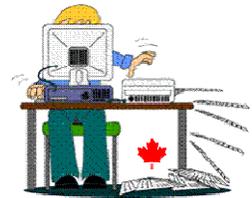


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

End-of-life care for vulnerable populations: Scroll to [Specialist Publications](#) and 'Young adult palliative care: Challenges and opportunities' (p.6), in *American Journal of Hospice & Palliative Medicine*.

## Canada

### Palliative care needs reform, Canadian Medical Association head says

QUEBEC | *The Montreal Gazette* – 8 November 2013 – The head of the Canadian Medical Association [CMA] says everyone in this country deserves the same top-notch compassionate care that his dying mother received during the last days of her life. As more Canadians struggle with end-of-life issues and the evolving needs of an aging population, former Dr. Louis Hugo Francescutti said much can be learned from the exemplary care being given at the West Island Palliative Care Residence where his mother, 82, died peacefully this summer... Unfortunately, palliative care is grossly underfunded and access to quality care is spotty, said Francescutti, who besides being head the powerful doctors' group is an emergency physician in Edmonton. As the CMA gets ready to revisit its stand on medical euthanasia, Francescutti says no one should fear dying alone and in pain. What Canada desperately needs is a national, well-funded strategy on palliative care so that the dying and their families can benefit from expert support as early as possible. <http://www.montrealgazette.com/health/Palliative+care+needs+reform+Canadian+Medical+Association+head+says/9144802/story.html>

Noted in Media Watch, 4 November 2013, #330 (p.1):

- SASKATCHEWAN | *The Regina-Leader Post* – 1 November 2013 – '**National Democratic Party presents bill to improve end-of-life care.**' The New Democratic Party called for a national framework to improve the quality of end-of-life care in Canada. The Party's health critic introduced a private member's bill in the House of Commons calling for a national strategy. <http://www.leaderpost.com/health/presents+bill+improve+life+care/9111548/story.html>

Noted in Media Watch, 21 October 2013, #328 (p.2):

- ONTARIO | *The Windsor Star* – 18 October 2013 – '**Patients demand better end-of-life care.**' With baby boomers entering their senior years ... helping them die well will be as important for physicians as helping them live well. "It's on the front burner now," said Ontario Medical Association president Dr. Scott Wooder, who has made developing a palliative care plan to present to the provincial government the cornerstone of his one-year term in office. <http://www.windsorstar.com/health/Patients+demand+better+life+care/9051499/story.html>

## End-of-life decisions Canadians face go beyond assisted suicide debate

CBC | *The National* (Commentary) – 4 November 2013 – Six months ago, when I [producer Lynn Burgess] started working on 'Last Right,' The National's documentary series on assisted suicide, I sensed a profound public fatigue with the right-to-die issue in Canada. For those in the trenches – on both sides of the debate – the commitment to the cause had never waned. But the issues hadn't changed either, and the public was tired of hearing about it. And so, a decision was made at The National not to debate the issue again, but to bring to our

[television] audience the stories of Canadians and the end-of-life decisions they face. <http://www.cbc.ca/news/canada/end-of-life-decisions-canadians-face-go-beyond-assisted-suicide-debate-1.2335805>

### Specialist Publications

'Physician-assisted suicide: Where is Canada going?' (p.17), in *McGill Journal of Law & Health*.

**N.B.** Part 1 (of 4), 'Last Right: Assisted Suicide in Canada,' was broadcast 28 October 2013. <http://www.cbc.ca/player/News/TV+Shows/The+National/ID/2414736522/> [Noted in Media Watch, 4 November 2013, #330 (p.3)]; Part 2, 'Last Right: Harriet Scott's Choice,' was broadcast 4 November 2013. <http://www.cbc.ca/player/News/TV+Shows/The+National/Health/ID/2415920640/>

## U.S.A.

### Hospice to pay \$3 million for Medicare billings

FLORIDA | CBS 12 News (West Palm Beach) – 5 November 2013 – A central Florida hospice company has agreed to pay \$3 million to resolve allegations that it submitted false claims to Medicare. The U.S. Department of Justice reported that Hospice of the Comforter Inc. had been accused of submitting false claims for hospice services provided to patients who were not eligible for the Medicare hospice benefit. As part of the settlement, the company's former CEO, Robert Wilson, has agreed to a three-year, voluntary exclusion from Medicare, Medicaid and other federal health care programs. The initial allegations arose from a lawsuit filed by a former employee. [http://www.cbs12.com/template/inews\\_wire/wires.regional.fl/3efaf5d6-www.cbs12.com.shtml](http://www.cbs12.com/template/inews_wire/wires.regional.fl/3efaf5d6-www.cbs12.com.shtml)

Noted in Media Watch, 6 May 2013, #304 (p.3):

- *THE WASHINGTON TIMES* | Online – 2 May 2013 – '**Feds sue hospice chain for false Medicare claims.**' The Justice Department filed a lawsuit against the largest for-profit hospice chain in the U.S., charging that the company knowingly submitted false claims to Medicare for services that were not necessary, not actually provided or not performed in accordance with Medicare requirements. <http://www.washingtontimes.com/news/2013/may/2/feds-sue-hospice-chain-false-medicare-claims/>

**N.B.** A representative list of articles on for-profit hospices noted in past issues of Media Watch appears in this issue of the weekly report (pp.3-4).

### End-of-life care policy development

#### Hospitals in state may face new disclosure rules

STATE OF WASHINGTON | *The Seattle Times* – 4 November 2013 – Proposed new rules for hospitals in [the State of] Washington, prompted by concerns about religious restrictions on medical services, would require them to post online their policies on end-of-life care and reproductive-health services. In addition to displaying the policies on their own websites, hospitals would have to submit them to the state Department of Health, which also would post them. In its analysis, the state said the requirement would help consumers make decisions about where to get health care. [http://seattletimes.com/html/localnews/2022192738\\_hospitalrulesxml.html](http://seattletimes.com/html/localnews/2022192738_hospitalrulesxml.html)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- PENNSYLVANIA | *The Morning Call* (Allentown) – 5 November 2013 – **'Pottsville assisted suicide case could affect state end-of-life care laws.'** There's a question that continues to surface in the case of Barbara Mancini, a Philadelphia nurse charged with assisted suicide for giving morphine to her 93-year-old terminally ill father: Why is the Pennsylvania attorney general's office investing its resources to see this case through? Joseph Yourshaw ... had suffered a stroke and was afflicted with renal and heart disease as well as diabetes. Both the prosecution and defense acknowledge that he had the right to self-administer as much morphine as needed to ease his pain even if it could accelerate his death. He had given his daughter authority over his medical decisions and made it clear that he did not wish to be resuscitated. This would have been enough evidence to dismiss the case if it had happened in Washington, Oregon or Vermont. But it happened in Schuylkill County when Pennsylvania is considering but has not enacted a "death with dignity" bill. <http://www.mcall.com/health/mc-barbara-mancini-assisted-suicide-1105-20131104.0.49266.story>

## Specialist Publications

'Characteristics and well-being of informal caregivers: Results from a nationally-representative U.S. survey' (p.7), in *Chronic Illness*.

'An aging population and growing disease burden will require a large and specialized health care workforce by 2025' (p.9), in *Health Affairs*.

'Hospitalizations of nursing home residents in the last year of life: Nursing home characteristics and variation in potentially avoidable hospitalizations' (p.11), in *Journal of the American Geriatrics Society*.

'Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota' (p.12), in *Journal of Palliative Medicine*.

'Pediatric palliative care programs in children's hospitals: A cross-sectional national survey' (p.14), in *Pediatrics*.

## 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.18.

## International

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

#### **Muslim family challenges "do not resuscitate" ruling over gravely ill man**

U.K. | *The Guardian* – 9 November 2013 – A court will this week decide whether a seriously ill Muslim man should not be revived if his condition deteriorates – against the wishes of his family, who say it is God's will that doctors must do all they can to keep him alive. The case, which will be seen in some quarters as a clash between the state and religion, is the first of its kind to deliver a judgment following a supreme court ruling last month that found doctors were right to withdraw treatment from a man in Liverpool. The Muslim man, who has been in hospital for five-and-a-half months since suffering a heart attack, is barely conscious. The National Health Service trust in charge of the hospital where he is being cared for, and which cannot be named for legal reasons, argues that to revive him is not in the man's best interests if his condition worsens. While both sides in the court of protection broadly agree that there is little chance the man's condition will improve, they are opposed over what happens if it deteriorates. <http://www.theguardian.com/lifeandstyle/2013/nov/09/muslim-family-do-not-resuscitate-challenge-liverpool>

#### Specialist Publications

'European perspectives on ethics and law in end-of-life care' (p.9), in *Handbook of Clinical Neurology*.

'A health economics response to the review of The Liverpool Care Pathway' (p.12), in *Journal of Palliative Medicine*.

'Transformations of palliative care in French hospitals: A survey in palliative care units, supportive teams and curative care services' (p.13), in *Médecine Palliative*.

#### **Dying in chains: Why do we treat sick prisoners like this?**

U.K. | *The Guardian* – 9 November 2013 – When Michael Tyrrell's oldest daughter visited her dying father in hospital and saw him handcuffed and chained to a prison guard, she was so shocked that she took photographs. Tyrrell, who was almost halfway through a 29-year sentence for drug smuggling, had throat cancer and pneumonia. He had not been a troublesome prisoner: after 13 years of good behaviour, he was due to be released in 2015. The handcuffs were taken off a few hours before he died the following day. <http://www.theguardian.com/society/2013/nov/09/sick-prisoners-handcuffing-terminally-ill>

Noted in Media Watch, 11 February 2013, #303 (p.8):

- U.K. (ENGLAND & WALES) | *The Guardian* – 5 February 2013 – '**Prisons ombudsman: Dying inmates "inappropriately" handcuffed or chained.**' The Prisons & Probation Ombudsman reported restraints such as escort chains and handcuffs were used on the majority of dying prisoners admitted to a hospital or hospice in the last months of their lives since 2007. <http://www.guardian.co.uk/society/2013/feb/05/prisons-ombudsman-dying-inmates-restrained>

**N.B.** Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.18.

## Music gives people a voice when words fail them at the end of their lives

U.K. | *The Guardian* – 5 November 2013 – In palliative care, when clients and their therapists get to know one another they do so with a shared knowledge, whether voiced or not, that while both of them are going to die eventually, at least one of them is going to be doing it very soon. The relationship between client and therapist is always unique. And whatever you may think about "therapy," all (or most) of it is based on a fundamental human process. Where there is trust and dialogue, there is an opportunity for creativity and healing. But how do you talk about dying when you know that it's about to happen? Are you frightened, angry, anxious or depressed? Are you full of remorse? Or are you relieved? What will you leave behind? Who will you leave behind? <http://www.theguardian.com/science/2013/nov/05/music-therapy-palliative-care>

Noted in Media Watch, 4 February 2013, #291 (p.13, under 'Worth Repeating'):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2003;20(2):129-134. **'Music therapy with imminently dying hospice patients and their families: Facilitating release near the time of death.'** When loved ones are anticipating the patient's impending death, they may find it difficult to express feelings, thoughts, and last wishes. Music therapy is a service modality that can help to facilitate such communication between the family and the patient who is actively dying... <http://ajh.sagepub.com/content/20/2/129.short>

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

#### Study shows people in Cambridge are least likely to die in hospital

U.K. (ENGLAND) | *Cambridge News* – 4 November 2013 – People who live in Cambridge are least likely to end their lives in hospital, a study has revealed.<sup>1</sup> Between 2009 and 2011, just 37.9% of people in Cambridge died in hospital – with more and more people dying either at home, in a care home, or inside a hospice. As a comparison, people who live in Waltham Forest in North East London are most likely to die in hospital, according to the study, as between 2009 and 2011 69.1% of residents there did. <http://www.cambridge-news.co.uk/Health/Wellbeing-and-fitness/Study-shows-people-in-Cambridge-are-least-likely-to-die-in-hospital-20131104060000.htm>

1. 'New report from Public Health England shows improvements in end of life care,' National End of Life Care Intelligence Network, 4 November 2013. [Noted in Media Watch, 4 November 2013, #330 (p.7)] <http://www.endoflifecare-intelligence.org.uk/news/>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | *EuroNews* – 8 November 2013 – **'Belgian politicians discuss legalising euthanasia for sick children.'** The Belgian parliament is debating a controversial new bill, which would extend the country's law on euthanasia to terminally ill people aged under 18. It would become the only country in the world to grant children the right to choose to die. Euthanasia for adults was legalised in Belgium in 2002. Advocates argue that euthanasia for minors, with the consent of their parents, should be an option in exceptional cases. A group of paediatricians published an open letter in Belgian newspapers this week asking politicians to support the bill, but many MPs remain bitterly opposed. <http://www.euronews.com/2013/11/08/belgian-politicians-discuss-legalising-euthanasia-for-sick-children/>

#### Quotable Quotes

*Once you witness an injustice, you are no longer an observer but a participant.* June Callwood (1924-2007), Canadian journalist, author and social activist, and one of the founders of Casey House, a Toronto Hospice for people living with AIDS.

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

### Young adult palliative care: Challenges and opportunities

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 November 2013 – This review examines the current data pertinent to young adult palliative care and discusses the challenges and opportunities where palliative medicine can enhance the care provided to this growing and vulnerable population. From the data, two primary themes emerged 1) ongoing young adult development not only generates unique biologic disease burdens and clinical treatment options but also requires frequent assessment and promotion, and 2) binary health care systems often leave young adults without access to developmentally appropriate health care. <http://ajh.sagepub.com/content/early/2013/11/06/1049909113510394.abstract>

Noted in Media Watch, 21 October 2013, #328 (p.13):

- *PALLIATIVE MEDICINE* | Online – 18 October 2013 – **'Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.'** Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Little is known about their transition experiences or how children's hospices can support a young adult population during/following transition. Transition planning [among the study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. <http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract>

Noted in Media Watch, 3 December 2012, #282 (p.7):

- U.K. | National Council for Palliative Care – 27 November 2012 – **'Call for better support for seriously ill young people moving into adult care.'** The All Party Parliamentary Group for Hospice & Palliative Care heard how Government, the National Health Service and professionals can improve care and support to young people with life-limiting and life-threatening conditions. <http://www.ncpc.org.uk/news/call-better-support-seriously-ill-young-people-moving-adult-care>

### The role of rehabilitation in palliative care services

*AMERICAN JOURNAL OF PHYSICAL MEDICINE & REHABILITATION* | Online – 5 November 2013 – In January 2013, the U.S. District Court for the District of Vermont approved a settlement agreement in the case of *Jimmo vs. Sebelius* that clarified the previously applied Improvement Standard, thereby making integration of rehabilitation into palliative care possible. The Improvement Standard was the narrowly interpreted Medicare guideline that restricted reimbursement of rehabilitation services to patients who demonstrated clear restorative potential. Although permitting services for new and acute conditions, this policy interpretation effectively excluded maintenance therapy to prevent further functional deterioration. The approved settlement agreement clarifies the Medicare guidelines to allow reimbursement of rehabilitation services for patients who require a level of skilled care to prevent or slow further deterioration in their critical condition... [http://journals.lww.com/ajpmr/Citation/publihahead/The\\_Role\\_of\\_Rehabilitation\\_in\\_Palliative\\_Care.99367.aspx](http://journals.lww.com/ajpmr/Citation/publihahead/The_Role_of_Rehabilitation_in_Palliative_Care.99367.aspx)

Noted in Media Watch, 23 April 2012, #250 (pp.7-8):

- *CHRONIC RESPIRATORY DISEASE* | Online – 12 April 2012 – **'Pulmonary rehabilitation and palliative care in COPD: Two sides of the same coin?'** Pulmonary rehabilitation and palliative care are remarkably similar in many respects. Both utilize a multidisciplinary team that focuses on the specific needs of the individual patient. <http://crd.sagepub.com/content/early/2012/04/03/1479972312441379.abstract>

Cont.

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 13 April 2012 – '**Palliative care and rehabilitation for stroke survivors: Managing symptoms and burden, maximizing function.**' Like palliative care, rehabilitation services are best incorporated across the continuum of care, starting in the acute post-stroke period as soon as the patient is medically stable. <http://www.springerlink.com/content/k0j249h15qw24452/fulltext.pdf>

Noted in Media Watch, 21 February 2011, #189 (p.10):

- *GERIATRIC REHABILITATION*, 2011;27(1):229-235. '**Geriatric rehabilitation and palliative care: Opportunity for collaboration or oxymoron?**' There has been much collaboration among clinicians in palliative care and several medical specialties, including physical medicine and rehabilitation which focuses on restoring function, coping with disability, and decreasing the illness burden of chronic disease. There is a natural compatibility between these two fields. [http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2011/01000/Geriatric\\_Rehabilitation\\_and\\_Palliative\\_Care\\_5.aspx](http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2011/01000/Geriatric_Rehabilitation_and_Palliative_Care_5.aspx)

### Medical futility procedures: What more do we need to know?

*CHEST*, 2013;144(5):1707-1711. Unilateral medical futility policies, which allow health-care providers to limit or withdraw life-sustaining treatment over patient or surrogate objections, are increasingly designed around a procedural approach. Medical or ethics committees follow a pre-specified process, the culmination of which is a justified decision about whether ongoing treatment should be withheld or withdrawn. These procedures have three stages. First, health-care providers must decide to refer patients for consideration of whether ongoing treatment is futile. Second, the committees involved must decide whether ongoing treatment is actually futile. Third, there is a clinical outcome that often is, but not always, patient death. The authors review the available data on procedure-based futility policies, arguing that there is limited information on their potential harms and how these harms are distributed. They consider the ethical implications of policy-making under informational uncertainty, invoking the precautionary principle – in the absence of clear data, if a policy has significant risk of significant harm, the burden of proof that it is not harmful falls on those recommending the policy – as the guiding moral standard for hospitals and professional organizations considering whether to adopt a procedural approach to medical futility. <http://journal.publications.chestnet.org/article.aspx?articleid=1761255>

### Characteristics and well-being of informal caregivers: Results from a nationally-representative U.S. survey

*CHRONIC ILLNESS* | Online – 23 October 2013 – The goal of this study was to characterize caregivers' socio-demographics, health, and well-being. The authors identified adults who provided informal care to friends or family members with a health problem, long-term illness, or disability. A total of 111,156 ... participants reported being caregivers, most of whom reported good mental health (90%), good general health (83%), and adequate social support (77%). Caregivers reported worse mental health than non-caregivers, but better general health. Men caregivers reported somewhat worse overall health than non-caregivers, whereas women reported better overall health. <http://chi.sagepub.com/content/early/2013/10/11/1742395313506947.abstract>

#### The Caregiver Well-Being Scale: Developing a short-form rapid assessment instrument

*HEALTH SOCIAL WORK* | Online – 30 October 2013 – This article describes development of a 16-item version of the Scale and discusses the methods used in testing the ... properties of the shortened version in a sample of 493 family caregivers. It concludes the shortened version is valid, reliable, and easier to use than the original version but has the same goals and continues to be applicable in research and clinical settings. <http://hsw.oxfordjournals.org/content/early/2013/10/30/hsw.hlt019.abstract>

Cont.

Of related interest:

- *GENERAL HOSPITAL PSYCHIATRY* | Online – 6 November 2013 – '**Determinants of a hopeful attitude among family caregivers in a palliative care setting.**' Healthcare providers need to pay attention to the psychological vulnerability of caregivers to encourage a hopeful attitude. Additional studies of longitudinal design for hopeful attitude throughout the trajectory of palliative care are necessary. [http://www.ghpjournal.com/article/S0163-8343\(13\)00312-5/abstract](http://www.ghpjournal.com/article/S0163-8343(13)00312-5/abstract)
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 31 October 2013 – '**Differential impacts of care-giving across three caregiver groups in Canada: End-of-life care, long-term care and short-term care.**' EOL [end of life] caregivers, overall, experienced greater negative impacts, including negative health outcomes, than did long-term or short-term caregivers. This provides the evidence for the assertion that EOL care-giving is the most intense type of care-giving, potentially causing the greatest caregiver burden; this is shown through the greater negative impacts experienced by the EOL caregivers when compared with the short-term and long-term caregivers. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12075/full>
- *PALLIATIVE MEDICINE* | Online – 7 November 2013 – '**Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature.**' This review identified a significant gap in the evidence base regarding the economic implications of providing care to a family member within a palliative care context. Economic costs and implications are likely to be significant, and research to address this gap is urgently needed, particularly given policy initiatives in a number of developed countries to move the provision of palliative and end-of-life care from hospital to community settings. <http://pmj.sagepub.com/content/early/2013/11/05/0269216313510588.abstract>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 4 November 2013 – '**Living through the end: The phenomenon of dying at home.**' 'The Meaning of Being at Home' revealed that for study participants, remaining home with hospice provided a richly familiar, quiet, and safe environment for being together over time and focusing on relationships. Exemplars included "Driving Her Own Course" and "Not Being a Burden." Salient themes encompassed patient and family characteristics, support, emotions, the value of time, and aspects of the healthcare team. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9063810>

### **Terminally ill patients who are supported by religious communities are more likely to receive aggressive end-of-life care rather than hospice care**

*EVIDENCE-BASED NURSING* | Online – 4 November 2013 – In this study, patients with higher perceived spiritual support from religious communities were less likely to receive hospice care, more likely to receive aggressive end-of-life interventions and were more likely to die in ICUs. For ethnic minorities and those with high religious coping, this effect was more pronounced. Those receiving additional spiritual support from the medical team had higher rates of hospice use, fewer aggressive interventions and fewer admissions to ICU. End-of-life care discussions were associated with fewer aggressive treatments. <http://ebn.bmj.com/content/early/2013/11/01/eb-2013-101509.extract>

Noted in Media Watch, 23 March 2009, #89 (p.9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 18 March 2009 – '**Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer.**' Despite evidence that religiousness is associated with preference for aggressive end-of-life care, it is unknown if religious factors influence the actual intensity of care received near death. The authors hypothesized that patients who rely heavily upon their religious faith to cope with advanced cancer would be more likely to receive intensive medical care near death. <http://jama.jamanetwork.com/article.aspx?articleid=183578&resultClick=3>

## European perspectives on ethics and law in end-of-life care

*HANDBOOK OF CLINICAL NEUROLOGY*, 2013;118(13):155-165. End-of-life care practices and attitudes in Europe are highly diverse, which is unsurprising given the variety of cultural and religious patterns across this region. The most marked differences are in the legal and ethical stances towards assisted dying, although there are also variations in limitation of life-sustaining treatment and the authority of advance directives to decline such treatment. Palliative care has made a rapid and impressive development in many European countries over the last decade, and alleviating symptoms at the end of life is permitted, even if the drugs used might (in the rare case) not only relieve suffering but also shorten life. Fueled by the politically led process of European harmonization, future policies and laws on end-of-life care might converge. However, at the base of many ethical conflicts there remain deeply rooted differences about promoting the sanctity of life, eradicating suffering, and respecting patients' autonomous wishes. <http://www.sciencedirect.com/science/article/pii/B9780444535016000135>

Representative list of articles on the provision and delivery of end-of-life care in the European Union noted in past issues of Media Watch:

- **'Comparison of legislation, regulations and national health strategies for palliative care in seven European countries: A descriptive study,'** *BMC Health Services Research*, published online 17 July 2013. [Noted in Media Watch, 29 July 2013, #316 (p.8)] <http://www.biomedcentral.com/content/pdf/1472-6963-13-275.pdf>
- **'Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project),'** *Palliative Medicine*, published online 16 July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.13)] <http://pmj.sagepub.com/content/early/2013/07/15/0269216313493952.abstract>
- **'Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe,'** *BMC Family Practice*, published online 3 June 2013. [Noted in Media Watch, 10 June 2013, #309 (p.8)] <http://www.biomedcentral.com/content/pdf/1471-2296-14-73.pdf>
- **'Atlas of palliative care in Europe 2013,'** *European Association for Palliative Care*, published online 29 May 2013. [Noted in Media Watch, 3 June 2013, #308 (p.10)] [http://issuu.com/universidaddenavarra/docs/atlas\\_europa\\_full\\_edition](http://issuu.com/universidaddenavarra/docs/atlas_europa_full_edition)
- **'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,'** *Psycho-Oncology*, published online 18 March 2013. [Noted in Media Watch, 25 March 2013, #298 (p.11)] <http://onlinelibrary.wiley.com/doi/10.1002/pon.3283/abstract>
- **'Learning from the public: Citizens describe the need to improve end-of-life care access, provision and recognition across Europe,'** *European Journal of Public Health*, published online 13 March 2013. [Noted in Media Watch, 18 March 2013, #297 (p.9)] <http://eurpub.oxfordjournals.org/content/early/2013/03/13/eurpub.ckt029.abstract>

## An aging population and growing disease burden will require a large and specialized health care workforce by 2025

*HEALTH AFFAIRS*, 2013;32(11):2013-2020. As the U.S. population ages, the increasing prevalence of chronic disease and complex medical conditions will have profound implications for the future health care system. Based on changing demographic characteristics and expanded medical coverage under the Affordable Care Act, the authors project that the demand for adult primary care services will grow by approximately 14% between 2013 and 2025. Failure to train sufficient numbers and the correct mix of specialists could exacerbate already long wait times for appointments, reduce access to care for some of the nation's most vulnerable patients, and reduce patients' quality of life. <http://content.healthaffairs.org/content/32/11/2013.abstract>

## Ageing prisoners in Ireland: Issues for probation and social work

*IRISH PROBATION JOURNAL*, 2013;10(1): 203-215. Interest in older prisoners is gaining momentum, and this is reflected in research undertaken in the U.S. and the U.K. over the past decade. Studies on this sub-population of prisoners have focused on prevalence, profile, specific health and social needs, and raised questions about how different sectors of the criminal justice sector should be adjusting policy and practice in response. This paper presents a review of the literature relating to older male prisoners alongside findings from a research study undertaken in an Irish prison in 2011. This study ... sought to provide a preliminary description of ageing male prisoners and their specific needs in Ireland. The implications ... for social work/probation policy and practice are considered, and directions for future service provision are recommended. Insights into the circumstances of older men imprisoned in Ireland are offered to the various professionals (including probation service/social work staff) working in the criminal justice system who strive towards providing

"prisoner well-being" and a "duty of care."  
<http://www.pbni.org.uk/archive/Guide%20to%20Information/The%20services%20we%20offer/Other%20Publications/IPJ%20latest/IPJ%20Vol%2010.pdf#page=205>

### Extract from *Irish Probation Journal* article

The increase in terminally ill older prisoners has been noted in the U.S. and the U.K., and hospice programmes have become a feature of service provision in many prisons. Accounts are given of these men experiencing increased isolation while ill, and "a dread of dying in prison." It is thought that this specific health need could pose real challenges for the various service providers working in Irish prisons as the older prisoner population increases.

**N.B.** Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.18.

## Introducing advance care planning in Japan

### Depression screening and possible applications of advance care planning

*JAPANESE JOURNAL OF GERIATRICS*, 2013;50(3):319-322. Depression screening was conducted to determine the health status of community-dwelling elderly individuals, and the concept of advance care planning was introduced. While depression screening among the elderly often uses the Geriatric Depression Scale, a single question regarding depressive mood also provides a valid measure of depression in elderly persons. Depression is associated with lower activities of daily living, competence, and subjective quality of life among the elderly living in Vietnam and Indonesia, as well as in Japan. Advance care planning is a process of discussion between individuals and their care providers to make decisions about future care preferences and priorities, while they are still capable. If they wish, they may prepare an advance directive to inform others about their decisions and best interests, such as a written advance decision to refuse treatment and/or appointment of a person with lasting powers of attorney. The purpose of advance care planning is to enable elderly persons to receive better end-of-life care. To promote introduction of advance care planning in Japan, voluntary discussion among family members should be encouraged.  
<http://europepmc.org/abstract/MED/23979330/reload=0;jsessionid=YNVlr8Jxtm9qGOpWSLzN.50>

Of related interest:

- **BMC PALLIATIVE CARE** | Online – 4 November 2013 – '**Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them: A systematic literature review.**' Discussing end of life preferences can be beneficial, and it is thought that the best time to have these conversations is usually when people are well. This review aims to establish current evidence for the effectiveness of community-based interventions to encourage people to consider, and to discuss with those closest to them, their preferences for end of life care or what they wish to happen after their death. <http://www.biomedcentral.com/content/pdf/1472-684X-12-40.pdf>

## Hospitalizations of nursing home residents in the last year of life

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 5 November 2013 – Almost 50% of hospital admissions for nursing home residents in their last year of life were for potentially avoidable conditions, costing Medicare \$1 billion. Five conditions were responsible for more than 80% of potentially avoidable hospitalizations. Quality measures ... showed significant variation. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12517/abstract;jsessionid=82436246F383313A675FAF118DF2944B.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

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

- *NEWS MEDICAL* | Online – 25 October 2013 – '**OPTIMISTIC study aims to reduce avoidable hospitalizations, increase access to palliative care.**' The OPTIMISTIC study, developed by research-clinicians from Indiana University and the Regenstrief Institute to improve health care, reduce avoidable hospitalizations, and increase access to palliative care, is now underway in nineteen nursing facilities throughout Central Indiana. <http://www.news-medical.net/news/20131025/OPTIMISTIC-study-aims-to-reduce-avoidable-hospitalizations-increase-access-to-palliative-care.aspx>

Noted in Media Watch, 21 November 2011, #228 (p.11):

- *PROGRESS IN PALLIATIVE CARE*, 2011;19(6):291-298. '**A narrative literature review of the evidence regarding the economic impact of avoidable hospitalizations amongst palliative care patients in the U.K.**' The evidence base ... relating to the economic impact of avoidable admissions in palliative care is limited. The feasibility of avoiding such admissions and the full economic consequences of such changes have not been clearly demonstrated. <http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000006/art00001>

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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.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 November 2013 – **'Racial disparities in receipt of hospice services among nursing home residents.'** Compared to White nursing home residents, Black, Hispanic and Asian residents who received hospice services were significantly less likely overall to have documented advance directives. All racial groups were also more likely to experience hospitalization, regardless of whether they had a documented "do not hospitalize" order. As nursing homes become more diverse, recognizing differences in hospice use and end-of-life planning will continue to increase in importance. <http://ajh.sagepub.com/content/early/2013/11/07/1049909113511144.abstract>

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

##### **A health economics response to the review of The Liverpool Care Pathway**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 November 2013 – In 2011 the Palliative Care Funding Review highlighted concerns about the funding, provision, and quality of care at the end of life [in the U.K.]. Two years on, an independent review of The Liverpool Care Pathway – prompted by a storm of negative media coverage – has raised concerns around a lack of funding, availability of support for the dying and their relatives, and patient centered care. There are recommendations to increase funding through a national tariff for palliative care services, address inconsistencies, and replace the Liverpool Care Pathway with individual end-of-life care plans. This paper explores the economic implications of the review's recommendations and links these to inadequacies with the current economic framework currently recommended for use in the U.K. by the National Institute for Health and Care Excellence, before highlighting aspects of ongoing research aimed at addressing these inadequacies. While there is a need for increased funding in the short term (highlighted in recent reviews), increasing funding to services that have little evidence base appears to be an irresponsible long-term strategy. Hence there should also be increased investment in research and increased emphasis in particular on developing economic tools to evaluate services. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0464>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online – 8 November 2013 – **'Patients' actual care pathways often differ markedly from doctors' perceptions.'** Seeing care through the eyes of patients is demanding and sometimes demoralising to clinicians, a recent conference at the King's Fund in London heard. The clinician's idealised view of the patient's care pathway had little in common with the actual experience of patients, especially those with a chronic illness, whose pathway typically involved occasional brief encounters with clinicians separated by many days and weeks, speakers said. Even acute interventions that cured a patient's illness could consist of more sandwich than filling. <http://www.bmj.com/content/347/bmj.f6728>

##### **Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 November 2013 – Hospice staff reported high levels of stress, with a small but significant proportion reporting moderate-to-severe symptoms of depression, anxiety, compassion fatigue, and burnout. Staff reported managing their stress through physical activity and social support, and they suggested that more opportunities to connect with coworkers and to exercise could help decrease staff burnout. Poor mental health places staff at risk for burnout and likely contributes to staff leaving hospice care; this is a critical issue as the profession attempts to attract new staff to meet the expanding demands for hospice care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0202>

Cont.

Noted in Media Watch, 5 August 2013, #317 (p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 4 August 2013 – **'The experiences, coping mechanisms and impact of death and dying on palliative medicine specialists.'** Despite the stressors and potential for burnout and compassion fatigue, [study] participants employed strategies that enhanced meaning-making and emphasized the rewards of their work. The consequences of work stressors cannot be underestimated in the practice of palliative care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8936522&fulltextType=RA&fileId=S1478951513000138>

Noted in Media Watch, 18 March 2013, #317 (p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2013;15(2):99-106. **'Do nurses who care for patients in palliative and end-of-life settings perform good self-care?'** This article shares descriptions of self-care among End-of-Life Nursing Education Consortium-trained nurses. [http://journals.lww.com/jhpn/Abstract/2013/04000/Do\\_Nurses\\_Who\\_Care\\_for\\_Patients\\_in\\_Palliative\\_and.8.aspx](http://journals.lww.com/jhpn/Abstract/2013/04000/Do_Nurses_Who_Care_for_Patients_in_Palliative_and.8.aspx)

### **Transformations of palliative care in French hospitals: A survey in palliative care units, supportive teams and curative care services**

*MÉDECINE PALLIATIVE* | Online – 8 November 2013 – The principal results [of this study] highlight a diversity of working configurations, reflecting the heterogeneity of the palliative care world (as concerns both its conceptions and practices of end-of-life care), and show that the debates which run through the palliative care teams tend not only to persist, but also to become more acute, as this activity unfolds in an open environment. If it is possible to act on certain factors to improve the dissemination of the "palliative approach" in hospital services (such as by training health care providers or by reorganizing the services), two other frequently underestimated factors tend to discourage changes in practice: the limited time in which the staff has to perform multiple tasks and the actual capacity of each professional "to care for the dying." <http://www.sciencedirect.com/science/article/pii/S1636652213001104>

### **Opportunities and barriers to forming a professional identity: Communities of practice within U.K. funeral directing**

*MORTALITY*, 2013;18(4):358-375. This paper examines perceptions of performance, alongside issues of mistrust and resistance to change. Data will show that participants conveyed a situation of competing forces in terms of a hierarchical structure within the industry that perpetuates a lack of incentive to invest in education and training. At the same time, a new generation of staff is developing an alternative vision of funeral directing, which includes wider public recognition of their skills. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2013.852527>

### **Hospice transfer for patients at the end of life: Part 1**

*NURSING STANDARDS*, 2013;28(8):42-48. The article describes a hospice transfer service developed by staff at a district general hospital and a hospice to improve end of life care for patients who otherwise might die in the hospital's medical assessment unit. It discusses the care received by patients in both settings, and the practicalities of offering patients the option of rapid transfer to the hospice for end of life care, where the emphasis of care is on palliation not acute intervention. Part 2 explores the ethical, legal and practical considerations involved in developing the service.<sup>1</sup> <http://rcnpublishing.com/doi/abs/10.7748/ns2013.10.28.8.42.e7756?prevSearch=fulltext%3A%28hospice%29&searchHistoryKey=>

1. 'Hospice transfer for patients at the end of life: Part 2,' *Nursing Standards*, 2013;28(8):44-49. <http://rcnpublishing.com/doi/abs/10.7748/ns2013.10.28.9.44.e7755?prevSearch=fulltext%3A%28hospice%29&searchHistoryKey=>

## **The clinical, operational, and financial worlds of neonatal palliative care: A focused ethnography**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 30 October 2013 – Due to multiple issues, integrated interdisciplinary palliative care teams in a neonatal intensive care unit may be difficult to access, sometimes fail to be implemented, or provide inconsistent or poorly coordinated care. When implementing an effective institution-specific neonatal palliative care program, it is critical to include stakeholders from the clinical, operational, and financial worlds of healthcare. In this study, researchers sought to gain a multidisciplinary perspective into issues that may impact the implementation of a formal neonatal palliative care program at a tertiary regional academic medical center. Healthcare professionals [i.e., study participants] described experiences that influenced their views on neonatal palliative care. Key themes included: a) uniqueness of neonatal palliative care; b) communication and conflict among providers; c) policy and protocol discrepancies; and, d) lack of administrative support. The present study highlighted several areas that are challenging in the provision of neonatal palliative care. Study findings underscored the importance of recognizing and procuring resources needed simultaneously from the clinical, operational, and financial worlds in order to implement and sustain a successful neonatal palliative care program. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9060201>

Noted in Media Watch, 5 August 2013, #317 (p.6):

- *ARCHIVES OF DISEASE IN CHILDHOOD: FETAL & NEONATAL EDITION* | Online – 30 July 2013 – **'End-of-life care in Toronto [Canada] neonatal intensive care units: Challenges for physician trainees.'** [Study] participants identified six domains of challenge in end of life care: 1) withdrawal of life-sustaining treatment based on poor outcome; 2) explaining "no resuscitation options" to parents; 3) clarifying "do not resuscitate" orders; 4) empowering families with knowledge and shared decision-making; 5) dealing with different cultures; and, 6) managing personal internal conflict. <http://fn.bmj.com/content/early/2013/07/30/archdischild-2012-303000.abstract>

Noted in Media Watch, 3 December 2012, #282 (pp.13-14):

- *SEMINARS IN FETAL & NEONATAL MEDICINE* | Online – 22 November 2012 – **'Evidence-based comfort care for neonates towards the end of life.'** When examining the evidence base for most interventions, it is lacking – but this is not unique to this aspect of neonatal care. <http://www.sciencedirect.com/science/article/pii/S1744165X1200131X>

## **Pediatric palliative care programs in children's hospitals: A cross-sectional [U.S.] national survey**

*PEDIATRICS* | Online – 4 November 2013 – The authors surveyed 226 hospitals as identified by the National Association of Children's Hospitals and Related Institutions. The survey instrument gathered data about whether their institution had a PPC [pediatric palliative care] program, and for hospitals with programs, it asked for a wide range of information including staffing, patient age range, services provided, and financial support. Of the 162 hospitals that provided data (71.7% response rate), 69% reported having a PPC program. The rate of new program creation peaked in 2008, with 12 new programs created that year, and 10 new programs in 2011. Most offer only inpatient services, and most only during the work week. The number of consults per year varied substantially across programs, and was positively associated with hospital bed size and number of funded staff members. PPC programs report a high level of dependence on hospital funding. <http://pediatrics.aappublications.org/content/early/2013/10/30/peds.2013-1286.abstract>

Cont.

Noted in Media Watch, 4 November 2013, #330 (p.13):

- *PEDIATRICS* | ONLINE – 28 OCTOBER 2013 – '**Pediatric palliative care and hospice care commitments, guidelines and recommendations.**' Guidelines and recommendations include ensuring all large health care organizations serving children with life-threatening conditions have dedicated interdisciplinary pediatric palliative care and pediatric hospice care teams which should develop collaborative relationships between hospital- and community-based teams. <http://pediatrics.aappublications.org/content/early/2013/10/23/peds.2013-2731.abstract>

Of related interest:

- INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK | Online – 8 November 2013 – '**Significant numbers of sick children suffer and die without access to palliative care.**' Less than 1% of children in Kenya and less than 5% of children in South African and Zimbabwe who are in need of palliative care are able to access these services. New research reveals an enormous gap between the need and provision of specialised children's palliative care services across these three countries. <http://www.icpcn.org/significant-numbers-of-sick-children-suffer-and-die-without-access-to-palliative-care/>
- *MEDSCAPE MEDICAL NEWS* | Online – 8 November 2013 – '**Children, parents open to palliative care talk at diagnosis.**' Children with a cancer diagnosis and their parents are more receptive to talking about palliative care at the time of diagnosis than anticipated, suggest preliminary findings from a multi-institutional study. There is a growing consensus that it is important to provide early palliative care for cancer patients. However ... palliative care remains underutilized in pediatric oncology. <http://www.medscape.com/viewarticle/814071>
- *PROGRESS IN PALLIATIVE CARE* | Online – 4 November 2013 – '**Paediatric palliative care in Malaysia: Survey of knowledge base and barriers to referral.**' Paediatric palliative care is underdeveloped, but there is recent increasing awareness and interest in this speciality. In 2012, the Health Minister of Malaysia launched an initiative to support a nationwide provision of this service. This study aims to explore the knowledge and practice of healthcare providers and their barriers to referral for palliative care prior to development of a nationwide service. [http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc\\_188](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_188)

### **Supporting adults with intellectual and developmental disabilities and communication disorders to express end-of-life wishes**

*PERSPECTIVES ON GERONTOLOGY*, 2013;18(3):380-387. This article addresses end-of-life communication issues faced by adults with intellectual and developmental disabilities, their caregivers, and medical professionals. The author has worked with adults with intellectual and developmental disabilities and communication deficits for many years. Her goal is to share patient experiences to illustrate strategies that can improve communication for these individuals at end of life. <http://div15perspectives.asha.org/content/18/3/80.abstract>

**N.B.** This issue of the journal includes several articles on different aspects of end-of-life care. Contents page: <http://div15perspectives.asha.org/content/current>

Noted in Media Watch, 22 April 2013, #302 (p.9):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES*, 2013;26(3):215-230. '**The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities.**' This paper looks at the experiences of staff in dealing with issues of death and dying. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12024/abstract>

**N.B.** This issue of the journal focuses on dying and death, and people living with intellectual disabilities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>

## Research with Australia's Aboriginal and Torres Strait Islander communities

### Respectful listening and reflective communication from the heart and with the spirit

*QUALITATIVE SOCIAL WORK* | Online – 31 October 2013 – My experience as a researcher in the *Seasons for Healing* project gave me an opportunity to consider this question.<sup>1</sup> Using an interpretive ethnographic approach, it became evident that I needed to recognize participants as whole people, not as mere instruments on which to conduct research, and that this engagement needed to occur in a relational way. Although I was an "outsider," I was able to engage in *dadirri*, the process of listening with one's ear but also with the heart. At the cultural interface, it was important to recognize the validity of different types of knowledge and that research should be conducted ethically and respectfully so that the interests of Indigenous communities were considered. Indeed, it was reinforced to me that there were different ways of knowing and each type of knowledge needed to be accorded validity. Respectful listening and reflective communication enabled me to experience life and culture from a different perspective and to gain insight via a different paradigm. <http://qsw.sagepub.com/content/early/2013/09/27/1473325013508596.abstract>

1. *Seasons for Healing* project website: <http://www.mackillopfoundation.org.au/projects/seasons-for-healing-in-apy-lands-training-delivery-by-good-grief/>

### Lessons on stigma: Teaching about HIV/AIDS

*TEACHING SOCIOLOGY* | Online – 28 October 2013 – Teaching about the sociology of HIV/AIDS involves teaching about the causes and effects of stigma. The authors describe a Sociology of HIV/AIDS course at the University of Alabama in which stigma reduction was assessed as a primary objective. The syllabus involved theory-based instruction, class visits, service learning, and student research on community attitudes toward HIV/AIDS. They report on how stigma affected the service learning and other elements of the course, calling for adjustments to our pedagogical approach. The authors also report how the course was evaluated in a pre-test/post-test assessment on attitudes toward people living with HIV/AIDS [PLWHA] (enacted stigma) and hypothetical reactions to being diagnosed with HIV (felt stigma). The results indicated greater tolerance for PLWHA following the class but also greater awareness of HIV stigma and its outcomes. They offer recommendations to help instructors avoid stigma-related materials and events that could jeopardize service learning and course objectives for sensitive topics such as HIV/AIDS. <http://tso.sagepub.com/content/early/2013/10/25/0092055X13510412.abstract>



### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF FORENSIC & LEGAL MEDICINE* | Online – 4 November 2013 – '**Assisted suicide in the care of mentally ill patients: The Lucio Magri's case.**' A year after Mario Monicelli's suicide, the death of another famous person in Italy, Lucio Magri, reawakened the Italian debate on social, ethical and juridical issues in end-of-life decisions. Unlike Monicelli, Lucio Magri decided to end his own life in Switzerland with the help of a physician because his mental illness rendered his life unbearable. Both Monicelli and Magri suffered from a severe depression. The authors analyze the ethical issues regarding the right to die for mentally ill patients and neurological disabled patients, discussing the decision-making autonomy in persons suffering from severe depression. The role of the psychiatry in the management of end of life decision requests is considered along with pros and cons of suicide prevention and rationale suicide. <http://www.sciencedirect.com/science/article/pii/S1752928X13002916>

Cont.

- *McGILL JOURNAL OF LAW & HEALTH* | Online – 1 November 2013 – '**Physician-assisted suicide: Where is Canada going?**' On 10 October 2013 the British Columbia Court of Appeal (BCCA) overturned a trial court decision that found the criminal ban on physician-assisted suicide to be unconstitutional. The BCCA upheld the ban, basing its decision on a previous Supreme Court of Canada case, *Rodriguez v. British Columbia (Attorney General)*, decided in 1993. [http://mjhl.mcgill.ca/blog.php?blog\\_id=92](http://mjhl.mcgill.ca/blog.php?blog_id=92)
  - *MÉDECINE PALLIATIVE* | Online – 5 November 2013 – '**Family negotiations in assisted suicide in Switzerland.**' The practice of assisted suicide is tolerated in Switzerland and a number of associations are involved in providing assisted suicide to patients. It is a phenomenon that has been insufficiently investigated from the perspective of close relatives, even though they could be deeply involved during decision making and afterwards. To investigate the experience of family members who have participated in an assisted suicide, the authors conducted 30 semi-structured interviews to bereaved relatives in several French-speaking and Italian speaking cantons in Switzerland. This article presents preliminary results. <http://www.sciencedirect.com/science/article/pii/S1636652213001116>
  - *MEDICAL LAW INTERNATIONAL* | Online – 23 October 2013 – '**Comparative reflections upon the Assisted Dying Bill 2013: A plea for a more European approach.**' Whilst assisted dying remains topical, a number of courts and committees have considered the potential legalisation of active voluntary euthanasia, and/or physician-assisted suicide, but concluded legalisation should not occur. Significantly this conclusion is attributed not simply to concern to uphold the sanctity of life, but more commonly the reasons given stress it would simply not be possible to legalise assisted dying whilst incorporating sufficient safeguards within the legislation to protect the vulnerable. This article considers the way in which the principle of dignity has been asserted to demand both a person has a right to die with dignity (where dignity is constructed as entailing a choice to die with medical assistance) and the prohibition of assisted dying be maintained in order to ensure the dignity of the person, regardless of whether that person is disabled or terminally ill. It assesses the validity of that argument by evaluating... <http://mli.sagepub.com/content/early/2013/10/23/0968533213508129.abstract>
- N.B. Assisted Dying Bill 2013 (U.K. government website):  
<http://services.parliament.uk/bills/2013-14/assisteddying.html>
- *MEDICINE, SCIENCE AND THE LAW* | Online – 4 November 2013 – '**The compassionate taking of life and assisted suicide.**' Mercy killing. Assisted suicide. The dependent patient. Withholding treatment. The practice of medicine and the civil and criminal law. Legal protection for patients and doctors. The role of judges. The role of politicians. <http://msl.sagepub.com/content/early/2013/10/31/0025802413502782.abstract>

## [Worth Repeating](#)

### **On patient autonomy and physician responsibility in end-of-life care**

*ARCHIVE OF INTERNAL MEDICINE*, 2011;171(9):849-853. In current medical practice, excessive or reflexive deference to an unreflective concept of patient autonomy may inadvertently compromise patient autonomy by placing unwanted and unreasonable responsibility for technical medical decisions on patients or their surrogate decision makers rather than on their physicians. Such practices can harm patients by depriving them of the expert, professional advice they both need and deserve to make important decisions about their health care. The authors describe how the patient-physician relationship has evolved in recent decades as more life-sustaining and life-saving treatments, such as cardiopulmonary resuscitation, have become available. They then examine respect for patient autonomy and describe how patient autonomy can be promoted while the physician's responsibility for technical medical decisions is simultaneously affirmed. The patient is the expert on his or her values, goals, and preferences, while the physician is the expert on the medical means for honoring the patient's perspective. The authors conclude that an intervention, such as cardiopulmonary resuscitation, should not be offered when, based on the patient's own criteria, it promises no physical or psychosocial benefit or would be far more harmful than beneficial. <http://archinte.jamanetwork.com/article.aspx?articleid=227286>

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/11/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.palliativecareconsultation.ca/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

### **Europe**

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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