

## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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In the search for meaning: Scroll down to **Specialist Publications** and 'Memorialisation and the metaphor of final journeys: Workers' experiences of dealing with death within care homes for the elderly' (p.12), published in *Mortality*.

## Canada

### Judicial stay granted on order to halt to life-sustaining treatments for comatose girl

ALBERTA | *Edmonton Journal* – 14 September 2012 – An Alberta Court of Appeal judge has temporarily stayed a lower-court ruling that life-saving measures be stopped for a comatose child allegedly abused by her parents. Justice Jean Cote stayed the order until next week, to give lawyers for the parents time to mount an appeal. Until then, the two-year-old will be kept on the ventilator she needs to live. Less than three hours earlier, Court of Queen's Bench Justice June Ross had ruled that the child should be taken off the ventilator. "I conclude and direct that the recommendation of (the girl's) medical team that she be withdrawn from life-sustaining treatment and be provided with palliative care is in (the girl's) best interests and that this course of treatment should be followed," Ross said. Ross was asked by Alberta Children & Youth Services to take over responsibility for the girl's medical care, including the decision whether or not to continue life-sustaining measures for the child, who doctors say is in a permanent coma...<http://www.edmontonjournal.com/news/edmonton/Judge+orders+halt+life+sustaining+treatments+comatose/7244807/story.html>

### Specialist Publications

Of particular interest:

'National standards urged for end-of-life care providers and facilities' (p.7), published in the *Canadian Medical Association Journal*.

'Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the view of Canadian health and social service professionals' (p.7), published in *BMC Palliative Care*.

### Important Update

Compassionate Care Benefits website updated September 2012: [http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)

## U.S.A.

### **Mayo Clinic specialist discusses divergent end-of-life scenarios**

MAINE | *Post Bulletin* (Rochester) – 11 September 2012 – Dr. Ed Creagan advises maintaining patient choice and control when death approaches. When an elderly patient continues to receive blood pressure medicine despite failure of chemotherapy for terminal cancer, there's a problem, he suggested. Why isn't health care throughout life more like care received during hospice, when providers ask about kids, pets, sports, faith, gardening and music? "The palliative care train needs not to be the caboose but to be the engine," he said. [Dr. Creagan is] an advocate for avoiding unnecessary care. Many patients with terminal cancer ... will have chemotherapy within the last 10 days of life, even when it's clear there's no bene-

fit. "Most of us will spend the last 10 days of our life with overwhelming pain if there is not a palliative-care specialist present," he said. <http://www.postbulletin.com/news/stories/display.php?id=1507976>

#### **Specialist Publications**

Of related interest:

**'Improving value in healthcare: Opportunities and challenges for palliative care professionals in the age of health reform'** (p.9), published in the *Journal of Hospice & Palliative Nursing*.

### **Religious burial and funeral rites**

#### **The human costs of judicial confirmation delays**

PENNSYLVANIA | *The Atlantic* – 9 September 2012 – Daniel Wasserman had seen enough. An Orthodox rabbi ... had grown tired of state interference with Jewish funeral rituals, ancient and eternal, which require burial within 24 hours and which prohibit embalming. He resented the threats of fines and penalties he was receiving from state officials trying to enforce a 19th-century funeral director's law. He believed he was being singled out for the practice of his religious beliefs. And so Rabbi Wasserman did what many people do in America when they believe their constitutional rights – their First Amendment rights, their rights to religious freedom – are being infringed by state action. He sued the state. On 6 August, in federal district court ... Rabbi Wasserman's lawyers sought an injunction to preclude state officials from continuing to threaten him for what he considers to be the lawful exercise of his religious beliefs. But justice won't come quickly for Rabbi Wasserman – if it comes at all. There simply aren't enough federal judges ... to handle his case. <http://www.theatlantic.com/politics/archive/2012/09/in-pennsylvania-the-human-costs-of-judicial-confirmation-delays/261862/>

#### **Dia de los Muertos (Day of the Dead)**

TEXAS | Fort Wayne Museum of Art – The Museum of Art's popular exhibit is back! Even if you are not familiar with the traditions of Dia de los Muertos, you probably recognize its images – brightly decorated sugar skulls, dancing skeletons still wearing the bright colored clothes of their less-ghostly pasts, and marigold-like flowers. This home-grown exhibit will feature traditional Mexican altars with sugar skulls, colorful tissue paper cut-outs, and photos of deceased relatives to honor the souls of the departed. The Day of the Dead, an ancient religious celebration that originally honored children and ancestors, has evolved from a blend of Meso-American and Christian cultures. The celebration is considered a festive time when family members remember and honor their dead and the continuity of life.



## International

### **'Who will look after our children?' Mother and father contemplate leaving their son and daughter orphans after BOTH are diagnosed with a terminal illness**

U.K. | *Daily Mail* – 14 September 2012 – A couple with two young children have both been told they are terminally ill. Paul and Clare Coulston have been making guardianship arrangements for their daughter Evelyn, four, and son Finlay, six. Mrs. Coulston, 36, a police sergeant, has been given just a 30% chance of surviving an aggressive form of oesophageal cancer. She was diagnosed in 2009. Mr. Coulston, 37, a deputy head teacher, has been told he has between three and five years to live with Motor Neurone Disease. He was diagnosed in April with the progressive condition which attacks the nerves in the brain and spinal cord, stopping the muscles working. To watch them joking with one another, laughing and smiling as they play with their children, it is hard to be-

lieve any heartache lies behind the Coulston's perfect family picture. But the couple ... are having to make plans no parents of young children should ever have to make. <http://www.dailymail.co.uk/health/article-2203250/Couple-boy-6-girl-4-BOTH-diagnosed-terminal-illness.html>

#### Specialist Publications

Of related interest:

**'How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients'** (p.11), published in the *Journal of Palliative Medicine*.

### **End of life home care plan considered in Wales**

U.K. (WALES) | BBC News – 13 September 2012 – Terminally ill patients who want to die at home should be given equal access to care services under new plans being considered in Wales.<sup>1</sup> The Welsh government says patients should be supported "wherever they die – at home, in hospital, in a care home or a hospice." The 'Together for Health – Delivering End of Life Care' plan sets out how inequalities ... will be addressed over the next four years. One of the plan's key aims is "24/7 support to all people entering the terminal phase of their illness" should be provided. <http://www.bbc.co.uk/news/uk-wales-19576593>

1. 'New plan to improve end-of-life care in Wales,' National Health Service Wales, September 2012. [A public consultation process will run through until the end of December 2012] <http://www.wales.nhs.uk/news/24119>



#### Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

#### 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>

## Palliative care in India

### **Morphine rules may be eased for terminally ill**

INDIA | *Times of India* (New Delhi) – 12 September 2012 – The availability of morphine – the cheapest and most effective painkiller – may soon be relaxed for medical use, helping reduce acute and chronic pain suffered by terminally ill cancer and HIV patients. The increased availability won't just be for patients in hospitals, but also for all those under home-based care. A multi-sectoral committee, set up by the Union health ministry, is working on amending the "draconian and restrictive" Narcotic & Psychotropic Act, 1985, which severely restricts availability of morphine for fear of misuse. The amendments may be passed during the winter session of parliament. With mounting pressure from palliative care experts who say that millions of Indians are in needless pain because morphine is being denied to them, a panel, which includes members from

the ministry of health, revenue and independent experts, finalized amendments on 30 August "an assured painless existence" of such patients for whom death is inevitable. <http://timesofindia.indiatimes.com/india/Morphine-rules-may-be-eased-for-terminally-ill/articleshow/16360481.cms>

### **Palliative care for kids at all public hospitals**

INDIA | *The Star* (Kuala Lumpur) – 14 September 2012 – The Health Ministry will set up dedicated paediatric palliative care facilities and teams at all public hospitals to help young children with life-limiting conditions led by paediatricians supported by multi-disciplinary healthcare professionals. <http://thestar.com.my/news/story.asp?file=/2012/9/14/nation/12026753&sec=nation>

## Trends

### **The cost of dying falls but funeral costs rise**

U.K. | BBC News – 12 September 2012 – The cost of dying has fallen in the last year, but the basic price of a funeral rose for the ninth consecutive year, research has suggested. The cost of dying includes funeral costs, as well as associated costs such as probate, headstones and flowers. This fell by 1.9% compared with the previous 12 months, to £7,114. However, the specific cost of a basic funeral was up by 6.2% in a year to £3,284, driven by burial costs. Cremation costs and funeral directors' bills also increased, the report said, although price competition and consumer awareness helped keep down the legal bills for estate administration. The report claimed that the government's support system to help the most vulnerable with funeral costs, called the Social Fund Funeral Payment Scheme, was facing mounting demands amid tough economic times. <http://www.bbc.co.uk/news/business-19576850>

Of related interest:

- U.K. | *The Independent* (London) – 16 September 2012 – **'The terminally ill deserve more care from insurers.'** The last thing families facing bereavement need is to be worried about a policy payout. <http://www.independent.co.uk/money/insurance/kate-hughes-the-terminally-ill-deserve-more-care-from-insurers-8142220.html>

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

Representative sample of recent news media coverage:

- U.K. | *Daily Telegraph* – 15 September 2012 – **'Recession strengthens case against assisted suicide, MPs say.'** MPS fear that moves to legalise assisted suicide in the midst of the current economic crisis could place frail and vulnerable people under added pressure to end their lives, the first poll of its kind has found. <http://www.telegraph.co.uk/news/politics/9543581/Recession-strengthens-case-against-assisted-suicide-MPs-say.html>

Cont.

- NEW ZEALAND | TVNZ News – 14 September 2012 – **'Majority of Kiwis support assisted suicide – poll.'** Up to 63% of New Zealanders support legalising assisted suicide for mentally competent adults suffering from a terminal illness, a new poll has found. The poll ... asked 2,969 respondents – reported to be a representative sample of adult New Zealanders - if they supported or opposed the assisted suicide in the case of mentally competent adults who are terminally ill. The poll found 62.9% were in support, 15.8% neutral, 12.3% opposed and 9% were not sure. <http://tvnz.co.nz/national-news/majority-kiwis-support-assisted-suicide-poll-5081168>
- BELGIUM | Agence France-Presse (Brussels) – 13 September 2012 – **'Belgian euthanasia law allows first death of a prisoner.'** A gravely ill prisoner serving a long jail sentence has become the first inmate to die under Belgian euthanasia laws introduced 10 years ago. The man, who was not identified, died earlier this year after seeking permission several times when doctors decided his suffering could not be helped. They gave no details of his illness or the circumstances of his case. [http://www.google.com/hostednews/afp/article/ALeqM5gmkZgR8d7jX\\_-4mMCNtNg24ZQz8A?docId=CNG.e64ab1ed0df19fc0cd2e7c6309819b63.501](http://www.google.com/hostednews/afp/article/ALeqM5gmkZgR8d7jX_-4mMCNtNg24ZQz8A?docId=CNG.e64ab1ed0df19fc0cd2e7c6309819b63.501)
- U.K. | *The Guardian* – 11 September 2012 – **'Assisted dying: Who's to decide when a life is not worth living?'** An extraordinary poll by the British Humanist Association<sup>1</sup> highlights the public ambivalence about assisted suicide and euthanasia. In conjunction with other recent surveys, it shows that more people are in favour of the law allowing the killing of relatively healthy patients ... who are terminally ill. <http://www.guardian.co.uk/commentisfree/andrewbrown/2012/sep/11/assisted-dying-who-decides?newsfeed=true>
  1. 'New poll shows strong public support for assisted dying,' British Humanist Association, September 2012. <http://www.humanism.org.uk/news/view/1108>
- U.K. (ENGLAND & WALES) | *Daily Telegraph* – 10 September 2012 – **'Norman Lamb second new health minister to call for reform of assisted dying laws.'** The Liberal Democrat minister, who is responsible for suicide strategy within the Department of Health, followed his Conservative colleague Anna Soubry, who said that the current laws on voluntary euthanasia were dishonest and needed to evolve to allow people to die at home. Coming two days after Miss Soubry's intervention, Mr. Lamb's words are certain to stoke the row. <http://www.telegraph.co.uk/news/9533091/Norman-Lamb-second-new-health-minister-to-call-for-reform-of-assisted-dying-laws.html>

Noted in Media Watch, 10 September 2012:

- U.K. (ENGLAND & WALES) | *Daily Telegraph* – 8 September 2012 – **'Terminal illness sufferers 'should be allowed help to die...'** <http://www.telegraph.co.uk/health/healthnews/9529790/Terminal-illness-sufferers-should-be-allowed-help-to-die-says-new-minister.html>

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

### **Managing grief and depression at the end of life**

*AMERICAN FAMILY PHYSICIAN*, 2012;86(3). Psychological distress is common in terminally ill persons and can be a source of great suffering. Grief is an adaptive, universal, and highly personalized response to the multiple losses that occur at the end of life. This response may be intense early on after a loss manifesting itself physically, emotionally, cognitively, behaviorally, and spiritually; however, the impact of grief on daily life generally decreases with time. Although pharmacologic interventions are not warranted for uncomplicated grief, physicians are encouraged to support patients by acknowledging their grief and encouraging the open expression of emotions. It is important for the physician to distinguish uncomplicated grief reactions from more disabling psychiatric disorders such as major depression. The symptoms of grief may overlap with those of major depression or a terminal illness or its treatment; however, grief is a distinct entity. Feelings of pervasive hopelessness, helplessness, worthlessness, guilt, lack of pleasure, and suicidal ideation are present in patients with depression, but not in those experiencing grief. <https://secure.aafp.org/login/>

## Surrogate decision making in the Internet age

*AMERICAN JOURNAL OF BIOETHICS* | Published online – 13 September 2012 – The computer revolution has had an enormous effect on all aspects of the practice of medicine, yet little thought has been given to the role of social media in identifying treatment choices for incompetent patients. We are currently living in the "Internet age" and many people have integrated social media into all aspects of their lives. As use becomes more prevalent, and as users age, social media are more likely to be viewed as a source of information regarding medical care preferences. This article explores the ethical and legal issues raised by the use of social media in surrogate decision making. <http://www.tandfonline.com/doi/full/10.1080/15265161.2012.708088>

## Home care program for patients at high risk of hospitalization

*AMERICAN JOURNAL OF MANAGED CARE*, 2012;18(8):e269-e276. This study demonstrates that a program using a home-based interdisciplinary team of medical and social service providers can improve patient satisfaction with healthcare provided by a managed care organization. In addition, findings of significant reductions in hospital days and the decreased probability of hospitalization for Choices for Healthy Aging intervention patients suggest that improved home care and support may reduce use of costly acute medical service. Despite significantly lower hospital use among the intervention group, this finding did not translate to a corresponding reduction in overall healthcare costs when adjusted for demographics and health conditions. Further investigation is needed to determine whether risk stratification is an effective method of determining need for interdisciplinary home care services. Another reason for the lack of reduction in total cost may be that the intervention costs with the interdisciplinary team were too high for the care required for the patient. <http://www.ajmc.com/articles/Home-Care-Program-for-Patients-at-High-Risk-of-Hospitalization>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Published online – 13 September 2012 – **'Impact of an oncology palliative care clinic on access to home care services.'** Home care (HC) is important for patients with cancer as performance status declines. This study at a Canadian cancer center examined the impact of an oncology palliative care clinic on HC referral. <http://ajh.sagepub.com/content/early/2012/09/09/1049909112452469.abstract>

### **Palliative care needs of terminally ill people living alone: A service provider perspective**

*COLLEGIAN JOURNAL* | Published online – 10 September 2012 – This paper investigated the support needs of people living alone with a terminal illness from a service provider perspective. Four main themes emerged: care challenges, differences in care provision, appropriate approaches to care and essentials for an effective service such as 24-hour care, cost-free provision of personal alarm systems, supported and coordinated housekeeping services, funded respite care and financial care packages. HSPs [health service providers] expressed a respect for the autonomy and independence of the clients, yet felt pressured to ensure that safe and attentive care was possible. HSPs recognised the central importance of maintaining the independence and autonomy of palliative care clients living alone. This study is the first in-depth account of what HSPs perceive they need to effectively look after home alone dying clients [providing] directions to inform service planning for this growing and challenging population group regarding adequate and timely services that will lead to more complying with the clients' wishes, more care being delivered at home, a reduction in hospitalisations, a better quality of life and a capacity to die at home. [http://www.collegianjournal.com/article/S1322-7696\(12\)00087-X/abstract](http://www.collegianjournal.com/article/S1322-7696(12)00087-X/abstract)

## **Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals**

*BMC PALLIATIVE CARE* | Published online – 15 September 2012 – [Study] participants identified key barriers to end-of-life care services for homeless persons, including: 1) insufficient availability of end-of-life care services; 2) exclusionary operating procedures; and, 3) poor continuity of care. Participants identified recommendations that they felt had the potential to minimize these barriers, including: 1) adopting low-threshold strategies (e.g., flexible behavioural policies and harm reduction strategies); 2) linking with population-specific health and social care providers (e.g., emergency shelters); and, 3) strengthening population-specific training. Homeless persons may be underserved by the end-of-life care system as a result of barriers that they face to accessing end-of-life care services. Changes in the rules and regulations that reflect the health needs and circumstances of homeless persons and measures to improve continuity of care have the potential to increase equity in the end-of-life care system for this underserved population.

<http://www.biomedcentral.com/content/pdf/1472-684X-11-14.pdf>

Noted in past issues of Media Watch:

- **'A qualitative study of homelessness and palliative care in a major urban center,'** *American Journal of Hospice & Palliative Medicine*, 5 June 2012.  
<http://ajh.sagepub.com/content/early/2012/06/03/1049909112448925.abstract>
- **'Homeless people need better palliative care...,'** *Community Care* (U.K.), 24 May 2011.  
<http://www.communitycare.co.uk/Articles/2011/05/24/116870/homeless-people-need-better-palliative-care-finds-charity.htm>
- **'Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of...,'** *Palliative Medicine*, 4 April 2011.  
<http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract>
- **'End-of-life care for the homeless,'** Canadian Healthcare Network, 9 November 2010.  
<http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956>

## **National standards urged for end-of-life care providers and facilities**

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Published online – 10 September 2012 – Pop quiz. If someone wants to start administering palliative, end-of-life or home care in Canada to the terminally ill or elderly, do they need training? Certification? Accreditation? Are they obliged to periodically demonstrate competence or compliance with any manner of standards? The short answer to all of the above? For the most part: No. The absence of national standards and legal requirements essentially means that, in most parts of the country, almost anybody can set themselves up as a provider of the non-pharmaceutical facets of end-of-life care, on an almost fly-by-night basis, even if they lack the resources or training to manage the myriad complexities associated with providing care. But while Canada isn't exactly overrun with erstwhile providers, sporadic reports of problems and abuses associated with end-of-life and home care indicate that the introduction of standards would elevate the quality of the industry, experts say. Accreditation of health care providers and facilities is mostly voluntary in Canada. There are few exceptions. It is required in all public and private health care institutions in Quebec, and all facilities supported by regional health authorities in Alberta. Manitoba is also in the process of developing legislation that would compel providers and facilities within regional health authorities to obtain and maintain accreditation. [http://www.cmaj.ca/site/earlyreleases/10sept12\\_national-standards-urged-for-end-of-life-care-providers-and-facilities.xhtml](http://www.cmaj.ca/site/earlyreleases/10sept12_national-standards-urged-for-end-of-life-care-providers-and-facilities.xhtml)

Noted in Media Watch, 10 September 2012:

- *TODAY'S HOSPITALIST* | Published online – 9 September 2012 – **'Do you need to be certified in palliative care?'** [http://todayshospitalist.com/index.php?b=articles\\_read&cnt=1524](http://todayshospitalist.com/index.php?b=articles_read&cnt=1524)

## The role of healthcare support workers in providing palliative and end-of-life care in the community: A systematic literature review

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Published online – 13 September 2012 – The findings [of this study] suggest three challenges in the HCSWs [Health Care Support Workers] role: emotional attachment, role ambiguity and inadequate training. Support factors such as informal peer grief-support groups, sense of cohesiveness among HCSWs and task orientation enabled HCSWs to overcome these challenges. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01092.x/abstract>

### Palliative care in Ireland

#### A new view of palliative care

*IRISH MEDICAL TIMES* | Online report – 10 September 2012 – While palliative care and cancer have been inextricably linked in the consciousness of healthcare staff for the longest time, it has become apparent that the needs of patients with other life-limiting diseases are not always being met. Research by the Irish Hospice Foundation has shown that while cancer accounts for 29% of all deaths in Ireland per annum, 46% – amounting to 13,000 deaths – are attributable to heart failure, dementia and respiratory disease. To this end, the 2008 Palliative Care for All report<sup>1</sup> ... made recommendations that care pathways should include provisions for patients with life-limiting dementia, heart failure and respiratory illness. On foot of this, three action research projects were undertaken in these areas. The 'Dementia and Palliative Care Action Research Project'<sup>1</sup> was established to examine palliative care responses for people with dementia in community and residential care settings. Similarly, the 'Action Research Project on Palliative Care and Advanced Respiratory Disease'<sup>1</sup> examined care for people with

respiratory illnesses, while the 'Heart Failure and Palliative Care Action Research Project'<sup>1</sup> assessed the palliative needs of patients with life-limiting cardiovascular illness. <http://www.imt.ie/features-opinion/2012/09/a-new-view-of-palliative-care.html>

#### **'Treat the patient, not the disease'**

*IRISH HEALTH* | Online report – 15 September 2012 – Hospital doctors and GPs must stop treating the disease and start caring holistically for the patient with a life-limiting condition. Prof. Scott Murray from Edinburgh University [pointed out that] there were four dimensions to caring for the person with a life-limiting condition – physical, psychological, social and spiritual. Prof. Murray said: "The perception about palliative care is that it is all about cancer and hospices. This needs to be challenged. Some progress has been made internationally in opening people's minds to the fact that most people who need palliative care do not have cancer. But it needs to be highlighted more in the medical community." <http://www.irishhealth.com/article.html?id=21060>

1. 'Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks,' Health Service Executive and the Irish Hospice Foundation, 2008. [http://www.hospice-foundation.ie/index.php?option=com\\_content&task=view&id=110&Itemid=42](http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=110&Itemid=42)

## U.S. Affordable Care Act

### **Improving value in healthcare: Opportunities and challenges for palliative care professionals in the age of health reform**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(7):452-459. Despite having the highest per capita spending on healthcare in the world, seriously ill patients in the U.S. often do not receive the highest quality care. Improving the value of healthcare by increasing quality while reducing escalating costs is at the heart of health reform. With ... the Patient Protection & Affordable Care Act of 2010, new healthcare delivery and payment models are being implemented to achieve these goals. This article reviews areas of health reform that have specific relevance for hospice and palliative care, highlights palliative care's positive outcomes, and reflects on current challenges within the healthcare system as well as within the field itself. Considerations regarding the language we use are explored, and recommendations are provided to ensure hospice and palliative care is represented in the planning and implementation of health reform initiatives. [http://journals.lww.com/jhpn/Abstract/2012/10000/Improving\\_Value\\_in\\_Healthcare\\_Opportunities\\_and.3.aspx](http://journals.lww.com/jhpn/Abstract/2012/10000/Improving_Value_in_Healthcare_Opportunities_and.3.aspx)

Of related interest:

- *MOUNT SINAI JOURNAL OF MEDICINE*, 2012;79(5):579-585. **'Integrating palliative care into primary care.'** This article reviews literature illustrating the benefits of palliative care; discusses why primary-care clinicians are ideally suited to incorporate palliative care into their practice; and provides guidance to primary-care clinicians regarding how and when to access palliative-care specialist services, how to gain more training in palliative care, and how to be reimbursed for palliative-care visits. <http://onlinelibrary.wiley.com/doi/10.1002/msj.21338/abstract>
- NURSE.COM (U.S.) | Published online – 10 September 2012 – **'Healthcare reform, aging population drive greater need for case managers.'** The [Patient Protection &] Affordable Care Act has put more pressure on hospitals to control costs, improve transitions to home care and prevent readmissions. All of these things take a new level of coordination, which has opened the door for case managers. <http://news.nurse.com/article/20120910/NY01/109100028>

### **The carelessness of affordable care**

*HASTINGS CENTER REPORT*, 2012;42(5):24-27. The Affordable Care Act [ACA] has been touted as a long-overdue remedy for what is perceived to be the chronic problem of large numbers of Americans living without adequate health insurance. While much of the discussion of the ACA has focused on its legality, it should also be assessed on the basis of its economic implications and its moral acceptability. On its face, the ACA appears to do well on both counts. Given that the uninsured often secure their health care from expensive emergency room treatment (from which they cannot be excluded and whose cost is often borne by third parties), expanding insurance to cover them (and hence to give them access to less expensive treatments) appears to make economic sense. Similarly, it might appear that providing access to insurance for people who otherwise could not afford it, or who would be denied it as a result of having medical conditions that they are not responsible for, would be morally laudable. These appearances deceive: The ACA is neither economically sound nor morally acceptable. <http://onlinelibrary.wiley.com/doi/10.1002/hast.72/abstract>



October 13 2012

## Approaches to suffering at the end of life: The use of sedation in the U.S. and Netherlands

*JOURNAL OF MEDICAL ETHICS* | Published online – 14 September 2012 – Studies describing physicians' experiences with sedation at the end of life are indispensable for informed palliative care practice, but they are scarce. The authors describe the accounts of physicians from the U.S. and the Netherlands, two countries with different regulations on end-of-life decisions regarding their use of sedation. In both countries, the use of sedation was described in diverse terms, especially in the U.S., and was often experienced as emotionally challenging. Respondents [i.e., study participants] stated different and sometimes multiple intentions for their use of sedation. Besides alleviating severe suffering, most Dutch respondents justified its use by stating that it does not hasten death, while most American respondents indicated that it might hasten death but that this was justifiable as long as that was not their primary intention. While many Dutch respondents indicated that they initiated open discussions about sedation proactively to inform patients about their options and to allow planning, the accounts of

American respondents showed fewer and less-open discussions, mostly late in the dying process and with the patient's relatives. The justification for sedation and the openness with which it is discussed were found to differ in the accounts of respondents from the U.S. and the Netherlands. Further clarification of practices and research into the effect and effectiveness of the use of sedation is recommended to enhance informed reflection and policy making. <http://jme.bmj.com/content/early/2012/09/13/medethics-2012-100561.abstract>

### Extract from *Journal of Medical Ethics* article

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Cont. on next page

### Media Watch: Editorial Practice

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

### Distribution

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

### Links to Sources

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

### Something Missed or Overlooked?

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

Noted in Media Watch, 10 September 2012:

- *CANADIAN ASSOCIATION OF NURSES IN ONCOLOGY JOURNAL*, 2012;22(3):195-199. 'Palliative sedation to alleviate existential suffering at end-of-life: Insight into a controversial practice.' <http://www.cano-acio.ca/~ASSETS/DOCUMENT/CONJ/conj-22-3-2012-195-199.pdf>

Noted in Media Watch, 20 August 2012:

- *JOURNAL OF MEDICAL ETHICS* | Published online – 14 August 2012 – 'Factors that facilitate or constrain the use of continuous sedation at the end of life by physicians and nurses in Belgium...' <http://jme.bmj.com/content/early/2012/08/13/medethics-2012-100571.abstract>

### Lessons learned for pediatric pandemic planning in palliative care: A case study

*JOURNAL OF PALLIATIVE CARE & MEDICINE*, 2012;2(5) | Published online – Understanding parental experience can contribute to the overall development of recommendations for future pandemic planning, with respect to the unique needs of dying children and their families. Specific recommendations such as flexible family access policies and the creative use of social media technologies are recommended as health care facilities embark on pandemic preparation plans. Given the significant lack of pandemic planning in pediatric palliative care, these findings are an important first step in developing a framework that supports children with a life threatening illness during a public health crisis. <http://omicsgroup.org/journals/2165-7386/2165-7386-2-120.pdf>

### How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients

*JOURNAL OF PALLIATIVE MEDICINE* | Published online – 14 September 2012 – Families with young children often struggle to talk about and cope with a parent's life-threatening illness and potential death. Adult interdisciplinary palliative medicine teams often feel unprepared to facilitate the open communication with these children that has been shown to reduce anxiety, depression, and other behavioral problems. In pediatric settings, child life specialists routinely provide this support to hospitalized children as well as their siblings and parents. Although these services are the standard of care in pediatrics, no research reports their use in the care of children of adults with serious illness. The authors describe a pilot child life consultation service for the children of seriously ill adult inpatients. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0019>

### Accuracy of do not resuscitate (DNR) in administrative data

*MEDICAL CARE RESEARCH & REVIEW* | Published online – 6 September 2012 – This article evaluates the accuracy of reporting do not resuscitate (DNR) orders in administrative data for use in risk-adjusted hospital assessments. The authors compared DNR reporting by 48 California hospitals in 2005 patient discharge data (PDD) with gold-standard assessments made by registered nurses (RNs) who reabstracted 1,673 records of patients with myocardial infarction, pneumonia, or heart failure. The PDD agreed with the RN reabstraction in 1,411 (84.3%) cases. The administrative data did not reflect a DNR order in 71 of 512 records where the RN indicated there was (14% false negative rates), and reflected a DNR order in 191 of 1,161 records where the RN indicated there was not (16% false positive rate). The accuracy of DNR was more problematic for patients who died, suggesting that hospital-reported DNR is problematic for capturing patient preferences for resuscitation that can be used for risk-adjusted outcomes assessments. <http://mcr.sagepub.com/content/early/2012/09/04/1077558712458455.abstract>

## **Memorialisation and the metaphor of final journeys: Workers' experiences of dealing with death within care homes for the elderly**

*MORTALITY*, 2012;17(3):221-239. This paper focuses on the 'final journey,' a metaphoric journey undertaken by dead residents which allowed workers in care homes for older people to cope with the amounts of death that they encountered working in care homes for the elderly. Movement plays a key role in the routine functioning of the home and the metaphoric language of a journey is an important conclusion to the stages that have preceded this. It helps explain the care that surrounds death and dying within the care home. Workers' experiences show that there is a rich oral tradition which symbolism, spirituality, ritual and memorial language explain and at the same time creates continuity for workers within care homes. The author argues that the search for meaning is important for staff as they continually face the deterioration of people during their working lives. <http://www.tandfonline.com/doi/full/10.1080/13576275.2012.696808>

Noted in Media Watch, 30 July 2012:

- *PALLIATIVE MEDICINE* | Online article – 24 July 2012 – '**The patient's use of metaphor within a palliative care...**' <http://pmj.sagepub.com/content/early/2012/07/20/0269216312451948.abstract>

Noted in Media Watch ('Worth Repeating'), 1 February 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 1998;15(5):282-284. '**Communicating with metaphor...**' <http://ajh.sagepub.com/cgi/content/abstract/15/5/282>

### **Media Watch Online**

#### **Canada**

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>

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

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

#### **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>

#### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

#### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *THE MODERN LAW REVIEW*, 2012;75(5):697-721. '**Compassionate killings: The case for a partial defence.**' The focus of this article is upon compassionate killings, that is, criminal cases where a parent/spouse has killed or assisted to die a child/spouse who was suffering from severe disabilities, debilitating injury, chronic or terminal illness. The authors argue that the partial defence of diminished responsibility, while appropriate for some cases, fails to acknowledge the compassionate and relational nature of these acts and thus fails to identify the quality of the harm committed. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-2230.2012.00921.x/abstract>

## Worth Repeating

### The experience of the moment of death in a specialist palliative care unit

*IRISH MEDICAL TIMES*, 2009;102(5):143-6. The authors have attempted to describe the moment of death in order to help others face that moment. In all interviews [with study participants] the moment of death is marked by the attentive presence of individuals, often silently, forming a community focused on one person with prayer ritualized by words and candles. It is a moment to be witnessed. This is part of tradition and an expression of love. The palliative care staff understands both. There is an art in being able to just stand quietly by, as achieved by staff members. At the moment of death families observe and remember the care in great detail. They value professionalism and courtesy. Knowing how to provide comfort requires insight into the complete landscape of a dying patient's experience. As families had already met the researcher regularly prior to the death of their relative, and trust had been established resulting in a willingness to

participate in the interviews and enriching the data. There is an awareness of life beyond death also prevalent in Irish people in the past where death was merely a slight movement from one form of existence to another. It is well to know what dying can be like. <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=3880>

#### Extract from *Irish Medical Times*

Doctors may not necessarily witness the dying process. Yet death is what we are preparing patients to face. This study describes dying and death. We cannot hear the stories of the dead. We can try to hear the stories of those who have witnessed dying. Relatives observe every detail, attending to their role and observing the role of others. They are valuable witnesses.

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