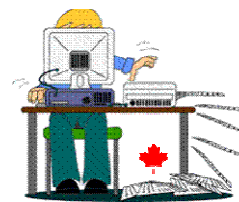


## **Media Watch...**

*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.*

**18 February 2013 Edition | Issue #293**



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

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

**Dying and death studies: Scroll down to [Specialist Publications](#) and 'Emotions and the research interview: What hospice workers can teach us' (p.10), in *Health Sociology Review*.**

## **Canada**

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

Representative sample of recent news media coverage:

- QUEBEC | Angus Reid Public Opinion – 14 February 2013 – **'Quebecers overwhelmingly call for assisted suicide guidelines.'** In an online survey of a representative sample of 804 Quebecers, 86% of respondents support enacting legislation aimed at allowing doctors to help some terminally ill patients end their lives. Only one-in-ten Quebecers (10%) are opposed to this idea, while four per cent are undecided. An Angus Reid survey on the topic of euthanasia conducted in 2010 showed that 78% of Quebecers supported the legalization of euthanasia in Canada, by far the largest proportion in any Canadian region and 15 points higher than the national average (63%). <http://www.angus-reid.com/polls/48661/quebecers-overwhelmingly-call-for-assisted-suicide-guidelines/>

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

### **Colorado prison hospice program helps inmates die with dignity**

COLORADO | *The Denver Post* – 17 February 2013 – Colorado's prison population is aging quickly and more inmates than ever are sick with illnesses that will kill them long before their sentences are up. In the first state prison hospice program in the nation, inmates of the Colorado Territorial Correctional Facility in Cañon City are trained to care for fellow prisoners as they follow the course of diseases such as cancer, HIV/AIDS and hepatitis C toward the inevitable. Colorado's total prison population more than doubled from 1991 to 2009, but the number of inmates age 50 or older increased 720%, according to "Old Behind Bars," a 2012 study by Human Rights Watch.<sup>1</sup> Nationwide, the number of people in prison who are 65 or older increased 67% in only three years to 26,200 in 2010. [http://www.denverpost.com/recommended/ci\\_22607208](http://www.denverpost.com/recommended/ci_22607208)

1. 'Old Behind Bars: The Aging Prison Population in the U.S.,' Human Rights Watch, Washington DC, January 2012. (ISBN: 1-56432-859-7) [Noted in Media Watch, 30 January 2012] [http://www.hrw.org/sites/default/files/reports/usprisons0112webwcover\\_0.pdf](http://www.hrw.org/sites/default/files/reports/usprisons0112webwcover_0.pdf)

Cont.

**N.B.** Photographs of the prison hospice program at Colorado Territorial Correctional Facility in Cañon City: <http://photos.denverpost.com/2013/02/15/photos-prison-hospice/>. 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.13.

### San Diego Hospice

#### **Hospice closing, but mission was accomplished**

CALIFORNIA | *U-T San Diego* – 15 February 2013 – She was there at the beginning, almost four decades ago, when other doctors would pat her on the hand and say, "You do have funny ideas." Dr. Doris Howell would shrug. "I believe in it," she'd tell them. "I hope one day you'll understand." Her funny idea was hospice, the revolutionary notion that people who are dying should be treated with as much care and dignity as those who are living. That death is a part of life – in fact, it is what makes life worth living. Right to the end. Back then, most doctors – people who are trained to save lives – felt that acceptance of a patient's terminal illness was an admission of failure. Almost nobody wanted to wave that white flag. So Howell ran it up her own flagpole. She spearheaded the creation of San Diego Hospice in 1977, then helped steer the non-profit into one of the largest and most innovative programs of its kind in the nation. There at the beginning, and now, at age 89, there at the end. San Diego Hospice is bankrupt and scheduled to close soon, its budget decimated in a crackdown on Medicare reimbursement practices. Hospice care is supposed to last at most six months; some cases there lasted more than a year. <http://www.utsandiego.com/news/2013/feb/16/tp-hospice-closing-but-mission-was-accomplished/>

- CALIFORNIA | *San Diego Business Journal* – 14 February 2013 – '**San Diego Hospice closes doors, transitions patient care...**' <http://www.sdbj.com/news/2013/feb/14/san-diego-hospice-closes-doors-transitions-patient/>

**N.B.** San Diego Hospice press release: <http://www.webwire.com/ViewPressRel.asp?ald=170043>

#### **Hospice of Michigan plans outreach in Hispanic community**

MICHIGAN LIVE | Online – 11 February 2013 – Hospice of Michigan is planning an outreach program in the Hispanic community of West Michigan to raise awareness of hospice services. A bilingual nurse will lead the program, which is being developed with the Hispanic Center of Western Michigan, hospice officials said. "Nationwide, Hispanics are less likely than Caucasians to use hospice services, although there is evidence that their need for services may actually be greater," said Marcie Hillary, vice president of resource development at the hospice. "To help change this situation locally, Hospice of Michigan is developing a program in the heart of Grand Rapids' Hispanic culture that will provide a greater awareness of hospice care and the benefits it provides." [http://www.mlive.com/news/grand-rapids/index.ssf/2013/02/hospice\\_of\\_michigan\\_plans\\_out.html](http://www.mlive.com/news/grand-rapids/index.ssf/2013/02/hospice_of_michigan_plans_out.html)

Noted in Media Watch (Worth Repeating), 10 September 2012:

- *PALLIATIVE MEDICINE*, 2010;24(4):427-434. "**The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with U.S.-born White, non-Latino cancer caregivers.**" <http://pmj.sagepub.com/content/24/4/427.short>

Of related interest:

- NBC LATINO | Online – 18 February 2013 – '**9 tips for caring for the family caregiver.**' For Latinos where "la familia" is everything, this [providing care to someone who is ill, disabled or aged] is a huge issue. According to a 2008 survey of Latino caregivers, a third of Latino households report having at least one family caregiver resulting in approximately 8.147 million Latino caregivers in the U.S. <http://nbclatino.com/2013/02/18/9-tips-for-caring-for-the-family-caregiver/>

## Organization helps terminal ill kids learn about firefighting

NEW MEXICO | *Fire Engineering* – 11 February 2013 – Fire Kids is a New Mexico based organization founded ... to work with municipal agencies and other organizations to identify children who are facing a life altering or terminal illness who have a wish to experience the life of a fire fighter. Working with local officials and the fire department Fire Kids will schedule with the fire department and its crews a day where the sponsored child will be integrated into the on-duty crew. <http://www.fireengineering.com/articles/2013/02/new-mexico-organization-helps-terminal-ill-kids-learn-about-fire.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | North Country Public Radio – 15 February 2013 – '**Vermont Senate passes end-of-life bill.**' After three days of intense debate, the Senate passed an end-of-life bill that will now make its way to the House. The bill is substantially changed. It addresses liability of doctors and caregivers, but doesn't say much about state requirements or palliative care. <http://www.northcountrypublicradio.org/news/story/21451/20130215/vt-senate-passes-end-of-life-bill>
- MONTANA | *San Francisco Chronicle* (California) – 13 February 2013 – '**Panel tables physician-assisted suicide bill.**' A Senate committee is again tabling a measure that aims to bring clarity to physician-assisted suicide in Montana. Supporters of Senate Bill 220 said it would establish legal definitions, clarify that doctors performing the procedure have legal immunity and ensure that doctors unwilling to perform the procedure are not required to do so. Physician-assisted suicide remains mired in controversy since the state Supreme Court ruled in 2009 that nothing in state law prohibits it. Opponents argue that the court decision did not specifically legalize the practice, and instead just gave doctors a defense if charged with a crime. <http://www.sfgate.com/news/article/Panel-tables-physician-assisted-suicide-bill-4276469.php>

## International

### Catholic hospitals will be forced to cut beds, surgery and staff levels due to funding cuts

AUSTRALIA (NEW SOUTH WALES) | *The Telegraph* (Sydney) – 18 February 2013 – Catholic public hospitals around the country will have to close 50 beds, reduce the amount of elective surgery they perform and sack staff as a result of a \$20 million federal government funding cut. The Gillard Government has cut \$1.5 billion from public hospital funding over the next four years in a move the states and Catholic Health Australia warn will lead to a blow out in waiting lists for elective surgery. Catholic hospitals have calculated they will have to wear \$20 million

worth of those cuts in the next seven months. <http://www.dailytelegraph.com.au/money/catholic-hospitals-will-be-forced-to-cut-beds-surgery-and-staff-levels-due-to-funding-cuts/story-e6frezc0-1226579777461>

#### Extract from *The Telegraph* report

Some regional hospitals in North South Wales are warning terminally ill patients will die without access to palliative care as a result of the cuts.

#### [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>

## The Liverpool Care Pathway [LCP]

### **Up to 50% of deaths at Mid-Staffs National Health Service [NHS] Trust on care pathway**

U.K. (ENGLAND) | *The Daily Telegraph* – 15 February 2013 – Figures disclosed by the hospital under the Freedom of Information Act show that use of the LCP rose markedly in the wake of the introduction of targets promoting its use in 2009. Mid-Staffordshire has been at the centre of a storm over standards in the NHS after a public inquiry into the unnecessary deaths of between 400 and 1,200 people at Mid-Staffs between 2005 and 2009. There is no evidence that any of those deaths were linked to the LCP, which was only implemented at the end of the period in question. But the figures show that its use at the trust has risen steadily from just over one in 10 of those who died in November 2009, to 41% in the same month a year later. The use of the LCP peaked at 50% of all deaths in September 2010 and has been between 20 and 30% virtually every month since. <http://www.telegraph.co.uk/health/healthnews/9871169/Up-to-50pc-of-deaths-at-Mid-Staffs-NHS-trust-on-Care-Pathway.html>

#### **Half of Britons don't expect high quality care from National Health Service in old age, survey finds**

U.K. | *The Daily Telegraph* – 13 February 2013 – Marie Curie Cancer Care found 53% of respondents doubted they would get high-quality care when they were terminally ill. People in London and Scotland are the most fearful, due to poor experience of those they have known who have died. Among those in the capital who knew someone who had recently passed away, one in 20 said the care was "very poor." Those in north east England and Northern Ireland expect the best care. The survey comes amid heated debate about The Liverpool Care Pathway, the protocol used in almost all National Health Service hospitals for those who are expected to die imminently. <http://www.telegraph.co.uk/health/healthnews/9869371/Half-of-Britons-dont-expect-high-quality-care-from-NHS-in-old-age-survey-finds.html>

**N.B.** Members of the public have been invited to share their experiences of the LCP – "both good and bad" – as part of an independent review, announced November 2012 by Care & Support Minister Norman Lamb. <http://mediacentre.dh.gov.uk/2013/02/16/independent-review-invites-public-to-share-their-experiences-of-the-liverpool-care-pathway/>

Of related interest:

- U.K. (WALES) | ITV News – 15 February 2013 – '**Ombudsman: 'Cultural change needed' for end-of-life care.**' <http://www.itv.com/news/wales/update/2013-02-15/ombudsman-cultural-change-is-needed-for-end-of-life-care/>

### **Quarter of homecare services for elderly are substandard, says health regulator**

U.K. (ENGLAND) | *The Guardian* – 13 February 2013 – A quarter of homecare services ... failed to meet quality and safety standards. In a review of 250 services, the Care Quality Commission [CQC] found evidence providers had missed calls, many staff did not understand whistle blowing procedures about abuse, and nurses turned up late to provide care.<sup>1</sup> More than 700,000 people above the age of 65 rely on home help and campaigners warned the system was becoming stretched in an age of austerity. The report comes after the coalition government announced plans for a £75,000 cap on the amount the elderly will have to pay for social care in England.<sup>2</sup> The CQC said homecare providers – largely private companies – had to work closely with local authorities to remedy the problems. The regulator warned the problems identified could have a "significant impact" on the elderly, many of whom did not complain because of a fear of reprisals or loyalty to their carer. The findings come after reports by the consumer group Which? and the Equality & Human Rights Commission have criticised homecare in the past 18 months.<sup>3,4</sup> <http://www.guardian.co.uk/society/2013/feb/13/homecare-services-elderly-substandard-regulator>

Cont.

1. 'Not Just a Number: Review of Home Care Services,' Care Quality Commission, February 2013. [http://www.cqc.org.uk/sites/default/files/media/documents/9331-cqc-home\\_care\\_report-web.pdf](http://www.cqc.org.uk/sites/default/files/media/documents/9331-cqc-home_care_report-web.pdf)
2. 'New funding reforms announced for care and support,' Department of Health, February 2013. <http://www.dh.gov.uk/health/2013/02/funding-socialcare/>  

**N.B.** The measures are based on recommendations made in 'Fairer Care Funding,' The Report of the Commission on Funding of Care & Support, July 2011. [Noted in Media Watch, 11 July 2011] <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>
3. 'Which? exposes failings in home care system,' *Which? Magazine*, March 2012. [Noted in Media Watch, 19 March 2012] <http://www.which.co.uk/news/2012/03/which-exposes-failings-in-home-care-system-281517/>
4. 'Close to Home: An Inquiry into Older People and Human Rights in Home Care,' Equality & Human Rights Commission, November 2011. [Noted in Media Watch, 28 November 2011] [http://www.equalityhumanrights.com/uploaded\\_files/homecareFI/home\\_care\\_report.pdf](http://www.equalityhumanrights.com/uploaded_files/homecareFI/home_care_report.pdf)

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

Representative sample of recent news media coverage:

- FRANCE | Agence France-Presse – 14 February 2013 – '**French medical body for euthanasia in 'exceptional' cases.**' France's medical ethics council said Thursday that euthanasia should be allowed in exceptional cases and when suffering patients make "persistent and lucid requests." Invoking a "duty to humanity," the body said that euthanasia should be reserved for "exceptional cases" like putting an end to "prolonged suffering" or "unbearable" pain. <http://www.france24.com/en/20130214-french-medical-body-euthanasia-exceptional-cases>

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

#### **Communicating with the minimally conscious: Ethical implications in end-of-life care**

*AMERICAN JOURNAL OF BIOETHICS: NEUROSCIENCE*, 2013;4(1):46-51. Recent research from electroencephalography and functional magnetic resonance (fMRI) studies appears to indicate that some patients diagnosed in a vegetative state may have some level of awareness and should instead be understood to be in a minimally conscious state (MCS). These results further suggest, with the help of neuroimaging, at least once the technology has been developed further, we may be able to communicate with some MCS patients. This article addresses ethical implications of the possibility of communication with minimally conscious patients. The author discusses these patients' level of awareness and communicative capacities discovered by recent neuroscientific findings. She then considers whether we are capable of formulating the right questions to communicate with an MCS patient, whether we are capable of understanding the patient's response, and whether it is necessary to obtain informed consent or assent from an MCS patient regarding future treatment. <http://www.tandfonline.com/doi/abs/10.1080/21507740.2012.740142>

#### **Heterogeneity and changes in preferences for dying at home: A systematic review**

*BMC PALLIATIVE CARE* | Online – 15 February 2013 – Home-based models of hospice and palliative care are promoted with the argument that most people prefer to die at home. The authors examined the heterogeneity in preferences for home death and explored, for the first time, changes of preference with illness progression. They found evidence that most people prefer to die at home. Around four fifths of patients did not change preference as their illness progressed. This supports focusing on home-based care for patients with advanced illness yet urges policy-makers to secure hospice and palliative care elsewhere for those who think differently or change their mind. There is an urgent need for studies examining change of preferences towards death. <http://www.biomedcentral.com/content/pdf/1472-684X-12-7.pdf>



**Collaborative palliative care for advanced heart failure:  
Outcomes and costs from the 'Better Together' pilot study**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2013;3(1):69-76. This pilot study provides tentative evidence that a collaborative home-based palliative care service for patients with advanced CHF may increase the likelihood of death in place of choice and reduce inpatient admissions. <http://spcare.bmj.com/content/3/1/69.abstract>

**Advance Care Planning in the U.S. and U.K.: A comparative analysis of policy, implementation and the social work role**

*BRITISH JOURNAL OF SOCIAL WORK* | Online – 14 February 2013 – The U.S. has a longer history of advance care planning [ACP] and one oriented towards the general public. The U.K. is newer to ACP and focuses its attention on the patient population, especially people with life-limiting illnesses. Who is meant to initiate ACP also differs between the U.S. and U.K. The U.S. and U.K. have different legal and informal documents related to ACP, with variations and inconsistencies within the U.S. and U.K. as well. As the key member of the hospice and palliative care team concerned with psychosocial care, social workers can assume vital roles, including patient and family education; promoting meaningful communication among patients, family members and health care providers; assisting people facing illness in documenting their preferences; and advocating for patients' wishes. <http://bjsw.oxfordjournals.org/content/early/2013/02/14/bjsw.bct013.abstract>

**Pediatric advance care planning: A systematic review**

*PEDIATRICS* | Online – 11 February 2013 – The authors included 5 qualitative and 8 quantitative studies. Only three pACP [pediatric ACP] programs were identified, all from the U.S. Two were informed by adult programs. Major pACP features are discussions between families and care providers, as well as advance directives. A chaplain and other providers may be involved if required. Programs vary in how well they are evaluated; only one was studied by using a randomized controlled trial. Preliminary data suggest that pACP can successfully be implemented and is perceived as helpful. It may be emotionally relieving and facilitate communication and decision-making. Major challenges are negative reactions from emergency services, schools, and the community. There are few systematic pACP programs worldwide and none in Europe. <http://pediatrics.aappublications.org/content/early/2013/02/05/peds.2012-2394.abstract>

Of related interest:

- *PATIENT EDUCATION & COUNSELING*, 2013;90(3):323-329. **'Advance care planning in terminally ill and frail older persons.'** There is a risk of pseudo-participation in case of non-acceptance of the nearing death or planning end-of-life situations outside the patient's power of imagination. This may result in end-of-life decisions not reflecting the patient's true wishes. [http://www.pec-journal.com/article/S0738-3991\(11\)00375-2/abstract](http://www.pec-journal.com/article/S0738-3991(11)00375-2/abstract)

**N.B.** This issue of the journal includes several articles on communication and informed decision making and related issues. Contents page: <http://www.pec-journal.com/current>

**Decriminalising an expected death in the home: A social work response**

*BRITISH JOURNAL OF SOCIAL WORK* | Online – 13 February 2013 – Sufficient mention of unnecessary police involvement is made in the palliative care literature to show that incidents like these have occurred throughout Australia, America, Canada and the U.K. This article examines the Australian context ... [and] ... argues for greater social work activity within the context of home-based palliative care, so the rights of informal carers to relevant information is improved, and expected deaths at home are no longer considered crime scenes warranting police investigation. <http://bjsw.oxfordjournals.org/content/early/2013/02/12/bjsw.bct016.abstract>

Cont.

Canadian perspective (noted in Media Watch, 6 February 2012)

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 1 February 2012 – **'Managing an expected home death.'** For a planned death, there is no need to call anyone except the physician involved in the deceased's care and the funeral home director. Some people don't realize this, however, and inadvertently turn an expected event into a false emergency. Some provinces have published guidelines on how to manage an expected home death.<sup>1-3</sup>  
[http://www.cmaj.ca/site/earlyreleases/1feb12\\_managing-an-expected-home-death.xhtml](http://www.cmaj.ca/site/earlyreleases/1feb12_managing-an-expected-home-death.xhtml)
  1. Nova Scotia: 'Preparing for an Unexpected Death at Home,' Department of Health & Home Care Nova Scotia. [www.gov.ns.ca/health/reports/pubs/PFEDH\\_brochure.pdf](http://www.gov.ns.ca/health/reports/pubs/PFEDH_brochure.pdf)
  2. Prince Edward Island: 'Caring for Your Loved One at Home: Guidelines for Managing the Expected Death at Home,' Palliative Care Program & Home Care Nursing. [www.gov.pe.ca/photos/original/hss\\_homedeath.pdf](http://www.gov.pe.ca/photos/original/hss_homedeath.pdf)
  3. Manitoba: 'Arrangements for the Expected Death at Home,' the College of Physicians & Surgeons of Manitoba, Guideline #1600. [www.cpsm.mb.ca/guidelines/gdl1600.pdf](http://www.cpsm.mb.ca/guidelines/gdl1600.pdf)

### **Complicated grief in the South African context: A social work perspective**

*BRITISH JOURNAL OF SOCIAL WORK* | Online – 13 February 2013 – Social work in South Africa in the last decade has been shaped by the 'White Paper for Social Welfare,' which promotes developmental social services and constitutes both traditional social work and social developmental practices.<sup>1</sup> Little consideration is given in social work literature and within the developmental welfare approach on the bereaved person whose social functioning is impaired by the death experience. Fatal motor vehicle accidents are a common phenomenon and crime-related deaths are reported daily. Although loss and bereavement may be included in graduate social work education in South Africa, social workers in practice are often not familiar with grief-related intervention.  
<http://bjsw.oxfordjournals.org/content/early/2013/02/12/bjsw.bct025.short>

1. 'White Paper for Social Welfare,' Department of Welfare, Republic of South Africa, 1997.  
<http://www.info.gov.za/view/DownloadFileAction?id=127937>

Of related interest:

- *PREVENTION SCIENCE* | Online – 13 February 2013 – **'Caregiver responsiveness to the Family Bereavement Program: What predicts responsiveness? What does responsiveness predict?'** The study developed a multidimensional measure to assess participant responsiveness to a preventive intervention and applied this measure to study how participant baseline characteristics predict responsiveness and how responsiveness predicts program outcomes. <http://link.springer.com/article/10.1007/s11121-012-0337-7>



#### **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>

## What do social workers think about the palliative care needs of people with Parkinson's disease?

*BRITISH JOURNAL OF SOCIAL WORK*, 2013;43(1):81-98. In this study, the authors set out to examine the social worker's role in the delivery of palliative care to clients with Parkinson's disease (PD). Differing perceptions of palliative care emerged: from a holistic approach to specialist care near the end of life. Negative associations of palliative care were identified. Other barriers also exist such as a lack of knowledge and experience of PD and a lack of resources that hinder the delivery of palliative care to clients with chronic conditions. Different interpretations of palliative care affect its delivery to clients with long-term chronic conditions. Very few clients with PD are referred to specialist palliative care specifically for management of their symptoms, which must prevent holistic care. Social workers have an important, yet underdeveloped, role in identifying and addressing palliative care needs. <http://bjsw.oxfordjournals.org/content/43/1/81.abstract>

Noted in Media Watch, 13 August 2012:

- *PARKINSONISM & RELATED DISORDERS* | Online article – 6 August 2012 – '**Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD.**' [http://www.prd-journal.com/article/S1353-8020\(12\)00251-9/abstract](http://www.prd-journal.com/article/S1353-8020(12)00251-9/abstract)

Noted in Media Watch, 16 July 2012:

- *PARKINSONISM & RELATED DISORDERS* | Online – 9 July 2012 – '**The conceptual framework of palliative care applied to advanced Parkinson's disease.**' [http://www.prd-journal.com/article/S1353-8020\(12\)00250-7/abstract](http://www.prd-journal.com/article/S1353-8020(12)00250-7/abstract)

Noted in Media Watch, 13 February 2012:

- NATIONAL COUNCIL FOR PALLIATIVE CARE (U.K.) | Online – 6 February 2012 – '**New guide to manage last days of life in Parkinson's disease.**' <http://www.ncpc.org.uk/news/83>

## Physician views on end-of-life issues vary widely

CANADIAN MEDICAL ASSOCIATION (CMA) | Online – 8 February 2013 – A survey of CMA members' views on major end-of-life issues has found that only 20% of respondents would be willing to participate if euthanasia is legalized in Canada, while twice as many (42%) would refuse to do so. Almost a quarter of respondents (23%) are not sure how they would respond, while 15% did not answer. The decision to conduct the survey, which was completed by 2,125 respondents, was made by the CMA Board in May 2011 as a result of a growing number of legal and ethical issues surrounding medical care and decision-making for dying patients. The CMA is also reviewing its existing policies in this area. Dr. Jeff Blackmer, the CMA's director of ethics, said the review is needed because of evolving societal values, new technology and changing laws. "I think you can draw a parallel to the CMA's Code of Ethics, which has been revised more than a dozen times since 1868," he said. "When it comes to issues as complex as these, noth-

ing is written in stone. We need to ensure that we are up to date." Blackmer said end-of-life issues are attracting legal attention on several different fronts. He also pointed to an end-of-life issue that is quite distinct from euthanasia and physician assisted suicide – physicians' right to withdraw or withhold treatment care when they consider it futile. [http://www.cma.ca/index.php?ci\\_id=205556&la\\_id=1](http://www.cma.ca/index.php?ci_id=205556&la_id=1)

### The CMA survey showed that...

...well over half of respondents (59%) have withheld a life-saving/sustaining intervention following a request from a patient. One in six respondents (16%) had received a request to euthanize a patient within the past five years (32% of family physicians). A quarter of respondents (24%) think assisted suicide should remain illegal (another 14% said probably illegal), while a total of 34% said it should probably or definitely be legal.

Cont.



Noted in Media Watch, 11 February 2013:

- BRITISH COLUMBIA | *The Vancouver Sun* – 8 February 2013 – '**Only 20% doctors would perform euthanasia if legal, poll of MDs finds.**' Only one in five doctors in Canada would be willing to perform euthanasia if physician-assisted dying were legalized in this country. <http://www.vancouversun.com/health/Only+cent+doctors+would+perform+euthanasia+legal+poll+finds/7939308/story.html>

**N.B.** The Canadian Society of Palliative Care Physicians position statement, which opposes to assisted suicide and euthanasia: <http://www.cspcp.ca/english/WebStoryFINAL4.pdf>

### **Evaluating educational initiatives to improve palliative care for people with dementia: A narrative review**

*DEMENTIA* | Online – 7 February 2013 – Dementia accounts for one in three deaths among people aged 65 and over, but end-of-life care for people with dementia is often sub-optimal. Palliative care for people with dementia poses particular challenges to those providing services, and current policy initiatives recommend education and training in palliative care for those working with patients with dementia. However, there are few evaluations of the effectiveness of dementia education and training. This paper presents a narrative review undertaken in 2011-2012 of evaluations of palliative care education for those working with people with dementia at the end of life. Eight papers were identified that described and evaluated such palliative care education; none reported benefits for people with dementia. There is a clear need to develop and evaluate educational interventions designed to improve palliative and end-of-life care for people with dementia. <http://dem.sagepub.com/content/early/2013/02/06/1471301212474140.abstract>

### **End-of-life care for non-cancer patients**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2013; 3(1). The origins and early development of palliative care focussed on patients with cancer, apart from sporadic developments in a few non-malignant diseases such as motor neuron disease and acquired immunodeficiency syndrome (AIDS). In the U.K., this has been compounded by the setting of palliative care outside the National Health Service, principally funded by cancer-related charities who, at the time, were instituted to relieve the suffering associated with cancer. When the modern hospice movement began, the course of malignant disease was seen as more predictable, with a defined palliative phase when anticancer treatments were no longer indicated. In the U.K. and many areas of the world where it was first adopted, such as Canada, the U.S., mainland Europe and Australia, this led to the traditional model of palliative care services, involved only in people with a prognosis of a few weeks or months. As a result, services have focused primarily on cancer leading to service and symptom management inequalities for equally needy patients with non-malignant diseases. <http://spcare.bmj.com/content/3/1/2.extract>

Noted in Media Watch, 20 August 2012:

- *DEMENTIA* | Online – 10 August 2012 – '**Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers.**' <http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 February 2013 – '**Exploring education and training needs among the palliative care workforce.**' More work is needed to examine and clarify the interplay of: behaviour change, setting, the 'cure' orientation approach, type of health professional and nature of any educational intervention in order to effect sustained behavioural change. <http://spcare.bmj.com/content/early/2013/02/13/bmjspcare-2012-000233.abstract>

## **Obstacles and helpful behaviors in providing end-of-life care to dying patients in intensive care units**

*DIMENSIONS OF CRITICAL CARE NURSING*, 2013;32(2):99-106. The results of this study show that for end-of-life care, nurses most strongly value factors that focus on the well-being of the family, and similar opinions were held by nurses from both adult and pediatric intensive care units. [http://journals.lww.com/dccjournal/Abstract/2013/03000/Obstacles\\_and\\_Helpful\\_Behaviors\\_in\\_Providing.11.aspx](http://journals.lww.com/dccjournal/Abstract/2013/03000/Obstacles_and_Helpful_Behaviors_in_Providing.11.aspx)

## **Emotions and the research interview: What hospice workers can teach us**

*HEALTH SOCIOLOGY REVIEW*, 2012;21(4):396-405. Positivist social scientific research methods often either ignore the emotions of the researcher or argue that emotional expressions are to be avoided in research, even when the topic is thought to inspire intense feelings – like death and dying. This article argues for taking an alternative position toward emotions in death and dying research. The author illustrates one potential way to productively and ethically share emotions during a research interview. This approach includes learning and being open to the "moderated cry," which involves minimal tears, the absence of sobbing, and an overt acknowledgment of the emotional reaction. <http://pubs.e-contentmanagement.com/doi/abs/10.5172/hesr.2012.21.4.396>

**N.B.** The theme of this issue of the journal is 'Culture, Death and Dying with Dignity.' Contents page: <http://pubs.e-contentmanagement.com/toc/hesr/21/4>

### **Media Watch Online**

#### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

#### **Australia**

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Links,' then to 'Media Watch')

#### **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.hpconnection.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>

#### **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>

#### **International**

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

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

## **Unmet needs of people with end-stage chronic obstructive pulmonary disease: Recommendations for change in Australia**

*INTERNAL MEDICINE JOURNAL*, 2013;43(2):183-190. This project demonstrated that the needs of people with COPD [chronic obstructive pulmonary disease] are not being met. There was an absence of a coordinated pathway for support. Care was fragmented, episodic and reactive. The role of carers was poorly recognised. Health professionals identified the lack of a clear transition to an end-stage and significant barriers to obtaining support for activities of daily living. Communication issues were identified in all studies, including the absence of advance care planning conversations. A flexible model of care is needed that assists people ... to navigate the health system. This should be patient centred and coordinated across primary, acute and community sectors. Neither respiratory nor palliative care services alone can adequately support people with COPD. The integration of a multidisciplinary palliative approach within a chronic disease management strategy will be central for the best care for people living with advanced COPD. <http://onlinelibrary.wiley.com/doi/10.1111/j.1445-5994.2012.02791.x/abstract>

Noted in Media Watch, 10 December 2012:

- *EUROPEAN RESPIRATORY REVIEW*, 2012;21(126):347-354. **'Palliative care in COPD patients: Is it only an end-of-life issue?'** <http://err.ersjournals.com/content/21/126/347.abstract>

Noted in Media Watch, 31 January 2011:

- *BRITISH MEDICAL JOURNAL* | Online article – 24 January 2011 – **'Palliative care in people with COPD.'** <http://www.bmj.com/content/342/bmj.d106.extract>

### **Qualitative descriptive study**

## **Finding meaning despite anxiety over life and death in amyotrophic lateral sclerosis patients [ALS]**

*JOURNAL OF CLINICAL NURSING* | Online – 7 February 2013 – Two themes emerged to illuminate the complex life situation of the interviewees: experiences of anxiety over life and death and finding meaning despite the illness. It became clear that the uncertain journey towards death was more frightening than death itself. Despite the incurable disease, which brought feelings of life and death anxiety, physical loss, unfairness, guilt, shame and existential loneliness, they also found meaning in life, which strengthened their will to live. Meaning was found through their family and friends, the act of giving and receiving help, the feeling of having a life of their own and accepting the present. The perspective of life was transferred to a deeper view where material things and quarrels were no longer in focus. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12071/abstract>

Noted in Media Watch, 4 June 2013:

- *MUSCLE & NERVE*, 2012;45(3):311-318. **'ALS and PC: Where we are, and the road ahead.'** <http://onlinelibrary.wiley.com/doi/10.1002/mus.22305/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Noted in Media Watch, 14 February 2011:

- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online – 5 February 2011 – **'PC in ALS: Review of current international guidelines and initiatives.'** <http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3>

Noted in Media Watch, 7 June 2010:

- *AMYOTROPHIC LATERAL SCLEROSIS* | Online – 17 March 2010 – **'Meaning in life in patients with ALS.'** <http://informahealthcare.com/doi/abs/10.3109/17482961003692604>

**The spiritual struggle of anger toward God:  
A study with family members of hospice patients**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 February 2013 – Surveys indicated that 43% of participants reported anger/disappointment toward God, albeit usually at low levels of intensity. Anger toward God was associated with more depressive symptoms, lower religiosity, more difficulty finding meaning, and belief that the patient was experiencing greater pain. Prayer was the most highly endorsed strategy for managing conflicts with God. Other commonly endorsed strategies included reading sacred texts; handling the feelings on one's own; and conversations with friends, family, clergy, or hospice staff. Self-help resources and therapy were less popular options. Anger toward God is an important spiritual issue among family members of hospice patients, one that is commonly experienced and linked with depressive symptoms. It is valuable for hospice staff to be informed about the issue of anger toward God, especially because many family members reported interest in talking with hospice team members about such conflicts. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0246>

**Oncology nurses' experiences with prognosis-related  
communication with patients who have advanced cancer**

*NURSING OUTLOOK* | Online – 11 February 2013 – Oncology nurses have opportunities to engage in prognosis-related communication with patients who have advanced cancer but encounter barriers that impede the patient's understanding of prognosis, delay transitions to end-of-life care, and contribute to non-beneficial treatments. Six themes were identified [in this study]: being in the middle, assessing the situation, barriers to prognosis communication, nurse actions, benefits of prognosis understanding, and negative outcomes. Nurses managed barriers through facilitation, collaboration, or independent actions to help patients with prognosis understanding. [http://www.nursingoutlook.org/article/S0029-6554\(12\)00307-7/abstract](http://www.nursingoutlook.org/article/S0029-6554(12)00307-7/abstract)

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**Media Watch: Editorial Practice**

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

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

**Something Missed or Overlooked?**

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

Of related interest:

- *NURSE EDUCATION TODAY* | Online – 11 February 2013 – **'Enhancing communication with distressed patients, families and colleagues: The value of the Simple Skills Secrets model of communication for the nursing and healthcare workforce.'** This model can be suggested as increasing the confidence of staff, in dealing with a myriad of situations which, if handled appropriately can lead to increased patient and carers' satisfaction. [http://www.nurseeducationtoday.com/article/S0260-6917\(13\)00006-3/abstract](http://www.nurseeducationtoday.com/article/S0260-6917(13)00006-3/abstract)

## **Worth Repeating**

### **When death precedes birth: Experience of a palliative care team on a labor and delivery unit**

*JOURNAL OF PALLIATIVE MEDICINE*, 2012;15(3):274-276. As a new palliative care consultation service in a large urban academic tertiary care setting, the authors found unanticipated palliative care needs on the labor and delivery unit. Women experiencing sudden intrauterine death, and the health care providers who care for them, have unique palliative care needs. In some circumstances, an interdisciplinary palliative care team may help to address acute grief and provide ongoing staff support. Case examples of our palliative care team's experience are instructive. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0269?prevSearch=unique&searchHistoryKey>

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