## 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

The illness experience: Scroll down to <u>Specialist Publications</u> and 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life-limiting conditions and their families" (p.12), in *Journal of Child Health Care*.

## Canada

## Aboriginal seniors face more health challenges, report suggests

CTV NEWS | Online - 28 November 2013 -First Nations, Metis and Inuit of advancing years often have poorer health than their non-aboriginal counterparts, but don't receive the same level of health-care services as other Canadian seniors.1 The health of aboriginal seniors can be compromised by poverty, inadequate housing and poor diet, especially for those living in remote areas where nutritious foods may be prohibitively expensive. Chronic conditions such as obesity, diabetes and heart disease are more prevalent among aboriginal Canadians, compared with the general population, and those disorders can worsen with age. Many older aboriginal Canadians also carry the scars of rampant societal racism and the trauma of being torn from their families to live in residential schools, where abuse, neglect and substandard health care were pervasive within the system. Those experiences have resulted in lingering mental health issues for some elders, such as depression or even post-traumatic stress disorder. But accessing health care can be physically, emotionally and financially challenging for many aboriginal seniors, who may have to travel to

urban centres for services that are unavailable in remote or isolated communities. <a href="http://www.ctvnews.ca/health/aboriginal-seniors-face-more-health-challenges-report-suggests-1.1564234">http://www.ctvnews.ca/health/aboriginal-seniors-face-more-health-challenges-report-suggests-1.1564234</a>

 Canada's Most Vulnerable: Improving Health Care for First Nations, Metis and Inuit Seniors, The Health Council of Canada, November 2013.http://healthcouncilcanada.ca/ rpt\_det\_gen.php?id=801&rf=2

## **Extract from Health Council of Canada report**

There is no funding for palliative/end-of-life care through the First Nations & Inuit Health Branch, and Health Canada's First Nations and Inuit Home and Community Care program is unable to provide 24-hour support for palliative clients and their families due to limited staffing and funds. Some research with seniors to define culturally appropriate end-of-life care yields a very different perspective from the Western model. In some Aboriginal cultures, death is part of life, and the care and comfort of heart and spirit take precedence over medical procedures and protocols.

Noted in Media Watch, 18 June 2012, #258 (p.15):

THE LANCET, 2012;379(9832):2137. 'Canada curbs aboriginal health leadership.' In late March, Canada's Conservative Government announced austerity measures that terminated funding for the First Nations Statistical Institute, the Pauktuutit Inuit Women of Canada, the National Centre for First Nations Governance, the Aboriginal Healing Foundation, and the National Aboriginal Health Organization, which was Canada's only organisation dedicated to developing common health policies for all of its more than 600 Aboriginal groups. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2812%2960928-3/fulltext

Noted in Media Watch, 7 May 2012, #252 (p.6):

BMJ PALLIATIVE & SUPPORTIVE CARE | Online – 3 May 2012 – 'Cultural understanding in the provision of supportive and palliative care: Perspectives in relation to an indigenous population.' The Mi'kmaq Nation lives in Atlantic Canada as well as New England in the eastern U.S. Themes were identified in the literature and through discussion with seven experts who have Mi'kmaq health and cultural research expertise. They focused on jurisdictional issues and cultural understanding. Jurisdictional issues experienced by the Mi'kmaq affect access, continuity and appropriateness of care. Cultural concepts were associated with world-view, spirituality, the role of family and community relationships, and communication norms... http://spcare.bmj.com/content/early/2012/05/03/bmjspcare-2011-000122.full.pdf+html

Noted in Media Watch, 4 October 2010, #169 (p.2):

SOCIAL SCIENCE & MEDICINE, 2011;72(3):355-364 'Aboriginal peoples, health and healing approaches: The effects of age and place on health.' The results [of this study] demonstrate that older Aboriginal people face unique challenges – e.g., loss of traditional approaches to healing, geographic isolation, identity politics, constitutional and legal divisions within the Aboriginal community – with respect to their health and access to health services. http://www.sciencedirect.com/science/article/pii/S0277953610006714

Noted in Media Watch, 20 April 2009, #93 (p.7):

CANADIAN FAMILY PHYSICIAN, 2009;55(4):394-395. 'Palliative care of First Nations people: A qualitative study of bereaved family members.' First Nations family members described palliative care as a community and extended family experience. They expressed the need for rooms and services that reflect this, including space to accommodate a larger number of visitors than is usual in Western society. Participants described the importance of communication strategies that involve respectful directness. http://www.cfp.ca/cgi/reprint/55/4/394

## Literature review:

CANADIAN FAMILY PHYSICIAN, 2007;53(9):1459-1465. 'End-of-life issues for aboriginal patients.' Aboriginal patient care might involve unspoken beliefs about end-of-life issues typically unexplored by physicians. These discussions can involve interpreters, family, and other key community members. Family members as interpreters might not be the best choice in these situations. The interplay of patients' individuality and of community and family concerns presents challenges for caregivers. Generalities might be useful to inform physicians of the potential scope of individual variation in end-of-life discussions, but each patient and family needs to be addressed individually. <a href="http://www.cfp.ca/content/53/9/1459.full?sid=6b690a13-a37d-4b21-b75f-5d00126f26b2">http://www.cfp.ca/content/53/9/1459.full?sid=6b690a13-a37d-4b21-b75f-5d00126f26b2</a>

#### **Quotable Quotes**

It does not require many words to speak the truth. Hin-mah-too-yah-lat-kekt (1840-1904), known as Chief Joseph, of the Nez Pierce.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ GLOBAL TV NEWS | Online – 27 November 2013 – ""Growing demand" for euthanasia and assisted suicide, health documents say.' The Conservative government refuses to reopen a debate about euthanasia and assisted suicide even though its own bureaucrats say that's what Canadians want. Briefing notes prepared for [the Federal] Health Minister Rona Ambrose in advance of a [recent] provincial health ministers' meeting [and obtain under the Canada's access to information laws] acknowledge a "growing demand" for death with dignity in Canada. http://globalnews.ca/news/993827/growing-demand-for-euthanasia-and-assisted-suicide-health-documents-say/

Noted in Media Watch, 7 October 2013, #326 (p.2):

■ THE GLOBE & MAIL | Online – 4 October 2013 – 'Ottawa leaves right-to-die debate to provinces.' The federal government will not legalize euthanasia, leaving the matter to the provinces – and possibly the courts – to sort out. Health Minister Rona Ambrose discussed assisted suicide with her provincial counterparts, including a proposal by Quebec's Réjean Hébert that would allow physicians to help terminally ill patients die in certain circumstances. <a href="http://www.theglobeandmail.com/news/national/health-minister-urges-legislatures-to-discuss-assisted-suicide/article14707199/">http://www.theglobeandmail.com/news/national/health-minister-urges-legislatures-to-discuss-assisted-suicide/article14707199/</a>

**N.B.** 'Euthanasia and Assisted Suicide in Canada,' Library of Parliament, 15 February 2013. [Noted in Media Watch, 22 April 2013, #302 (p.1)] <a href="http://www.parl.gc.ca/Content/LOP/ResearchPublications/2010-68-e.htm">http://www.parl.gc.ca/Content/LOP/ResearchPublications/2010-68-e.htm</a>

THE NATIONAL POST | Online – 26 November 2013 – 'Death by doctor.' As Canada moves toward legalizing assisted suicide, the daily newspaper's series looks at the places it is already happening. <a href="http://news.nationalpost.com/tag/death-by-doctor/">http://news.nationalpost.com/tag/death-by-doctor/</a>

## U.S.A.

## End-of-life directives not binding under Massachusetts law

MASSACHUSETTS | *The Republican* (Springfield) – 1 December 2013 – A living will, or an advanced directive, is a document in which you state, specifically, medical decisions in advance of an actual need... These documents are not recognized by Massachusetts law. Although a living will is not recognized in Massachusetts, it may be advisable to obtain a form, and work through the ideas and decisions it addresses ... to think about the possible medical issues and concerns that may confront their health-care agent, and then tell their agent their preferences and directions regarding the same. To the extent you have completed a living will, your health-care proxy can certainly refer to your living will or advanced directive as a guide in making the proxy's own determination. However, it is important to understand that, in Massachusetts, your agent will have the authority to make the decision in the moment. <a href="http://www.masslive.com/business-news/index.ssf/2013/12/ask">http://www.masslive.com/business-news/index.ssf/2013/12/ask</a> the experts end-of-life directives n.html

### Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

#### No matter the species

## All dogs may go to heaven. These days, some go to hospice

THE NEW YORK TIMES | Online – 30 November 2013 – More and more, cats and dogs get the human treatment. There are pet spas, pet therapists, pet clothes. And as it goes in life, so it now goes in the twilight. The latest phenomenon: pet hospice. Around the country, a growing number of veterinarians are offering hospice care, and marketing it as a way to give cats and dogs – and their owners – a less anxious, more comfortable passing. The approach, in the spirit of the human variety, entails ceasing aggressive medical treatment and giving pain and even anti-anxiety drugs. Unlike in hospice care for humans, euthanasia is an option – and in fact, is a big part of this end-of-life turn. When it's time, the vet performs it in the living room, bedroom or wherever the family feels comfortable. <a href="http://www.nytimes.com/2013/12/01/business/all-dogs-may-go-to-heaven-these-days-some-go-to-hospice.html">http://www.nytimes.com/2013/12/01/business/all-dogs-may-go-to-heaven-these-days-some-go-to-hospice.html? r=0</a>

Noted in Media Watch, 10 June 2013, #309 (p.12).

 BRITISH JOURNAL OF GENERAL PRACTICE, 2013;63(611):317. 'The death of my dog: Lessons learned from the palliative care of an animal.' Abstract or link to article unavailable. <a href="http://www.ingentaconnect.com/content/rcgp/bjgp/2013/00000063/00000611/art00022">http://www.ingentaconnect.com/content/rcgp/bjgp/2013/00000063/00000611/art00022</a>

Noted in Media Watch, 16 April 2012, #249 (p.4):

U.S. | The New York Times – 9 April 2012 – 'An ethical quandary, no matter the species.' Crucial conversations between veterinarians and pet owners are most helpful. And perhaps our consideration of these issues for our pets will foster more discussion of these vital matters in the treatment and end-of-life care for our human loved ones and ourselves. <a href="http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pethealth-care/an-ethical-quandary-no-matter-the-species">http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pethealth-care/an-ethical-quandary-no-matter-the-species</a>

#### Federal judge: Illinois same-sex couple facing terminal illness can marry immediately

ILLINOIS | Think Progress – 26 November 2013 – Marriage equality is now law in Illinois, but that law does not take effect until 1 June 2014. A federal judge has ruled, however, that one same-sex couple will not have to wait. Vernita Gray and Patricia Ewert have been in a committed relationship for five years, but Gray has been fighting cancer since 1996 and her life is now in serious jeopardy. Because of her terminal illness, a judge granted a restraining order ensuring she can marry now. <a href="http://thinkprogress.org/lgbt/2013/11/26/2995871/federal-judge-illinois-sex-couple-facing-terminal-illness-marry-immediately/">http://thinkprogress.org/lgbt/2013/11/26/2995871/federal-judge-illinois-sex-couple-facing-terminal-illness-marry-immediately/</a>

## Surrogates often make call to deactivate heart devices

REUTERS | Online – 26 November 2013 – People who have implanted heart devices rarely have advance directives indicating whether they want them deactivated near the end of life, according to a new study. <sup>1,2</sup> So the decision often has to be made by loved ones. Hundreds of thousands of Americans have an implanted device that keeps their heart beating properly, even when they are extremely ill and at the end of life. Some doctors feel these devices prolong life unnaturally. And ICDs [implantable cardioverter defibrillators] send shocks to the heart in the final days, which is uncomfortable for patients and frightening for loved ones. "Because of the increasing prevalence of patients with these devices, we were encountering an increasing number of patients approaching the end of life ... requesting that the device be 'turned off' so that the device doesn't interfere with a peaceful or natural death from unhelpful and uncomfortable ICD shocks," Dr. Paul Mueller told Reuters. Mueller, the study's senior author, is chair of the Division of General Internal Medicine at the Mayo Clinic in Rochester, Minnesota. <a href="http://www.reuters.com/article/2013/11/26/us-surrogates-often-make-call-to-deactiv-idUSBRE9AP13A20131126">http://www.reuters.com/article/2013/11/26/us-surrogates-often-make-call-to-deactiv-idUSBRE9AP13A20131126</a>

- 'Features and outcomes of patients who underwent cardiac device deactivation,' JAMA Internal Medicine, 25 November 2013. <a href="http://archinte.jamanetwork.com/article.aspx?articleid=1783304">http://archinte.jamanetwork.com/article.aspx?articleid=1783304</a>
- 'Deathbed shock: Causes and cures,' JAMA Internal Medicine, 25 November 2013. http://archinte.jamanetwork.com/article.aspx?articleid=1783300

Noted in Media Watch, 27 February 2012, #242 (p.13):

■ THEORETICAL MEDICINE & BIOETHICS, 2012;33(6):421-433. 'Pacemaker deactivation: Withdrawal of support or active ending of life?' The authors argue that clinicians uncomfortable with pacemaker deactivation are nevertheless correct to see it as incompatible with the traditional medical ethics of withdrawal of support. Traditional medical ethics is presently taken by many to sanction pacemaker deactivation when such deactivation honors the patient's right to refuse treatment. http://link.springer.com/article/10.1007/s11017-012-9213-5

**N.B.** Footnoted in this issue of Media Watch is additional articles on ethical issues on defibrillator deactivation in end-of-life care noted in past issues of the weekly report.

## <u>International</u>

### Pakistan's Christian hospice to close after 50 years

PAKISTAN | Voice of America – 29 November 2013 – In the crowded, winding streets of the Rawalpindi, a small Christian hospice led by Irish nuns has taken care of the destitute and disabled for 50 years. But the hospice that caters mainly to Muslim patients is now being forced to close because of falling donations and rising costs. Although the hospice cares for people of all religions, many think that, as a Christian institution, its own faith community should be responsible to raise the money. But sectarian violence has pushed many of Pakistan's wealthier Christians to depart, leaving few donors. While there are many charitable organizations in Pakistan, St. Joseph's is unique, says Dr. Munawar Sher Khan, a Muslim who has been involved with the hospice for 40 years. <a href="http://www.voanews.com/content/pakistans-christian-hospice-to-ckose-after-fifty-years/1800622.html">http://www.voanews.com/content/pakistans-christian-hospice-to-ckose-after-fifty-years/1800622.html</a>

## Atlas de Cuidados Paliativos en Latinoamérica: Edición Carográphica 2013

(Atlas of Palliative Care in Latin America: Cartographic Edition 2013)

ASOCIACIÓN LATINOAMERICANA DE CUIDADOS PALIATIVOS | Online – Accessed 28 November 2013 – The main objective of the Atlas [published in Spanish] is to evaluate development of palliative care (PC) in Latin America. Secondary objectives include ... [to] ... facilitate access to information and communication between regional institutions and associations dedicated to the PC, identify the key people involved in the development of PC in each country, and promote the development of PC regionally. The Atlas includes a regional summary, the list of participants, and reports by country. <a href="http://issuu.com/universidaddenavarra/docs/atlas\_latinoamerica">http://issuu.com/universidaddenavarra/docs/atlas\_latinoamerica</a>

Noted In Media Watch, 28 October 2013, #329 (p.8):

- CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online 21 October 2013 –
   'Status of palliative care in Latin America: Looking through the Latin America Atlas of Palliative Care.' This article provides a summary of the current situation as reported in the Atlas of Palliative Care recently completed by the Latin American Association for Palliative Care. http://www.ncbi.nlm.nih.gov/pubmed/24145682
  - 'Atlas de cuidados paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)] <a href="http://dspace.unav.es/dspace/bitstream/10171/34465/1/Atlas%20de%20Cuidados%20Paliativos%20de%20Latinoamerica.pdf">http://dspace.unav.es/dspace/bitstream/10171/34465/1/Atlas%20de%20Cuidados%20Paliativos%20de%20Latinoamerica.pdf</a>

#### End-of-life care in Australia

### Pilot palliative care scheme in limbo

AUSTRALIA (NEW SOUTH WALES) | *The Central Western Daily* (Orange) – 27 November 2013 – Six months after the sudden closure of a medical ward at Orange hospital that cared for palliatively ill patients, the Orange Health Service is still waiting on any benefits of a \$35 million statewide palliative care package. The package was announced by Health Minister Jillian Skinner in September and designed to provide support for people who wish to die at home. Western Local Health District cancer and innovative services director Ruth Jones said Orange was still waiting to finalise details of a contract it has drawn up with Hammond Care to provide care workers for families caring for someone with a terminal illness at home. The closure of the medical ward several months ago caused an outcry in the community, and was labelled a cost-cutting exercise. <a href="http://www.centralwesterndaily.com.au/story/1934050/pilot-palliative-care-scheme-in-limbo/?cs=103">http://www.centralwesterndaily.com.au/story/1934050/pilot-palliative-care-scheme-in-limbo/?cs=103</a>

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

## End-of-life care in India

## Cry for law to help ease cancer pain

INDIA | The Telegraph (Calcutta) – 26 November 2013 – Nagesh Simha, a palliative care physician in Bangalore ... is among doctors waiting for the government to revise narcotics rules to make morphine available to end-stage cancer patients, amid concerns that hundreds of thousands of such patients across India receive inadequate pain medication. The Indian Association for Palliative Care (IAPC) issued a fresh call to the government to speed up passage of the bill amending the Narcotic Drugs & Psychotropic Substances Act, easing for hospitals the process of procuring morphine for terminally

ill patients. The bill was introduced in 2011. <a href="http://www.telegraphindia.com/1131126/jsp/">http://www.telegraphindia.com/1131126/jsp/</a> nation/story 17613001.jsp#.UpTRjdJwrhc

### **Specialist Publications**

'The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East' (p.9), in *Annals of Oncology*.

Noted in Media Watch, 5 August 2013, #317 (p.4)

INDIA | The Hindu (Chennai) - 31 July 2013 - 'The amended narcotic drugs law must be passed soon as more effective palliative care for cancer patients hinges on it.' The Revenue Ministry ... amended the Narcotic Drugs & Psychotropic Substances Bill [1985] so that access to oral morphine for pain control would no longer be the prerogative of a lucky few. <a href="http://www.thehindu.com/opinion/op-ed/nursing-the-morphine-dream/article4971105.ece?homepage=true">http://www.thehindu.com/opinion/op-ed/nursing-the-morphine-dream/article4971105.ece?homepage=true</a>

### Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap – to foster teaching and interaction, exchange of ideas, information and materials. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

#### End-of-life care in Ireland

## Health Service Executive has lesson to learn in Fleming medical card case, says Taoiseac

IRELAND | The Irish Times (Dublin) - 26 November 2013 - Taoiseach [Prime Minister] Enda Kenny said he accepts the Health Service Executive [HSE] ... has a lesson to learn following the difficulty terminally ill Multiple Sclerosis sufferer Marie Fleming had in retaining her medical card. He added there should be a simple and effective way of dealing with a person who was terminally ill. Mr. Kenny said it was something "that, unfortunately, in this case, points out where a change must occur in the process of renewal so that people do not have to deal with the verification of an illness that is terminal." http://www.irishtimes.com/news/ireland/irishnews/hse-has-lesson-to-learn-in-flemingmedical-card-case-says-taoiseach-1.1608142

## Hospice Foundation fears for services amid Health Service Executive cutbacks

IRELAND | The Irish Examiner (Cork) – 29 November 2013 – The Foundation says it fears it will not be able to provide home care services for children because of HSE cutbacks. The planned €666m in ... cutbacks throws the government's commitment to fund three of the country's eight Children's Outreach Nurses into doubt. The Foundation itself funds 85% of the children's programme, a level it says is "unsustainable." <a href="http://www.irishexaminer.com/breakingnews/ireland/hospice-foundation-fears-for-services-amid-hse-cutbacks-615683.html">http://www.irishexaminer.com/breakingnews/ireland/hospice-foundation-fears-for-services-amid-hse-cutbacks-615683.html</a>

 'MS sufferer Marie Fleming asked for proof of illness,' The Irish Times (Dublin), 26 November 2013. The partner of terminally ill MS sufferer Marie Fleming has said his wife has had difficulty retaining her medical card. Ms. Fleming (59), who took an unsuccessful "right to die" case to the Supreme Court, received a letter in October asking if her circumstances had changed. <a href="http://www.irishtimes.com/news/ireland/irish-news/ms-sufferer-marie-fleming-asked-for-proof-of-illness-1.1608059">http://www.irishtimes.com/news/ireland/irish-news/ms-sufferer-marie-fleming-asked-for-proof-of-illness-1.1608059</a>

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

■ IRELAND | The Independent (Dublin) – 29 April 2013 – 'Marie Fleming loses Supreme Court right-to-die case.' A full, seven-judge Supreme Court gave its ruling in a "right to die" action brought by Ms. [Marie] Fleming, who wants to be helped to end her life at a time of her choosing. Chief Justice Susan Denham said there is no constitutional right to commit suicide or to arrange for the termination of one's life at the time of their own choosing. <a href="http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html">http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html</a>

#### The rhetoric of cancer

U.K. | BBC Radio (Documentary) – Accessed 25 November 2013 – When Andrew Graystone was diagnosed with cancer he soon realised the language commonly employed to approach this disease revolves around military metaphors: "The language of war dominates cancer discourse, so whether we want to fight or not, people with cancer are conscripted into a battle against the self. Our bodies [are] made into war zones, with cancer as the enemy, medical professionals as infallible heroes, and treatments of search-and-destroy by any means possible." He discusses the language clinicians choose and the words patients bring to the consulting room themselves. <a href="http://www.bbc.co.uk/iplayer/episode/p01lf8vh/The Documentary The Rhetoric of Cancer/">http://www.bbc.co.uk/iplayer/episode/p01lf8vh/The Documentary The Rhetoric of Cancer/</a>

#### **Specialist Publications**

'Referring advanced cancer patients for palliative treatment: A national structured vignette survey of Australian GPs' (p.15), in Family Practice.

'Dignity in death: The triumph of politics over evidence' (p.11), in *The Lancet* Oncology.

Noted in Media Watch, 31 January 2011, #186 (p.7):

■ BIOETHICS FORUM | Online – 21 January 2011 – 'Words matter: How "EOL" rhetoric undermines good palliative care.' Key words can be powerful in shaping cultural norms, including the norms of sub-cultures that flourish in hospitals and training programs. At the beginning of a large-scale social change, such as the new public prominence of debates over Medicare policy and palliative care, a telling phrase that emerges early can influence how the change becomes manifest, for better and ill, and often in ways their originators did not intend. http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5109&blogid=140

#### Government response to the Mid Staffordshire Public Inquiry

### Hard Truths: The Journey to Putting Patients First

U.K. (ENGLAND) | Secretary of State for Health – 19 November 2013 – No one joins the NHS [National Health Service] to deliver anything other than exceptional care. But NHS staff are often faced with a system that can sometimes make that difficult, or even impossible. This response includes many measures to address that, but fundamentally requires a deep-rooted change of culture that always puts patients first. Nobody who reads Robert Francis's report of the Mid Staffordshire NHS Foundation Trust Public Inquiry can think that the terrible failings in professional conduct, leadership, safety and compassion at Mid Staffordshire were simply the result of one organisation losing its way. The wider system, a system whose primary purpose was to support the delivery of safe, effective care, and to act when that did not happen, failed as well. It did not see, or did not want to see what was going on in Mid Staffordshire. Patients and the public want to know how this could ever have been allowed to happen. They also want to know whether Mid Staffordshire was an isolated case or whether other hospitals or services are failing their patients as Mid Staffordshire did. They want to know what will be done to prevent such terrible failings in care from happening again. It is important to underline the fact that the vast majority of NHS staff and the organisations they work for are dedicated and committed to improving the care they offer. But it would be wrong to use this to justify complacency, or to permit a sense that the problems of Mid Staffordshire were something that happened "over there" and "back then."

#### Extract from Hard Truths...

Effective compassionate care relies upon an understanding of the needs, wants and aspirations of people in all their variety; and there is no better way of forming that understanding than getting to know someone as a person; and fewer times when this matters more than at the end of life.

#### Volume 1:

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/259648/34658 Cm 8754 Vol 1 accessible.pdf

#### Volume 2:

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/259649/34659\_Cm\_8754\_Vol\_2\_accessible.pdf

## The State of Health Care & Adult Social Care in England

U.K. (ENGLAND) | Quality Care Commission – 21 November 2013 – The Commission carried out more than 35,000 inspections in 2012/2013 across the care sectors it regulates. In around 90% of cases, people were treated with dignity and respect and were receiving care, treatment and support that met their needs... But, despite improvements in each type of care setting, the Commission is disappointed that in around 10% of cases people received poor quality care. <a href="http://www.cqc.org.uk/sites/default/files/media/documents/cqc.org.uk/sites

 'Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013, #292 (p.5)] <a href="http://www.midstaffspublicinquiry.com/report">http://www.midstaffspublicinquiry.com/report</a>

#### Of related interest:

■ U.K. (ENGLAND) | BBC News – 25 November 2013 – 'Warminster care home told update end-of-life policy.' A nursing home has been warned to update its "dying policy" after failing to tell a resident's only regular visitor that she had died. Mary Bromhead, 93, died at Warminster's Henford House Care Home in Wiltshire, but her niece-in-law Susan Walter, only found out six days later. A Wiltshire Council inquiry concluded it was "unreasonable" she was not told. http://www.bbc.co.uk/news/uk-england-wiltshire-25084945

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | CNN International 27 November 2013 'Lawmakers back allowing minors to request euthanasia.' A controversial bill that would extend the right to request euthanasia to children suffering terminal illnesses and adults with dementia cleared a vote in a Belgian Senate committee. The panel voted 13-4 to allow minors to seek euthanasia under certain conditions. The vote is one stage in a legislative process the bill must clear other hurdles before it becomes law. http://www.cnn.com/2013/11/27/world/europe/belgium-euthanasia-children/
- THE PHILIPPINES | The Sun Star (Manila) 26 November 2013 'Santiago files Natural Death bill for terminally ill patients.' Senator Miriam Defensor Santiago filed a bill that would allow a terminally ill patient to end his life in order to put a stop to prolonged suffering under certain circumstances. The lawmaker said the purpose of the bill is to provide individuals with a choice to end their lives specifically those who are suffering from a terminal illness likely to cause death or from irreversible physical or mental condition that is considered unbearable. <a href="http://www.sunstar.com.ph/manila/local-news/2013/11/26/santiago-files-natural-death-bill-terminally-ill-patients-315690">http://www.sunstar.com.ph/manila/local-news/2013/11/26/santiago-files-natural-death-bill-terminally-ill-patients-315690</a>

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

The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology

ANNALS OF ONCOLOGY, 2013;24(suppl11):xi7-xi13. As the follow-up to a successful project to evaluate the availability and accessibility of opioids and regulatory barriers in Europe, the European Society for Medical Oncology and the European Association for Palliative Care undertook to expand their research to those parts of the world where data were lacking regarding these aspects of care, in particular Africa, Asia, the Middle East, Latin America and the Caribbean, and the states of India. This project has been undertaken in collaboration with the Union for International Cancer Control, the Pain and Policy Studies Group of the University of Wisconsin, and the World Health Organization, together with a consortium of 17 international oncology and palliative care societies. http://annonc.oxfordjournals.org/content/24/suppl 11/xi7.abstract

**N.B.** The *Annals of Oncology* supplement focuses on barriers to accessibility of opioids for cancer pain. Supplement contents page: <a href="http://annonc.oxfordjournals.org/content/24/suppl\_11.toc">http://annonc.oxfordjournals.org/content/24/suppl\_11.toc</a>

## **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.16.

## Advance care planning discussions among residents of long term care and designated assisted living: Experience from Calgary, Alberta

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 November 2013 – 166 charts were reviewed and 90% had a documented goals of care order. Less than half of residents (47%) were documented as participating in conversations and they were less likely to participate if they had cognitive impairment and were living in LTC [long term care]. Documented family participation was more prevalent in LTC. Nurses participated in 67% of documented conversations with only 34% of discussions documenting physician involvement. This study identifies the lack of documented resident participation in ACP [advance care planning] in LTC ... [and] ... raises questions about the optimal approach to ACP in LTC. ACP appears to be more about relational autonomy than it is about patient autonomy. <a href="http://spcare.bmj.com/content/early/2013/11/25/bmjspcare-2013-000444.abstract">http://spcare.bmj.com/content/early/2013/11/25/bmjspcare-2013-000444.abstract</a>

#### Of related interest:

■ SOCIAL SCIENCE & MEDICINE | Online – 23 November 2013 – 'Discussing dying in the diaspora: Attitudes towards advance care planning among first generation Dutch and Italian migrants in rural Australia.' Dutch participants framed ACP [advance care planning] discussions with reference to euthanasia, and adopted a more individualist approach to medical decision-making. Italian participants often spoke of familial roles and emphasized a family-based decision making style. The importance of migrant identity has been neglected in previous discussions of cultural factors influencing ACP uptake among ethnic minority groups. http://www.sciencedirect.com/science/article/pii/S0277953613006357

## Prolonged grief: Where to after Diagnostic & Statistical Manual of Mental Disorders, 5th Edition?

CURRENT OPINION IN PSYCHIATRY | Online – 21 November 2013 – Convergent evidence indicates that prolonged grief characterized by persistently severe yearning for the deceased is a distinct construct from bereavement-related depression and anxiety, is associated with marked functional impairment, is responsive to targeted treatments for prolonged grief, and has been validated across different cultures, age groups and types of bereavement. Although DSM-5 [Diagnostic & Statistical Manual of Mental Disorders, 5th Edition] has rejected the construct as a formal diagnosis, evidence continues to emerge on related mechanisms, including maladaptive appraisals, memory and attentional processes, immunological and arousal responses, and neural circuitry. It is probable the DSM-5 decision may result in more prolonged grief patients being incorrectly diagnosed with depression after bereavement and possibly incorrectly treated.

**N.B.** Link to an abstract of the article was unavailable at the time of distribution of Media Watch (check journal's home page: <a href="http://journals.lww.com/co-psychiatry/pages/default.aspx">http://journals.lww.com/co-psychiatry/pages/default.aspx</a>) See selected articles on *DSM-5* noted in past issues of the weekly report: 30 September 2013, #325 (p.12); 13 May 2013, #305 (pp.4-5).

## The practice of hope: A longitudinal, multi-perspective qualitative study among South Asian Sikhs and Muslims with life-limiting illness in Scotland

ETHNICITY & HEALTH | Online – 22 November 2013 – Hope emerged as a central construct in the accounts of illness constructed by the participants as they struggled to make sense of and uphold a meaningful life. Clinical encounters and, for some, religious beliefs served as sources of hope for participants. Hope unfolded as an active process that enabled them to live with the personal and in particular the social ramifications of their illness. Changing images of hope were formulated and reflected as illness progressed or treatments failed. These ranged from hoping for cure, prolonged life, the regaining of lost capabilities needed to fulfil social roles, or at times death when suffering and the consequences for the family became too hard to bear. <a href="http://www.tandfonline.com/doi/abs/10.1080/13557858.2013.858108#.UpdmP9Jwrhc">http://www.tandfonline.com/doi/abs/10.1080/13557858.2013.858108#.UpdmP9Jwrhc</a>

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

## Transitions to palliative care for older people in acute hospitals: A mixed-methods study

HEALTH SERVICES & DELIVERY RESEARCH, 2013;1(11). Of the 514 patients in the inpatient survey sample, just over one-third met one or more of the [U.K.] Gold Standards Framework (GSF) prognostic indicator criteria for palliative care needs. The most common GSF prognostic indicator was frailty, with almost one-third of patients (27%) meeting this criteria. Agreement between medical and nursing staff and the GSF with respect to identifying patients with palliative care needs was poor. In focus groups, health professionals reported difficulties in recognising that a patient had entered the last 12 months of life. In-depth interviews with patients found that many of those interviewed were unaware of their prognosis and showed little insight into what they could expect from the trajectory of their disease. The retrospective case note review found that 35 (7.2%) admissions were potentially avoidable. The potential annual cost saving across both hospitals of preventing these admissions was approximately £5.3M. However, a 2- or 3-day reduction in length of stay for these admissions would result in an annual cost saving of £21.6M or £32.4M respectively. Patients with palliative care needs represent a significant proportion of the hospital inpatient population. There is a significant gap between National Health Service policy regarding palliative and end-of-life care management in acute hospitals in England and current practice. http://www.journalslibrary.nihr.ac.uk/hsdr/volume-1/issue-11

#### Of related interest:

- THE LANCET ONCOLOGY, 2013;14(13):1243. 'Dignity in death: The triumph of politics over evidence.' With high-income countries facing ageing populations, and an increasing number of people with terminal illnesses such as cancer, the number of people dying in care settings will continue to increase. Now, more than ever, is the time to create a care system that gives every person a dignified death. Yet ... only 37% of relatives found the quality of care given to a deceased family member in a hospital during the end of life to be "excellent" or "outstanding," compared with 63% of those whose relatives died at home. http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70559-X/fulltext?rss=yes
  - 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012. [Noted in Media Watch, July 2012, #261 (p.4)] <a href="http://www.ons.gov.uk/ons/dcp171778">http://www.ons.gov.uk/ons/dcp171778</a> 269914.pdf
- MEDICAL EDUCATION ONLINE | Online 22 November 2013 'Death is not always a failure: Outcomes from implementing an online virtual patient clinical case in palliative care for family medicine clerkship.' The dying patient is a reality of medicine. Medical students, however, feel unprepared to effectively manage the complex end-of-life (EOL) management issues of the dying patient and want increased experiential learning in palliative care. The online VP [virtual patient] case in palliative care is a useful teaching tool that may help to address the need for increased formal palliative care experience in medical school training programs. http://med-ed-online.net/index.php/meo/article/view/22711/html
- NATIONAL INSTITUTE OF HEALTH RESEARCH JOURNALS LIBRARY | Online Accessed 28 November 2013 'Failure to discuss prognosis is detrimental for patients nearing the end of their life.' A ground-breaking study conducted into the provision of palliative and end of life care at two hospitals in England, found there was a significant gap between National Health Service palliative care policy and current practice. Researchers discovered a lack of communication between medical staff and patients, and their families, with regards to their prognosis which severely limits their ability to be involved in important decisions about their care and treatment. http://www.sheffield.ac.uk/news/nr/palliative-care-research-1.330456

pg. 11

## Paying the price: The pressing need for quality, cost, and outcomes data to improve correctional health care for older prisoners

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2013;61(11):2013-2019. Despite a recent decline in the U.S. prison population, the older prisoner population is growing rapidly. U.S. prisons are constitutionally required to provide health care to prisoners. As the population ages, healthcare costs rise, states are forced to cut spending, and many correctional agencies struggle to meet this legal standard of care. Failure to meet the healthcare needs of older prisoners, who now account for nearly 10% of the prison population, can cause avoidable suffering in a medically vulnerable population and violation of the constitutional mandate for timely access to an appropriate level of care while incarcerated. Older prisoners who cannot access adequate health care in prison also affect community healthcare systems because more than 95% of prisoners are eventually released, many to urban communities where healthcare disparities are common and acute healthcare resources are overused. A lack of uniform quality and cost data has significantly hampered innovations in policy and practice to improve value in correctional health care (achieving desired health outcomes at sustainable costs). This article delineates the basic health, cost, and outcomes data that geriatricians and gerontologists need to respond to this crisis, identifies gaps in the available data, and anticipates barriers to data collection that, if addressed, could enable clinicians and policy-makers to evaluate and improve the value of geriatric prison health care. http://onlinelibrary.wiley.com/doi/10.1111/jgs.12510/abstract?deniedAccessCustomisedMessage= &userIsAuthenticated=false

**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.17.

## 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life-limiting conditions and their families

JOURNAL OF CHILD HEALTH CARE | Online – 21 November 2013 – The authors consulted with children, young people, their parents and local professionals to gain a more informed picture of issues affecting them prior to preparing a bid to evaluate services in the area. Multiple methods included focus groups, face-to-face and telephone interviews and participatory activities. An overarching theme from parents was "Why does it happen like this?" Services did not seem designed to meet their needs. Whilst children and young people expressed ideas related to quality of environment, services and social life, professionals focused on ways of meeting the families' needs. The theme that linked families' concerns with those of professionals was "assessing individual needs." Two questions to be addressed by the evaluation are: 1) to what extent are services designed to meet the needs of children and families; and, 2) to what extent are children, young people and their families consulted about what they need? Consultations with families and service providers encouraged us to continue their involvement as partners in the evaluation. http://chc.sagepub.com/content/early/2013/10/29/1367493513510630.abstract

### Of related interest:

PALLIATIVE MEDICINE | Online – 26 November 2013 – 'The Paediatric Palliative Screening Scale: Further validity testing.' According to this second step of psychometric testing of the Paediatric Palliative Screening Scale, the strongest and most urgent necessity indicators for a palliative care approach are life expectancy and child/family preferences ... somewhat discrepant with results from the previous validation of the instrument as well as previous research findings. <a href="http://pmj.sagepub.com/content/early/2013/11/22/0269216313512886.abstract">http://pmj.sagepub.com/content/early/2013/11/22/0269216313512886.abstract</a>

## Shared decision making in palliative cancer care: A literature review

JOURNAL OF RADIOTHERAPY IN PRACTICE | Online – 8 November 2013 – Ethical and legal issues regarding the practicality of including palliative cancer patients in SDM [shared decision making] discussions raises questions about validity of consent. For SDM to be considered a valid methodology to obtain informed consent, open and honest communication between the patient and multidisciplinary team is essential. Treatment options for palliative cancer patients are often complex and SDM allows healthcare professionals and patients to exchange information and negotiate feasible treatment options based on medical expertise and patient preferences. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9067650">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9067650</a>

#### Of related interest:

- CLINICAL RESEARCH & BIOETHICS, 2013;4(4). 'Accepting end of life care realities when the choices are limited.' As a nursing instructor, I was rounding with my students in the Intensive Care Unit when my junior colleagues expressed discomfort about the management of a 25-years-old man, admitted after head injury in a road traffic accident. The gentleman in question was being ventilated for the last ten days although declared brain dead. However, despite effective communication, family refused to give consent to disconnect the ventilator. <a href="http://www.omicsonline.org/accepting-end-of-life-care-realities-when-the-choices-are-limited-2155-9627-4-163.pdf">http://www.omicsonline.org/accepting-end-of-life-care-realities-when-the-choices-are-limited-2155-9627-4-163.pdf</a>
- HEALTH CARE ANALYSIS | Online 25 November 2013 'Deciding together? Best interests and shared decision-making in paediatric intensive care.' In the western healthcare, shared decision making has become the orthodox approach to making healthcare choices as a way of promoting patient autonomy. Despite the fact the autonomy paradigm is poorly suited to paediatric decision making, such an approach is enshrined in English common law. When reaching moral decisions, for instance when it is unclear whether treatment or non-treatment will serve a child's best interests, shared decision making is particularly questionable because agreement does not ensure moral validity. <a href="http://link.springer.com/article/10.1007/s10728-013-0267-y">http://link.springer.com/article/10.1007/s10728-013-0267-y</a>
- NATURE REVIEWS CLINICAL ONCOLOGY | Online 26 November 2013 'End-of-life care what do cancer patients want?' The authors discuss the preferences of patients with cancer regarding their end of life care, including the importance of early provision of palliative care, and the central role of advance care planning in meeting patients' preferences. They discuss the factors that contribute to the place of death, including environmental factors, disease-specific issues, and the availability of resources. There has been a recent upward trend in the number of patients with cancer who die in their preferred place of care... http://www.nature.com/nrclinonc/journal/vaop/ncurrent/full/nrclinonc.2013.217.html
- THE PERMANENTE JOURNAL, 2013;17(3):23-27. 'Non-beneficial treatment and conflict resolution: Building consensus.' The authors established a fair and explicit non-beneficial treatment and conflict resolution policy at their medical center. The policy was designed to help acknowledge and respect both patients and clinicians involved in treatment planning and decision making ... [and resulted in] ... a high level of consensus between patients/surrogates and the treatment teams responsible for their care when treatment is withheld or withdrawn. <a href="http://www.thepermanentejournal.org/issues/2013/summer/5146-conflict-resolution.html">http://www.thepermanentejournal.org/issues/2013/summer/5146-conflict-resolution.html</a>

Noted in Media Watch, 30 September 2013, #325 (p.8):

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 23 September 2013 – 'The value of sharing treatment decision making with patients: Expecting too much?' The growing emphasis on patient-centered care is increasing the demand on physicians' time and effort to more fully engage patients and their families in treatment decision making. Thus, it is important to understand the potential effects of shared decision making with patients on the outcomes of clinical encounters. Shared decision making is being strongly promoted for several reasons, http://iama.iamanetwork.com/article.aspx?articleid=1741778

Noted in Media Watch, 15 July 2013, #314 (p.7):

THE HASTINGS REPORT, 2013;43(4):13-16. 'What's not being shared in shared decision-making?' The notion that programs to inform and elicit patient choice might also help to align health care delivery with patient preferences for less invasive and therefore less costly treatment options seems the rarest of mutual wins in health care, in which what is best for the individual might also benefit the whole. Yet there has been scant attention to how the goals of patient care and cost-containment, and perhaps even profitability, coincide or conflict. http://onlinelibrary.wiley.com/doi/10.1002/hast.188/abstract

## Improving end-of-life care for end-stage renal disease patients: an initiative for professionals

NEPHROLOGY NEWS & ISSUES, 2013;27(10):30-32. The Coalition for Supportive Care of Kidney Patients convened subject matter experts to assess the current state of palliative care for pre-dialysis (chronic kidney disease) and end-stage renal disease patients (stages 3-5). The experts noted that in the final month of life, dialysis patients have the higher percentage of hospitalizations, longer length of stay, greater intensive care admissions, and higher number of deaths in hospitals than cancer or heart failure patients, but use hospice only half as much as these two groups. They identified a strategic approach and framework for achieving specific aims to improve palliative care education of health care providers, raise awareness of supportive care resources, define palliative care skills for nephrologists, and continue implementation of shared decision making for ... patient-centered care. <a href="http://europepmc.org/abstract/MED/24266270">http://europepmc.org/abstract/MED/24266270</a>

### **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.

## Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers

PALLIATIVE MEDICINE | Online - 29 November 2013 - The unmet needs of palliative care patients and carers from the perspective of current patients and their carers have received little research attention. Nine qualitative studies, three quantitative studies, and three mixed-design studies were identified. The most frequently reported unmet need was effective communication with health-care professionals, the lack of which negatively impacted on the care received by patients and carers. Physical care needs were met, which indicates that the examined palliative home care services were delivering satisfactory care in this domain, but lacking in other areas. The focus ... should be on improving other aspects of patient care, including communication by health professionals to prevent or reduce suffering in areas such as psychosocial domains. Valid and reliable quantitative measures of unmet needs in palliative care are needed to examine this area more rigorously. http://pmj.sagepub.com/content/early/2013/1 1/28/0269216313511141.abstract

# End-of-life care and achieving preferences for place of death in England: Results of a population-based survey...

PALLIATIVE MEDICINE | Online – 29 November 2013 - 35.7% of respondents reported that the deceased said where they wanted to die, and 49.3% of these were reported to achieve this. Whilst 73.9% of those who ... cited home as the preferred place, only 13.3% of the sample died at home. Cancer patients were more likely to be reported to achieve preferences than patients with other conditions. Being reported to have a record of preferences for place of death increased the likelihood of dying at home. When rating care in the last 2 days, respondents were more likely to rate "excellent" or "good" for nursing care, relief of pain and other symptoms, emotional support and privacy of patient's environment if their relative died in their preferred place. http://pmj.sagepub.com/content/early/2013/11/26/ 0269216313512012.abstract

#### Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 27 November 2013 'Enhancing provider knowledge and patient screening for palliative care needs in chronic multi-morbid patients receiving home-based primary care.' This article describes a pilot model to increase palliative care (PC) knowledge and collaboration among providers and to systematically identify chronic multi-morbid home care patients who would benefit from focused discussion of potential PC needs. The Palliative Performance Scale (PPS) tool was used to trigger discussions of potential palliative needs at team rounds for patients who scored below a cut-off point on the tool. PPS implementation added little burden on nurses and triggered a discussion in 51 flagged patients. The tool successfully identified 75% of patients who died or were discharged. Screening was systematic and consistent and resulted in targeted discussions about PC needs without generating additional burden on our PC consult service. http://ajh.sagepub.com/content/early/2013/11/25/1049909113514475.abstract
- FAMILY PRACTICE | Online 25 November 2013 'Referring advanced cancer patients for palliative treatment: A national structured vignette survey of Australian GPs.' The aim of this study was to explore, using structured vignettes, how GPs might manage patients presenting with advanced cancer. Participant responses were compared with responses provided by an expert panel. There was wide variation (31-97%) in the proportion of respondents who agreed with the expert panel. The odds of referral for radiotherapy varied the most. Significant predictive variables included patient age, mobility and prognosis and respondent demographics. GPs' referral decisions for patients with advanced cancer appear to deviate from expert opinion and can be predicted using respondent and patient characteristics. http://fampra.oxfordjournals.org/content/early/2013/11/23/fampra.cmt068.abstract

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

■ PALLIATIVE MEDICINE | Online – 26 November 2013 – 'Why do older people oppose physician-assisted dying? A qualitative study.' An important finding of the study suggests that how some older individuals think about physician-assisted dying is strongly influenced by their past experiences of dying and death. While some participants had witnessed good, well-managed dying and death experiences, which confirmed for them the view that physician-assisted dying was unnecessary, those who had witnessed poor dying and death experiences opposed physician-assisted dying on the grounds that such practices could come to be abused by others. http://pmi.sagepub.com/content/early/2013/11/26/0269216313511284.abstract

#### **Media Watch Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <a href="http://hospicecare.com/about-iahpc/newsletter/2013/11/media-watch/">http://hospicecare.com/about-iahpc/newsletter/2013/11/media-watch/</a>

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

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

PALLIMED (Hospice & Palliative Medicine Blog): <a href="http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html">http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</a> (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): <a href="http://centres.sg/updates/international-palliative-care-resource-center-media-watch/">http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</a>

#### Australia

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

#### Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health Practitioners/resources.htm?mediawatch=1

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <a href="http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx">http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx</a> (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: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm</a>? PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

## **Worth Repeating**

### Silent sorrow: Grief and the loss of significant others

DEATH STUDIES, 1987;11(6):455-469. Studies of grief and bereavement have long recognized that relationship and attachment to the deceased is a critical determinant of the intensity of grief. Yet most studies only examine the impact of death on the immediate family or close kin. There is often an implicit assumption that such close relationships only exist among spouses or other members of the immediate family. This paper considers the impact of grief on non-traditional relationships. These include extramarital affairs, cohabitation, and homosexual relationships. Utilizing existing literature and case studies, the author discusses the ways in which the tasks of bereavement can be complicated in non-traditional relationships. While grief may be intensified, resources for resolving grief are often limited. It may not be possible to utilize formal and informal support systems effectively. Religion and rituals may constrain, rather than facilitate, grief work. The author describes five dimensions that bear upon the resolution of grief in non-traditional relationships. These include affect/meaning, openness-secrecy, acceptance-rejection, opportunity for replacement, and social support. The paper also describes the ways in which such grief might be manifested and offers suggestions for assisting people in recognizing and resolving grief. http://www.tandfonline.com/doi/abs/10.1080/07481188708252210

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