# Media Watch...

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

# 20 February 2012 Edition | Issue #241



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

Compiled & Annotated by Barry R. Ashpole

Addressing barriers to end-of-life care: Scroll down to Specialist Publications and 'Palliative care for vulnerable populations' (p.11), published in Palliative & Supportive Care.

## Canada

# Ontario delisting OxyContin and its substitute from drug benefit program

ONTARIO | Toronto Star - 17 February 2012 – Ontario is delisting the prescription painkiller OxyContin ... from the province's drug benefit program. The change ... is an attempt to curb an addiction epidemic in the province by making it harder for physicians to prescribe - and patients to get - the highly addictive drug. In recent years, Oxy-Contin prescriptions have skyrocketed in Ontario. The drug, sometimes called "hillbilly heroin," is sold on the street for its heroinlike high and causes hundreds of overdose deaths each year. This is the first time the province has delisted a drug due to its addictive properties. However, the ministry said it is not uncommon to pull drugs due to safety concerns."Overprescribing and abuse of opioids - OxyContin in particular - is a problem in Ontario that we take very seriously," provincial Health Minister Deb Matthews said. Physicians, addictions specialists and those who treat chronic pain said removing

OxyContin and its successor from the Ontario Drug Benefit program will help prevent people from abusing the drug while still helping those who depend on it for pain management, including those with spinal cord injuries and patients in palliative care. <a href="http://www.thestar.com/news/canada/article/1133247--ontario-to-delist-oxycontin-and-its-substitute-from-drug-benefit-program">http://www.thestar.com/news/canada/article/1133247--ontario-to-delist-oxycontin-and-its-substitute-from-drug-benefit-program</a>

#### Extract from Toronto Star report

Physicians, addictions specialists and those who treat chronic pain said removing OxyContin and its successor from the Ontario Drug Benefit program will help prevent people from abusing the drug while still helping those who depend on it for pain management, including those with spinal cord injuries and patients in palliative care.

#### Of related interest:

NOVA SCOTIA | Daily News (Truro) – 15 February 2012 – 'Palliative home care patients eligible for free drug coverage.' Patients receiving palliative care at home are eligible for full drug coverage at no cost with the launch of the new, expanded Palliative Home Care Drug Coverage Program. <a href="http://www.trurodaily.com/News/Local/2012-02-15/article-2896085/Palliative-home-care-patients-eligible-for-free-drug-coverage/1">http://www.trurodaily.com/News/Local/2012-02-15/article-2896085/Palliative-home-care-patients-eligible-for-free-drug-coverage/1</a>

## Drummond report stresses home-based health care

ONTARIO | CBC News (Toronto) – 15 February 2012 – About a quarter of the 360 recommendations in Ontario's new austerity blueprint are aimed at health-care costs, with economist Don Drummond pushing to move services out of hospitals and toward home-based care. The Drummond report<sup>1</sup> zeroed in on health because it eats up about 40% of the province's budget. Ontario spent \$44.77 billion on health care last year. http://www.cbc.ca/news/canada/toronto/story/2012/02/15/toronto-drummond-report-health-care.html

#### **Extract from Drummond report**

In addition to recommendations contained in 'Caring for Our Aging Population and Addressing Alternate Level of Care, <sup>1</sup> there is a need for more and varied palliative care – at home and in residential hospices.

- 1. 'Caring for Our Aging Population and Addressing Alternate Level of Care,' report submitted to the Ministry of Health & Long Term Care, June 2011. <a href="http://www.health.gov.on.ca/en/public/publications/ministry\_reports/walker\_2011/walker\_2011.pdf">http://www.health.gov.on.ca/en/public/publications/ministry\_reports/walker\_2011/walker\_2011.pdf</a>
- 1. 'Public Services for Ontarians: A Path to Sustainability and Excellence,' Commission on the Reform of Ontario's Public Services, February 2012. <a href="http://www.fin.gov.on.ca/en/reformcommission/">http://www.fin.gov.on.ca/en/reformcommission/</a>

### B.C. seniors' care action plan announced

BRITISH COLUMBIA | CBC News (Vancouver) - 14 February 2012 - The B.C. government has unveiled a seniors' action plan in response to a sweeping review by Ombudsperson Kim Carter. 1 Carter had announced a system-wide review of seniors' issues in August 2008 after her office fielded dozens of complaints about neglect in care facilities, spouses being separated and the closure of seniors facilities. In response, Health Minister Mike de Jong pledged to establish a comprehensive action plan, including the establishment of an advocate, to ensure transparency in seniors' care. http://www.cbc.ca/news/canada/britishcolumbia/story/2012/02/14/bc-seniorsagenda-legislature.html

## **Extract from Ombudsperson report**

More privacy and flexibility with daily routines are needed in the provision of appropriate end-of-life care. Counselling services, pain and symptom management and compassionate nursing care should be planned and coordinated in a way that respects the dignity and choices of seniors who are nearing death.

 'The Best of Care: Getting it Right for Seniors in British Columbia (Part 2),' February 2012. http://www.ombudsman.bc.ca/images/pdf/seniors/Seniors Report Volume 2.pdf

# 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

# U.S.A.

## Dying at home was complicated

COLORADO | *Denver Post* (Commentary) – 20 February 2012 – Up to one-third of the elderly who suffer a low-impact fracture die within a year. The doctor suggested hospice. We decided to give it a try. The hospice nurse came and evaluated Alice. Because Alice spoke more than six words and because she had not lost 10% of her prior weight ... the nurse was not sure that Alice qualified. But she was willing to consider a month-long trial. My wife had cared for her mother by herself up to then, had changed her, bathed her, and turned her so she did not get bed sores. Hospice offered no benefits there. Hospice did offer two benefits we could not provide: respite care and the right to die at home without the need to call 911. But hospice had a drawback: With its social workers, chaplains, aides and nurses, all coming and going throughout the day, hospice was intrusive on our privacy. And what was the point, if she did not qualify? We canceled hospice. http://www.denverpost.com/opinion/ci 19983326

## Poll finds wide gap between the care patients want and receive at end of life

CALIFORNIA | *Wall Street Journal* – 14 February 2012 – When it comes to how they want to spend their final days, Californians prefer to die a natural death at home without being a burden, financially or emotionally, on their families. Yet according to a new poll<sup>1</sup> ... a disparity exists between what people say they want at the end of life and what actually occurs. The survey finds nearly 8 in 10 Californians say if seriously ill, they would want to speak with their doctor about end-of-life care, but fewer than 1 in 10 report having had a conversation, including just 13% of those age 65 or older. Additionally, while 82% say that it is important to put their wishes in writing, less than one quarter have actually done so. More than half say they have not talked with a loved one about the kind of care they want at the end of life. The survey explores differences in attitudes toward death and dying among major ethnic groups in California. Top concerns vary. For example, Latinos rate "living as long as possible" much more highly than other groups. <a href="http://www.marketwatch.com/story/poll-finds-wide-gap-between-the-care-patients-want-and-receive-at-end-of-life-2012-02-14">http://www.marketwatch.com/story/poll-finds-wide-gap-between-the-care-patients-want-and-receive-at-end-of-life-2012-02-14</a>

 'Final Chapter: Californians' Attitudes and Experiences with Death and Dying,' California Health-Care Foundation,' February 2012. <a href="http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf">http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf</a>

### Palliative care challenges New York hospitals

NEW YORK | *Crain's Health Pulse* – 14 February 2012 – The time when a physician or a patient's family could decide to withhold a dire prognosis is long gone, given that both medical ethics and hospital finances now force doctors to make full disclosures. "In general, the state doesn't allow us to keep secrets from patients," said Dr. James Fausto, Montefiore's director of palliative care. In fact, since 2010 three laws have been enacted that require providers to develop protocols, rules and documents for informing patients when they are not likely to recover from an illness, said Dr. Fausto. "The law is very clear. There are no cultural or other exemptions," he said. On a practical level, though, all the new regulations bring with them new forms and paperwork. To help cope, there is discussion about creating an electronic record that would flag certain diagnoses – Stage 4 lung cancer, for example – and ping the doctor with a reminder to discuss end-of-life care. Montefiore is working on such a system. It is getting a "mixed reaction" from physicians, some of whom balk at telling patients some care might be futile, said Dr. Fausto. Doctors reassure patients that they are only telling them about the options because the state requires it. <a href="http://www.crainsnewyork.com/article/20120214/PULSE/120219965">http://www.crainsnewyork.com/article/20120214/PULSE/120219965</a>

## Mourning in America: Whitney Houston and the social speed of grief

THE ATLANTIC | Online article – 13 February 2012 – Mourning is murkier now. It is less regulated, less public, less prescribed. The 20th century brought a reshaping of grieving as an institution ... transforming it from a public ritual to a private burden and reframing it as something that could be kept ... "under complete control by strength of will and character, so that it need be given no public expression." Or, more specifically, no time for public expression. At the turn of the century, the historian Philippe Ariès says, "the death of a man still solemnly altered the space and time of a social group that could be extended to include the entire community." Today, though, the time we allow it to do the altering is contracting, and quickly. Ever the optimists, we emphasize moving on; how we do that, though, is no longer laid out for us in neat phases and frames. <a href="http://www.theatlantic.com/technology/archive/2012/02/mourning-in-america-whitney-houston-and-the-social-speed-of-grief/252994/">http://www.theatlantic.com/technology/archive/2012/02/mourning-in-america-whitney-houston-and-the-social-speed-of-grief/252994/</a>

From Media Watch dated 16 January 2012:

■ U.S. | New York Times (OpEd) – 13 January 2012 – 'Mourning in a digital age.' I have found myself in a season of loss. Every few weeks for the last six months, friends in the prime of life have suffered the death of a close family member. These deaths included a mother, a father, a sister, a brother, a spouse and, in one particularly painful case, a teenage child who died on Christmas morning. The convergence of these passings brought home an awkward truth: I had little idea how to respond. http://www.nytimes.com/2012/01/15/fashion/mourning-in-the-age-of-facebook.html

# <u>International</u>

## Palliative route avoids unnecessary treatment

AUSTRALIA (NEW SOUTH WALES) | Aged Care Insight – 20 February 2012 – A study has identified ways to move frail and dying patients from residential to palliative units to avoid hospital emergency procedures. Victoria's Eastern Health Palliative Care team is trying to address the needs of dying residential aged care clients as well as possible, within an acute health system not designed for their needs. The team, along with researchers from Deakin University, has just completed a research project looking at the care given to residential aged care clients who were admitted via the emergency departments of Maroondah and Box Hill hospitals, and went on to die during their admission. The aim of the project was to identify the needs of this population and to identify the triggers to a referral to the palliative care team, said Eastern Health's Dr. Sonia Fullerton.http://www.agedcareinsite.com.au/pages/section/article.php?s=Clinical&ss=Palliative+Care&idArticle=23110

## Hospice is extending its care of the terminally ill beyond cancer

MALTA | *Times of Malta* – 17 February 2012 – End-of-life care is gradually being extended beyond cancer patients by the Hospice Movement, which is working on opening it up to sufferers of renal failure next year. A relatively new subject, palliative care originally focused on cancer, but this was eventually considered a social injustice by the World Health Organisation. <a href="http://www.timesofmalta.com/articles/view/20120217/local/How-to-have-a-good-death.407208">http://www.timesofmalta.com/articles/view/20120217/local/How-to-have-a-good-death.407208</a>

#### Speech pathology

#### Dealing with death

AUSTRALIA | ABC News (Central Victoria) – 16 February 2012 – Speech pathologists aren't the first professionals that come to mind when thinking about palliative care. It seems universities don't think of palliative care either, when designing speech pathology courses. The head of La Trobe University's Speech Pathology program at their Bendigo campus is hoping to change all that. http://www.abc.net.au/local/audio/2012/02/16/3432413.htm

#### **Eco-friendly burials**

#### Past is dead and buried

SOUTH AFRICA | *Daily News* (Cape Town) – 16 February 2012 – The burden of an increasing global population forces us to reconsider how we deal with our dead. Our present system of burials and cremations is not only wasteful, it is unsustainable. Most of us now live in cities where space is at a premium. Using our limited land to house the dead is an anachronism. Incinerating dead bodies demands huge amounts of energy and releases serious pollutants. Therefore, we not only need to tread more carefully on the earth when we are alive, but we also need to reconsider how we dispose of our earthly remains. Welcome to the age of the green funeral. <a href="http://www.iol.co.za/dailynews/opinion/past-is-dead-and-buried-1.1235620">http://www.iol.co.za/dailynews/opinion/past-is-dead-and-buried-1.1235620</a>

## Terminal illness: What doctors don't tell you

SOUTH AFRICA | *The Star* (Cape Town) – 15 February 2012 – Most people – patients and their relatives – have hugely unrealistic expectations about what modern medicine can do to help those with life-threatening illnesses. With pancreatic cancer, for example, which is often diagnosed late, the average length of time between diagnosis and death is usually less than six months. If I had the disease, I would not attempt any of the treatments for it, such as chemotherapy, because it can be gruelling and misery-making, and the success rate is extremely low. I would rather have painkilling palliative care, which can do great things in helping to make you feel comfortable while you are dying. Most doctors would know it was time to throw in the towel if they were told by a specialist that they had advanced, aggressive cancer, and that their treatment could, at best, improve their chances of surviving for five years by 5%. Medics' scepticism about the worth of their own "lifesaving" interventions has long been suspected. In one poll, about half of German specialists admitted that they would not undergo the operations they recommended to their patients. <a href="https://www.iol.co.za/the-star/terminal-illness-what-doctors-don-t-tell-you-1.1234701">https://www.iol.co.za/the-star/terminal-illness-what-doctors-don-t-tell-you-1.1234701</a>

From Media Watch dated 23 January 2012:

- U.S. | Time Magazine 16 January 2012 'What doctors know and we can learn about dying.' Last month, an essay posted by retired physician Ken Murray<sup>1</sup> ... got a huge amount of attention, some negative but mostly positive. <a href="http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit">http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit</a>
  - 'How doctors die,' Zócalo Public Square, Center for Social Cohesion (posting undated). http://zocalopublicsquare.org/thepublicsquare/2011/11/30/how-doctors-die/read/nexus/

# National Health Service accused of putting 'do not resuscitate' notices on patients with learning disabilities without consulting with their families

U.K. | Daily Mail – 15 February 2012 – A leading charity has accused NHS [National Health Service] staff of thinking patients with learning abilities are not worth treating, often giving them 'do not resuscitate' notices without telling their families. A Mencap report said the deaths in NHS care of 74 people with learning disabilities could have been avoided – and were a direct result of institutional discrimination. Mencap said the staggering number of deaths had occurred in the past decade, and it called on the Government to 'make the NHS safe for people with a learning disability'. <a href="http://www.dailymail.co.uk/health/article-2101445/NHS-accused-letting-patients-learning-disabilities-die-consulting-families.html">http://www.dailymail.co.uk/health/article-2101445/NHS-accused-letting-patients-learning-disabilities-die-consulting-families.html</a>

1. 'Death by indifference: 74 deaths and counting – a progress report 5 years on, Mencap,' January 2012. http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference.pdf

## Building communities and environments to support people to live well and die well

U.K. I NATIONAL COUNCIL FOR PALLIA-TIVE CARE (NCPC) online posting – 15 February 2012 – Millions of British people in their late 40s and 50s are facing a miserable retirement living in poor health for longer, residing in unsuitable housing and dying without adequate care and support, according to a new report out today by NCPC and the National Care Forum. The report ... warns that urgent action is needed to deal with demographic and social changes, including an increase in the number of people aged 60 and over of over 5 million by 2030 to 19.9 million, more people living longer with chronic life-limiting conditions, growing numbers of people living alone and planned increases to the state pension age. Amongst the report's recommendations are proposals for the creation of a long-term government vision for older people and greater partnership and innovative working across health, social care and housing. The report calls for more open discussion about getting older and dying within society, help for people to

plan for the cost of later life, building homes that are capable of being adapted as people get older, new innovative models of housing and support, a better understanding of older people's needs, work to combat social isolation of older people and better use of new technology to support older people to live independently.http://www.ncpc.org.uk/news/85

### **Specialist Publications**

Of particular interest:

'Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain' (p.8), published in *Annals of Oncology.* 

'Complexity in non-pharmacological caregiving activities at the end of life: An international qualitative study' (p.12), published in *PLoS Medicine*.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SWITZERLAND | Swissinfo.ch 19 February 2012 'Assisted suicide numbers up in 2011.' The number of people who ended their lives with the help of assisted suicide organisations increased significantly in 2011... Dignitas, which caters mainly for people from abroad, accompanied 144 people choosing to die at their premises in Pfäffikon near Zurich, an increase of 35% on 2010. <a href="http://www.swissinfo.ch/eng/swiss news/Assisted suicide numbers up in 2011.html?cid=321494">http://www.swissinfo.ch/eng/swiss news/Assisted suicide numbers up in 2011.html?cid=321494</a>
- AUSTRALIA (TASMANIA) | 936 ABC (Hobart) 17 February 2012 'Euthanasia back in the news as states struggle to fund health budgets.' Euthanasia activist Dr. Philip Nitschke has been in Tasmania, conducting workshops to discuss ways people can end their lives. Leon asked him whether there would be growing support for legal euthanasia, given the difficulties states like Tasmania were having paying public health budgets. Senator Helen Polley also rang in to argue against any legal change. <a href="http://blogs.abc.net.au/tasmania/2012/02/euthanasia-back-in-the-news-as-states-struggle-to-fund-health-budgets.html">http://blogs.abc.net.au/tasmania/2012/02/euthanasia-back-in-the-news-as-states-struggle-to-fund-health-budgets.html</a>
- AUSTRALIA | THE AUSTRALIAN 17 February 2012 'Jail for helping friend suicide 'a savage first." A former Queensland teacher is said to be the first Australian to get a full-time jail term for the crime of assisting suicide. <a href="http://www.theaustralian.com.au/news/nation/jail-for-helping-friend-suicide-a-savage-first/story-e6frg6nf-1226273204671">http://www.theaustralian.com.au/news/nation/jail-for-helping-friend-suicide-a-savage-first/story-e6frg6nf-1226273204671</a>

## 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. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

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

# Regional variation in the association between advance directives and end-of-life Medicare expenditures

ARCHIVES OF INTERNAL MEDICINE, 2012;172(3):266-268. It is unclear if advance directives (living wills) are associated with end-of-life expenditures and treatments. http://archinte.amaassn.org/cgi/content/short/172/3/266

## Intention, procedure, outcome and personhood in palliative sedation and euthanasia

BMJ SUPPORTIVE & PALLIATIVE CARE, 2012;2(1):9-11. Palliative sedation at the end of life has become an important lastresort treatment strategy for managing refractory symptoms as well as a topic of controversy within palliative care. Furthermore, palliative sedation is prominent in the public debate about the possible legalisation of voluntary assisted dying (physician-assisted suicide and euthanasia). This article attempts to demonstrate that palliative sedation is fundamentally different from euthanasia when it comes to intention, procedure, outcome and the status of the person. Nonetheless, palliative sedation in its most radical form of terminal deep sedation parallels euthanasia in one respect: both end the experience of suffering. How-ever, only the latter intentionally ends life and also has this as its goal. There is the danger that deep sedation could bring death forward in time due to particular side effects of the treatment. Still that would, if it hap-pens, not be intended, and accordingly is defensible in view of the doctrine of double effect. http://spcare.bmj.com/content/2/1/9.abstract

### A bioethicist and a journalist discuss end-of-life care

THE HASTINGS CENTER | Online interview -Accessed 17 February 2012 – Writers always hope for a response from their readers. But when Lisa Krieger, a science and medicine writer for the Mercury News in San Jose, California, wrote ... about the death of her 88 year-old father<sup>1</sup> – a death that was prolonged, at a cost of \$323,000, despite his "do not resuscitate" and "desire for a natural death" directives - she was stunned by the flood of reactions. One of them was from Daniel Callahan, cofounder of the Hastings Center, who was interviewed in the article. Callahan, who has been writing about end-of-life issues for more than 40 years, was so impressed by the article that he proposed to Krieger that they "reverse roles" – he would interview her about her article and, particularly, the response that it got. "I would like to ask you, on looking back, at what point should the life-sustaining efforts have been stopped," he told her. "It was as if people just wanted permission to talk about dying," she told Callahan. "I opened the door." The interview, which includes Krieger's advice to people in a situation similar to the one she described, appears in Bioethics Forum.2 http://www.thehastingscenter.org/News/Detail.as

px?id=5734

- 1. 'The cost of dying: It's hard to reject care even as costs soar,' San Jose Mercury News, 6 February 2012 (noted in Media Watch dated 13 February 2012). http://www.mercurynews.com/health/ci 19898736?sour ce=rss
- 2. 'The trial of "Death by Medicine": An interview with Lisa Krieger, Bioethics Forum, The Hastings Center, 13 February 2012. http://www.thehastingscenter.org/Bioethicsforum/Post.a spx?id=5730&blogid=140

#### Of related interest:

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article - 13 February 2012 - 'Considerations of physicians about the depth of palliative sedation at the end of life. [In this study the authors] found two approaches toward the depth of continuous sedation: starting with mild sedation and only increasing the depth if necessary, and deep sedation right from the start. Study participants described similar determinants for both approaches, including titration of sedatives to the relief of refractory symptoms, patient preferences, wishes of relatives, expert advice and esthetic consequences of the sedation.http://www.cmaj.ca/content/early/2012/02/13/cmaj.110847.1

# Has there been any progress in improving the quality of hospitalised death? Replication of a U.S. chart audit study

BMJ SUPPORTIVE & PALLIATIVE CARE, 2012;2(1):17-23. [In this study] 63 of 159 inpatients received a PCC [palliative care consultation]. Decedents receiving a PCC were less likely to die in an intensive care unit, had fewer invasive interventions ... and were more likely to have advance directives, do-not-resuscitate orders and comfort measures orders than those who did not receive a PCC. Higher rates of emotional and pastoral care were also noted. Compared with the historical sample, 2008 decedents had a higher rate of invasive interventions, but fewer invasive intervenetions were noted in the 2008 PCC subsample. Less invasive EOL [end of life] care was observed in decedents who received a PCC. http://spcare.bmj.com/content/2/1/17.abstract

#### Of related interest:

ANNALS OF INTENSIVE CARE | Online article – 16 February 2012 – 'Integrating palliative care with intensive care for critically ill patients with lung cancer.' Critical care and palliative care are not mutually exclusive but, rather, mutually enhancing approaches to the care of ICU patients, including those with lung cancer. Through early and continuing integration of these approaches, intensivists can improve patient and family well-being while optimizing disease-directed and restorative treatments. <a href="http://www.annalsofintensivecare.com/content/pdf/2110-5820-2-3.pdf">http://www.annalsofintensivecare.com/content/pdf/2110-5820-2-3.pdf</a>

# Where do patients known to a community palliative care service die?

BMJ SUPPORTIVE & PALLIATIVE CARE, 2012;2(1):43-47. [In this service evaluation] 69% of patients who expressed a preference to die at home and 82% of patients who expressed a preference to die as inpatients in the hospice fulfilled these preferences. 71% of patients who wanted to die in their current place of residence achieved this preference. 54% of patients who declined to express a preference for end-of-life care subsequently died in hospital, reflecting the importance of advance care planning. http://spcare.bmj.com/content/2/1/43.abstract

## Of related interest:

ANNALS OF ONCOLOGY | Online article – 16 February 2012 – 'Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain.' At least two-thirds of people prefer a home death in all but one country studied. http://annonc.oxfordjournals.org/content/early/2012/02/15/annonc.mdr602.abstract

# Palliative care for the newborn in the U.K.

EARLY HUMAN DEVELOPMENT, 2012;88(2):73-77. Palliative care for the newborn is a developing area. There are more than 2000 estimated neonatal deaths each year in the U.K. from causes likely to benefit from palliative care. There is an increasing recognition that while the goals of care may be different for dying newborns, they deserve the same high standard of care as those babies who go on to survive. Recent neonatal palliative care guidance is available from the British Association for Perinatal Medicine, the General Medical Council, and ACT (the U.K. association for children's palliative care). The authors attempt to answer the question: 'What does the provision of good neonatal palliative care look like?' by examining the factors important in the provision of such care. http://www.sciencedirect.com/science/article/pii/S0378378211003793

From Media Watch dated 6 February 2012:

ADVANCES IN NEONATAL CARE, 2012;12(1):28-36. 'A model program for perinatal palliative services.' This article describes a perinatal ... program in which a) care is provided at the time of diagnoses/antenatally and includes home visits by members of an interdisciplinary hospice team; b) care is collaborative, community-based, and family-centered, and takes place in labor and delivery and on the mother baby unit; and, c) follow-up to the family continues for 1 year after the death. <a href="http://journals.lww.com/advancesinneonatalcare/Abstract/2012/02000/A\_Model\_Program\_for\_Perinatal\_Palliative\_Services.9.aspx">http://journals.lww.com/advancesinneonatalcare/Abstract/2012/02000/A\_Model\_Program\_for\_Perinatal\_Palliative\_Services.9.aspx</a>

## Practically speaking: Emergency medicine and the palliative care movement

EMERGENCY MEDICINE AUSTRALASIA, 2012;24(1):4-6. Daily experience in the ED [emergency medicine] suggests that patients suffering from chronic life-limiting illnesses are all too often caught in a revolving door of emergency care that wastes resources and fails to properly address their stage of disease and goals of care. With regularity, these patients cycle from acute episode to acute episode – from the ED to a hospital bed and home again – without being offered palliative care services that could ease distressing symptoms, improve coordination of services and provide caregiver relief. Critical decisions made in the ED can determine the subsequent intensity and trajectory of medical treatments for life-limiting illnesses, which include appropriate levels of hospital care. Thus, the ED is a crucial setting for identifying unmet palliative care needs and initiating end-of-life discussions with patients, families and primary care physicians to ensure appropriate care. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01531.x/full">http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01531.x/full</a>

EMERGENCY MEDICINE AUSTRALASIA, 2012;24(1):102-104. 'Palliative care in the emergency department: An oxymoron or just good medicine?' This article discusses the rationale for integrating a palliative approach in the ED. We need to engage our palliative care colleagues to increase clinical support to meet the needs of these vulnerable patients and to foster collaborative educational opportunities. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01505.x/abstract">http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01505.x/abstract</a>

From Media Watch dated 13 February 2012:

NEW JERSEY | Channel 5 News – 8 February 2012 – 'Relieving the stress of dying – palliative care.' <a href="http://www.newschannel5.com/story/16768559/relieving-the-stress-of-dying-palliative-care">http://www.newschannel5.com/story/16768559/relieving-the-stress-of-dying-palliative-care</a>

From Media Watch dated 9 January 2012:

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2012;43(1):1-9. 'Does palliative care have a
future in the emergency department? Discussions with attending emergency physicians.'
http://www.jpsmjournal.com/article/S0885-3924(11)00272-7/abstract

## Out-of-hours palliative care

# Introducing an electronic Palliative Care Summary (ePCS) in Scotland: Patient, carer and professional perspectives

FAMILY PRACTICE | Online article – 15 February 2012 – An electronic Palliative Care Summary (ePCS) is currently being implemented throughout Scotland to provide out-of-hours (OOH) staff with up-to-date summaries of medical history, patient understanding and wishes, medications and decisions regarding treatment of patients requiring palliative care: automatic twice daily updates of information from GP records to a central electronic repository are available to OOH services. The ePCS has clear potential to improve patient care although several implementation issues and technical problems require to be addressed first to enable this. GPs and community nurses should identify more patients with malignant and non-malignant illnesses for completion of the ePCS. http://fampra.oxfordjournals.org/content/early/2012/02/14/fampra.cms011.abstract

# Pilot projects help GPs to talk about end-of-life care

GP (U.K.) | Online report – 13 February 2012 – A training scheme backed by the Royal College of General Practitioners has dramatically increased the confidence of GPs in talking to patients about death and dying and in turn improved end-of-life care. Pilot projects organised by the Dying Matters Coalition involved 113 GPs across 76 practices undertaking communication skills training. At the beginning, 45% rated themselves as 'not' or 'not very' confident in having conversations with patients about death and dying. By the end of the pilot, 94% rated themselves 'confident' or 'very confident.' The researchers found that nine out of 10 times, the patient continued the conversation the GP had started. <a href="http://www.gponline.com/News/article/1116449/pilot-projects-help-gps-talk-end-of-life-care/">http://www.gponline.com/News/article/1116449/pilot-projects-help-gps-talk-end-of-life-care/</a>

# Report of the Geriatrics-Hospice & Palliative Medicine Work Group: American Geriatrics Society and American Academy of Hospice & Palliative Medicine Leadership Collaboration

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article - 13 February 2012 -Although the fields of hospice and palliative medicine and geriatrics have developed from separate origins, they share much in common. They share concerns for optimizing care of older adults with advanced illness. They both seek to address the common problem of care fragmentation for those with chronic illness. Both subspecialties see the patient and their loved ones as a unit requiring thoughtful, integrated care, rather than seeing the patient as a cluster of organ systems and conditions. The fields also share many core principles, including an emphasis on interdisciplinary care and care coordination. As increasing emphasis is placed on the medical home. chronic and advanced illness care, and systems changes to decrease care fragmentation, geriatrics and hospice and palliative medicine stand to benefit by blending efforts and common interests to improve care for patients and their loved ones. In 2009, a collaborative effort was begun involving the leadership of the American Geriatrics Society, the American Academy of Hospice and Palliative Medicine, and the John A. Hartford Foundation. The goal of the collaboration was to convene leaders in geriatrics and hospice and palliative medicine to identify areas of potential synergy between the two subspecialties and to design a plan for exploring and developing these areas of common interest. This article describes the progress of the collaborative effort to date. http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03864.x/abstract

#### **Media Watch Online**

The weekly report can be accessed at several websites, among them:

#### Canada

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

#### U.S.A.

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

#### Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <a href="http://www.omega.uk.net/news.htm">http://www.omega.uk.net/news.htm</a> (Scroll down to 'International End of Life Roundup')

## International

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

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

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

## New regulation of the right to a dignified dying in Spain: Repercussions for nursing

NURSING ETHICS | Online article – 8 February 2012 – Preserving dignity during the dying process requires reviewing the roles of those involved in the treatment, care methods and decision-making. This article examines the participation and responsibility assigned to nurses regarding decision-making in the final stages of life, as laid out in the Rights to and Guarantee of Dignity for the Individual During the Process of Death Act. This text has been analysed on the levels of socio-cultural practice and discourse practice, using the critical discourse analysis methodology. http://nej.sagepub.com/content/early/2012/01/30/0969733011429016.abstract

**N.B.** Spain was rated 26<sup>th</sup> in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD\_main\_final\_edition\_Jul12\_toprint.pdf">http://graphics.eiu.com/upload/QOD\_main\_final\_edition\_Jul12\_toprint.pdf</a>

#### Palliative care in Central & Eastern Europe

PALIAŢIA (Romania) | Online article – Accessed 16 February 2012 – Palliative care comes with a new philosophy of care bringing the patient as a suffering person with all his/her needs in the centre of care. In ex-communist countries (and outside) this model is a challenge for the existing disease orientated health care system and, as a result, resistance is occurring in the process of integrating palliative care. On the other hand palliative care is resonating with deep human values, is addressing a real need and is extremely important for that period in the person's life when vulnerability and need of support is huge. Fortunately, palliative care is continuously gaining supporters among health care professionals, communities, medical authorities and policy makers. Despite economic crisis and poverty palliative care is steadily spreading in the Central and Eastern Europe. When moving forward palliative care there are several ways to push for decisions: the human rights arguments, economic arguments, research data, collaborative work and praising, "shaming and blaming," etc. Now recent examples of success and pitfalls are presented, we may expect further action from policymakers in Central and Eastern European countries. http://www.paliatia.eu/modules/smartsection/item.php?itemid=300

## Palliative care for vulnerable populations

PALLIATIVE & SUPPORTIVE CARE, 2012;10(1):37-42. Experiences of marginalization often result, intentionally or unintentionally, in differential treatment in healthcare. This increased vulnerability may result from attitudes of healthcare providers or from barriers as a result of "normal" care practices and policies that may exclude or stigmatize certain populations. This may include identifying when palliative care is necessary, who receives palliative care and where, and what is necessary to complement palliative care. Inclusive and accessible palliative care can become possible through building on the existing strengths in palliative care, as well as addressing existing barriers. This may include treating the whole person and that person's support team, including paid support workers, as part of the unit of care. It involves ensuring physically accessible hospice and palliative care locations, as well as thinking creatively about how to include those excluded in traditional locations. Inclusive palliative care ensures coordination with other care services. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8487877&fulltextype=RA&fileId=S1478951511000563

## Of related interest:

SOCIAL SCIENCE & MEDICINE | Online article – 17 February 2012 – 'Medical end-of-life decisions: Does its use differ in vulnerable patient groups? A systematic review and meta-analysis.' [The authors] conclude that the administration of medication with a potential or certain life-shortening effect seemed generally to be practiced less often among the elderly, females and less well-educated patients compared with younger, male or more educated patients, while decisions that include the withdrawal or withholding of treatments seem to be more common in these groups. http://www.sciencedirect.com/science/article/pii/S0277953612001049?v=s5

# Complexity in non-pharmacological caregiving activities at the end of life: An international qualitative study

*PLoS MEDICINE*, 2012;9(2):1-10. Palliative care staff at 16 units in nine countries listed in detail non-pharmacological caregiving activities they performed over several weeks. Several forms for communication were described; information and advice was at one end of a continuum, and communicating through non-verbal presence and bodily contact at the other. Rituals surrounding death and dying included not only spiritual/religious issues, but also more subtle existential, legal, and professional rituals. An unexpected and hitherto under-researched area of focus was on creating an aesthetic, safe, and pleasing environment, both at home and in institutional care settings. http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001173

# Death confrontation, spiritual-existential experience and caring attitudes in palliative care nurses: An interpretative phenomenological analysis

QUALITATIVE RESEARCH IN PSYCHOLOGY, 2012;9(2):151-172. The present qualitative study aims to a) better understand how palliative care nurses handle death proximity; b) describe their subjective spiritual-existential experience; and, c) explore the potential links between death confrontation and spiritual-existential experience in nurses. Eleven palliative care nurses participated in a semi-structured interview. Data were analysed using interpretative phenomenological analysis. The first level analysis allowed for a description of the emerging themes of nurses' experience of death confrontation, spiritual-existential experience, and caring attitudes. The second level analysis allowed for the emergence of a typology, identifying a higher meaning for the nurses' mechanisms of subjective regulation of death proximity, integrating death, fighting death, and suffering death. Results were interpreted within a humanist-existential perspective. http://www.tandfonline.com/doi/abs/10.1080/14780881003663424

#### **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.

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### **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.

Barry R. Ashpole Beamsville, Ontario CANADA 'phone: 905.563.0044

e-mail: barryashpole@bellnet.ca