10.1007/s10912-014-9303-7>

## Spiritual care in the training of Bavarian hospice volunteers

*ZEITSCHRIFT FÜR PALLIATIVMEDIZIN*, 2014;15(4):174-179. Spirituality is considered to be an important issue in volunteers' training, urging trainees to reflect on their individual spirituality. However, the approach to spirituality and spiritual care differs extensively. The amount of time spent on discussing spiritual care issues, the use of definitions as well as defining training aims, depends on coordinator, educator, or institution. Two thirds of training institutions hire external teaching staff with a background in pastoral care/theology and/or hospice/palliative care. The results indicate that the meaning of spiritual care is discussed, although there is a lack of clarity in terms of specific spiritual care competencies. A conceptualised curriculum containing themes, methods, and aims is needed in order to prepare the hospice volunteers for their work. This study demonstrates that generating an educational agenda that prepares

volunteers for spiritual care and is sensitive towards their individual perception of spirituality is a complex and challenging task. <http://cat.inist.fr/?aModele=afficheN&cpsidt=28570019>

### Limits and responsibilities of physicians addressing spiritual suffering in terminally ill patients

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 August 2014 – A majority of physicians [i.e., study participants] believe spiritual suffering tends to intensify physical pain and physicians should seek to relieve such suffering. Physicians who believe they should address spiritual suffering just as much as physical pain report more success in relieving patient's suffering. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00410-2/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00410-2/abstract)

**N.B.** German language article.

Of related interest:

- *CRITICAL CARE MEDICINE*, 2014;42(9):1991-2000. **'The association of spiritual care providers' activities with family members' satisfaction with care after a death in the ICU.'** Findings [of this study] provide insight into spiritual care provider activities and provide guidance for interventions to improve spiritual care delivered to families of critically ill patients. [http://journals.lww.com/ccmjjournal/Abstract/2014/09000/The Association of Spiritual Care Providers\\_4.aspx](http://journals.lww.com/ccmjjournal/Abstract/2014/09000/The_Association_of_Spiritual_Care_Providers_4.aspx)

Selected articles on spirituality and end-of-life care noted in past issues of Media Watch:

- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. **'Six understandings of the word 'spirituality' in a secular country.'** Spirituality is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>
- *JOURNAL OF PASTORAL CARE & COUNSELING*, 2014;68(1). **'In the shadow of death: Existential and spiritual concerns among persons receiving palliative care.'** This study explores existential and spiritual concerns from the perspective of people receiving palliative care. Findings reveal existential and spiritual aspects as interconnected and an integral part of the participants' everyday existence. [Noted in Media Watch, 31 March, 2014, #351 (p.9)] <http://journals.sfu.ca/jpcp/index.php/jpcp/article/view/691>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3):111. **'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.'** This issue of the journal gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care. [Noted in Media Watch, 24 June 2013, #311 (p.12)] Contents: <http://www.tandfonline.com/toc/wswe20/current>

Cont.



- *ONCOLOGY NURSING FORUM*, 2014;41(1):33-39. **'Spirituality and uncertainty at the end of life.'** Health professionals must recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the need to frequently assess for spiritual uncertainty. Recommendations are provided in addressing spiritual uncertainty with patients. [Noted in Media Watch, 6 January 2014, #339 (p.13)] <http://ons.metapress.com/content/qu254t23r3126830/>
- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 25 May 2014 – **'Describing spirituality at the end of life.'** Researchers have not been able to agree on a universal definition of spirituality reducing the effectiveness of spiritual research. Analysis [of the literature] identified attributes that most commonly described the essence of spirituality, including meaning, beliefs, connecting, self-transcendence, and value. [Noted in Media Watch, 2 June 2014, #360 (p.12)] <http://wjn.sagepub.com/content/early/2014/05/23/0193945914535509.abstract>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 19 August 2014 – **'Conscience should guide doctors at end-of-life.'** All doctors have the right to follow their conscience when deciding whether to assist dying patients physically or to provide them with the means to end their lives – within the bounds of legislation, delegates to the Canadian Medical Association's annual meeting have voted. As Canada considers changing its laws concerning assisted death, Canada's doctors considered their stance on the second day of the Canadian Medical Association's (CMA). In the end, they voted 91% in favour of allowing individual physicians to follow their conscience in deciding whether or not to provide assistance. The association's current 2007 policy states that physicians should not provide such assistance, but as laws change, most recently Bill 52 in Quebec, CMA decided to revisit its policy. CMA President Dr. Louis Hugo Francescutti says general council's wishes will be discussed by the CMA Board of Directors later this week or in October. "I can't predict what is going to come out of it, but I am hopeful." [https://www.google.ca/?gws\\_rd=ssl#q=forgotton+italian+opera+singers](https://www.google.ca/?gws_rd=ssl#q=forgotton+italian+opera+singers)
- *EVIDENCED BASED NURSING* | Online – 20 August 2014 – **'Legalising assisted suicide: what does the evidence say?'** Whether or not assisted suicide (AS) for the terminally ill (assisted dying) should be legalised in England & Wales was debated in the House of Lords in July. As ever this generated much media interest and a flurry of activity on social media. *The Economist* [magazine] claims most people in the Western world believe AS should be legalised and that the law should change because of this, whereas the *Spectator* [newspaper] argues support for AS can be attributed to the publicity given in recent years to several heart-rending individual cases. Further, a systematic literature review concluded that more than 75% of U.K. doctors oppose the introduction of AS. Do doctors have a greater understanding of the issues involved than the general public? <http://ebn.bmj.com/content/early/2014/08/20/eb-2014-101949.extract>
- *MEDICINE, SCIENCE AND THE LAW* | Online – 19 August 2014 – **'Assisted suicide: Models of legal regulation in selected European countries and the case law of the European Court of Human Rights.'** The current legal regime governing assisted suicide in The Netherlands is described where both euthanasia and assisted suicide have been legalised. This section includes some empirical data on euthanasia and assisted-suicide practices in The Netherlands, as well as a comparison with the current legal legislation in Belgium and Luxembourg. Switzerland is presented as a country where euthanasia is punishable by law but assisted suicide is legally allowed, provided it is not carried out with selfish motives. This section also focuses on the assisted-suicide-related case law of the Swiss Federal Supreme Court and the European Court of Human Rights. The current legal situation regarding assisted suicide in Austria and Germany is described. While the Austrian Penal Code explicitly prohibits assisted suicide, assistance with suicide is not specifically regulated by the German Penal Code. However, medical doctors are not allowed to assist suicides according to the professional codes of conduct drawn up by the German medical associations under the supervision of the health authorities. <http://msl.sagepub.com/content/early/2014/08/19/0025802414540636.abstract>

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/8/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 Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

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 | 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://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>

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